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Orphanhood, informal orphan caregiving and the impact of community-based organizations in the context of HIV/AIDS, in Nyanza, Kenya.

Tamara M. M. Landry
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**Orphanhood, Informal Orphan Caregiving
and the Impact of Community Based Organizations
in the context of HIV/AIDS, in Nyanza, Kenya**

by
Tamara M. M. Landry

**A Thesis
Submitted to the Faculty of Graduate Studies and Research
through the Department of Sociology and Anthropology
in Partial Fulfilment of the Requirements for
the Degree of Master of Arts at the
University of Windsor.**

Windsor, Ontario, Canada

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ABSTRACT

The purpose of this study was to examine the stressors the orphans and informal orphan caregivers were experiencing following the death of the orphans' parent(s), their coping strategies and the care and support provided by community based organizations (CBOs), in the context of HIV/AIDS in Nyanza, Kenya. This study was informed by conceptual realms within the Stress Process theory. Focus group discussions with orphans (thirty-one participants) and CBO members (16 participants) and in-depth interviews with informal orphan caregivers (4 participants) and CBO leaders (2 participants) were used in this study. For the orphans, it was found that the primary stressor they experienced was the death of their parent(s). Death of parent(s) resulted in secondary stressors such as concern over who would take care of them; their relationship with the new caregiver; moving to a new residence; a change in responsibilities/duties; the separation from their siblings; and problems in school. These stressors manifested into emotional distress, absenteeism from school, being forced to do work, being treated differently at home and not being allowed to visit siblings. For the informal orphan caregivers, their role of caring for orphans emerged as the main primary stressor. The resulting secondary stressors were, lack of community support, not able to work and the treatment of orphans. These stressors manifested into challenges of caregiving and multiple roles, providing basic necessities and school fees to orphans, and the effects of problem children. Both orphans and informal orphan caregivers also used various coping mechanisms to combat the stressors they experienced. The orphans used strategies such

as withdrawal, sublimation and altruism to cope. The informal orphan caregivers, on the other hand, used methods such as spirituality and religion, income generating activities, CBO membership, training and education and CBO care and support. While CBOs attempt to provide care and support for orphans and caregivers, they are faced with many problems including the growing number of orphans, educating the children, financing children's future, lack of funds and resources and lack of belief about HIV/AIDS. This study makes a contribution to the stress process literature by extending our understanding on issues related to orphanhood and orphan caregiving in a developing country in the context of HIV/AIDS and by showing how primary and secondary stressors experienced by orphans and caregivers are manifested into other stressors. It also provides evidence of coping strategies used by orphans and informal orphan caregivers.

**To my husband
for his love, support and inspiration,
and for believing in me, always.**

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CHAPTER I INTRODUCTION

The AIDS pandemic is the world's most deadly undeclared war, and Africa has so far borne its brunt (UNAIDS, 1999; UNICEF, 1999).

In the wake of the AIDS pandemic the threat of orphanhood and informal orphan caregiving is increasing. Now in its third decade, HIV/AIDS has had a world wide impact, disproportionately affecting third world countries. Since the beginning of the HIV/AIDS epidemic, more than 60 million people have become infected and more than 20 million people have died of HIV/AIDS, including 3 million deaths in 2001, 3.1 million deaths in 2002, and more than 3 million deaths in 2003 alone (UNAIDS, 2003). There are approximately 14 million orphans because of HIV/AIDS and 42 million people infected with HIV. Sub-Saharan Africa accounts for 29.4 million of all HIV/AIDS cases (UNAIDS, 2003). In Sub-Saharan Africa, there are approximately 11 million orphans. HIV/AIDS is the leading cause of death in sub-Saharan Africa and the fourth leading cause of death worldwide (see UNAIDS, UNICEF, WHO, 2002).

HIV/AIDS is a crisis of unsurpassed magnitude in sub-Saharan Africa. Almost 80% of the more than 20 million deaths from HIV/AIDS since the beginning of the epidemic have occurred in Africa (Kenya Report: In the Shadow of Death, 2001). Kenya is estimated to have an HIV prevalence rate of 11 per cent (ICASA, 2003). Approximately 892,000 orphans in Kenya illustrate only a portion of the population of children affected by AIDS (AIDS Orphans in Africa, 2003; Kenya Report: In the Shadow of Death, 2001; UNAIDS, 2003). It is estimated that one in every fifteen adults is

infected with HIV, and each day an estimated 600 Kenyans die of AIDS. It is currently estimated that 21% of the total AIDS cases in Kenya are in Nyanza Province (LVEMP, 2003). The emergence of HIV/AIDS and the high prevalence recorded in the region have had a negative impact on health institutions and general socio economic development. HIV/AIDS is claiming the productive segment of the society, leaving behind destitute orphans and the elderly. More children have been orphaned by HIV/AIDS in Africa than anywhere else. In African countries that have already suffered long, harsh epidemics, HIV/AIDS is creating orphans so quickly that extended families can no longer cope. The consequence of increasing numbers of orphans and the deterioration of extended family caregiving networks leads to physical, social, economic and psychological challenges and an increased vulnerability to HIV infection (Beers et al., 1988), especially when the majority of caregivers are elderly or orphans themselves.

There is an extensive literature focussing on the impact of HIV/AIDS on orphans and caregivers, as well as on how communities and Community Based Organizations (CBOs) are responding to the needs of those infected or affected by HIV/AIDS in the developing world. Recent studies on orphanhood have looked at the increasing number of orphans, and the problems orphans face, the psychological well-being as well as the vulnerability of orphans (e.g., Ali, 1997; Aspaas, 1999; Bicego et al., 2003; Deininger et al., 2003; Forehand et al., 1999; Foster et al., 1995; Foster, 1998; Foster, 2002; Kamali et al., 1996; Makame et al., 2002; Ntozi & Mukiza-Gapere, 1995; Nyambedha et al., 2003). There has also been considerable research on orphan care and support, as well as the impact of community-based orphan programs (e.g., Ayieko, 1997; Foster et al., 1996;

Foster et al., 1997a; Gilborn et al., 2001; Lee et al., 2002;). Furthermore, there is considerable literature on caregiving, but this is restricted primarily to the developed world. Recent studies have focussed on informal caregiving for persons with HIV/AIDS (e.g., Coleman & Toledo, 2002; Knowlton, 2003; LeBlanc et al., 1997; London et al., 1998; Reynolds and Alonzo, 1998; Smith and Rapkin, 1996; Soskolne et al., 2000; Turner and Catania, 1997; Wight et al., 1998); HIV/AIDS infected caregivers of persons with HIV or AIDS (e.g., Land et al., 2003; Wight, 2000); and informal orphan caregiving (e.g., Aspaas, 1999; Ntozi & Mukiza-Gapere, 1995; Nyambedha et al., 2003). Even though informal caregiving has been documented in developed nations such as the United States (e.g., Folkman et al., 1994; Knowlton, 2003; LeBlanc, London & Aneshensel, 1997; Rosengard & Folkman, 1997; Wight, 2000;) relatively few studies have focussed on sub-Saharan Africa where HIV/AIDS and orphan caregiving are at their peak (e.g., Ansell & Young, 2004; Baylies, 2002; Foster et al., 1996, 1997b; Loening-Voysey, 2002; Nyambedha et al., 2003; Nyangweso, 1998; Salami et al., 2003).

Although the literature on CBOs is scarce, there are some recent studies on home based care for persons with HIV or AIDS (e.g., Desmond et al., 2002; Jackson & Kerkhoven, 1995) and community based orphan care and support programs in the developing world (e.g., Ali, 1997; Desmond et al., 2002; Drew et al., 1998; Foster et al., 1996; Harber, 1996; Jackson & Kerkhoven, 1995; Nyambedha et al., 2001; UNAIDS, 1999; UNICEF, 1999). In many countries, Non Governmental Organizations (NGOs), CBOs, and religious institutions have tried to provide direct assistance focussing on strengthening families and extended families (UNICEF, 1999b). Despite their

involvement, a critical issue that still remains is how to encourage CBOs to become even more involved in the provision of care for orphans and informal caregivers. Where CBOs are involved, they are providing care and support to orphans and informal caregivers (e.g., Foster et al., 1998; UNAIDS, 1999; UNICEF, 1999;).

This study is part of a larger HIV/AIDS prevention and care (HAPAC) research program to investigate the challenges facing different subgroups and the alternative care and support systems provided by CBOs to assist them. The purpose of this study was to focus on orphans, informal caregiving and community-based organizations, with the following primary objectives:

- *to examine the primary and secondary stressors affecting the lives of the orphans and informal orphan caregivers¹ affected by HIV/AIDS*
- *to examine the manifestation of stress to see if the stress they experience manifests or creates other stresses, and*
- *to examine the coping mechanisms employed by the caregivers and the orphans and the resources available to them, as well as the social support provided by the Community-Based Organizations (CBOs).*

This will be a secondary data analysis, using data that were collected in focus group discussions and in-depth interviews between September and November 2002 in Nyanza, Kenya.

1

For the purpose of this study, informal caregiver will be defined as a relative or volunteer who is not a medical professional, who provides needed care and support in their own home, and without compensation.

CHAPTER II LITERATURE REVIEW

HIV/AIDS Orphans

Many communities in AIDS epidemic countries, especially in Africa, are now struggling with the increasing phenomenon of orphaned children (e.g., Drew et al., 1996; Forehand et al., 1999; Foster, 2000; 2002; Gilborn et al., 2001;). It has been estimated that by 2010, the number of orphans will increase to between 25 and 40 million (AIDS Orphans in Africa, 2003).

Most African cultures are characterized by strong extended family networks that operate as social support systems in times of need. Within this system, orphans are cared for by relatives (Gilborn et al., 2001). As the prevalence of HIV/AIDS escalates and the number of orphans increases, the extended family is no longer able to meet orphans' needs, particularly in terms of education, health, and basic necessities (Forsythe & Rau 1996; Nyambedha, 2000; Republic of Kenya, 1994;).

Initially, the extended family readily absorbed orphans. Now, as Foster et al. (1995) point out based on their study in Zimbabwe, HIV-infected parents are in constant worry about who will care for their children when they die. As the number of orphaned children in a community increases, and as AIDS spreads with HIV infecting uncles and aunts, the traditional first choice substitute caregivers become unavailable and the way is paved to overburdened caregivers (Foster, 2000). It is often grandparents, the last resort as caregivers, who are recruited to take care of orphans when other relatives have refused, died or are otherwise unavailable.

Orphanhood also has significant implications for child survivors (Foster, 1998). While grandparents are seemingly the last resort for orphan care, orphans themselves are partners in this “last resort” when they are enlisted as caregivers of younger siblings. According to Barnett and Blaikie (1992) who reviewed the situation of AIDS in Africa, many orphans below the age of 18 were looking after their younger siblings. Elderly caregivers may be too frail or weak to generate income to care for orphans and young caregivers may be unable to find work and most often have to leave school to support orphans in their care. In such situations, children are most likely to end up as household heads. The result of inadequate resources puts orphans', as well as their caregivers', future in jeopardy.

The number of child headed households (CHH) is increasing dramatically (Ayieko, 1997; Foster, 2000; Gilborn et al., 2001). CHH have been observed especially in communities where severe AIDS epidemics have weakened the extended family safety nets. Foster (2000) reported instances in Zimbabwe where extended family members declined to take orphans into their households, suggesting that CHH could be viewed as a form of coping and abandonment. Also, one third of the CHH were as a result of illness or death of a grandparent. In addition, in an earlier study Foster et al. (1996) found that of 308 households, 11(4%) caregivers were older brothers and sisters, 6 sibling-headed households contained 19 orphans and one household was headed temporarily by a sister of 13 years old. Foster commented, based on his research, that once CHHs begin to occur in AIDS epidemic countries, it is likely that their numbers will increase and younger children will be recruited into caregiving (Foster, 1998). Orphans who belong to families

that have little regular contact with their relatives are at risk of being abandoned. Children from households headed by single mothers or commercial sex workers are particularly likely to slip through the weakened extended family safety net (Foster, 1998; 2000). The increasing numbers of CHHs in SSA suggests that the extended family safety net has been overwhelmed by large numbers of orphans. While the separation of orphaned siblings is an undesirable solution to the problem of orphan care in the context of HIV/AIDS (e.g., Foster et al., 1997b), such separation appears to be an increasingly common strategy of families in order to share the economic burden of care of orphans across or among several relatives. In CHHs, children under five were often fostered, leaving older siblings living by themselves. In most cases, where adequate care is not forthcoming, children are vulnerable to extremes of hunger and exploitation (e.g., Foster et al., 1997b; Nyandiya Bundy & Bundy, 2002). There are also widespread claims by children of physical abuse and unequal treatment in their step families, resulting in feelings of despair (see Nyandiya Bundy & Bundy, 2002).

Work in both Zimbabwe and Zambia has demonstrated that children who have been orphaned by HIV/AIDS are vulnerable in nearly every facet of their lives (Foster et al., 1995; Foster et al., 1997a; Haworth et al., 1991). Their vulnerability begins well before the death of a parent. Emotional suffering begins with the parent's illness and progresses as the disease produces extreme changes in traditional family structure. This results in an economic toll which requires the elderly and young children to become caregivers, therefore fuelling conflict as a result of stigma and rejection (Focus: AIDS and Orphans Report, 2002). In African countries, the ability of both traditional and

modern institutions to adapt to the needs of the orphans in the HIV/AIDS context is severely constrained by the stigma attached to the disease (Nyandiya Bundy & Bundy, 2002). Numerous studies in Africa have shown that orphans experience stigmatization and discriminatory treatment at school, in their foster homes and in the wider community (Gilborn et al., 2001; Murungu, 1998). In Uganda, for example, Gilborn et al. (1998) showed that orphans had poorer nutrition and lower school enrollment than the biological children of their foster parents (Gilborn et al., 2001). Compared to children who have parents to care for them, AIDS orphans often face a greater risk of not having basic necessities. They are also at risk of HIV-infection, physical and emotional abuse, malnutrition and mistreatment. This was seen in Makame et al.'s (2002) work in Tanzania where orphans' had to move to a different home, were often separated from their siblings, had a frequent change in caregivers, were often absent from school because of the stigma and fear attached to the disease or due to work duties, and had to do more work than other children in the household.

The combined effect of sibling separation, child abuse, discrimination and stigma can put immense psychosocial pressure on orphans. Foster (2002) notes that concerns about the socioeconomic impact of AIDS on orphans have overshadowed concern for the psychosocial impact of orphanhood. Psychosocial impacts, on face value seem less pressing than material problems. It is understandable that physiological and safety needs appear to require more urgent attention than psychosocial problems. Further, both local and external agencies find it easier to meet socioeconomic needs than more demanding, culturally based psychosocial interventions. What is overlooked, however, is that

psychosocial health is the precondition for sustainable material and educational support (Forehand et al., 1999; Makame et al., 2002).

Coping mechanisms for orphans are complex and vary according to differing cultural, geographic, economic and social settings. In general, where traditional values are maintained, such as in rural communities, the extended family safety net is better preserved. Where communities are more urbanized, extended family safety nets are weakened (Foster, 2000). In the context of HIV/AIDS there is, therefore, a need to gain a better culturally based understanding of psychosocial issues faced by orphans and raise awareness at the CBO and community level. Foster (2002) suggests that psychological support should be integrated into community based programs through involvement with orphans prior to parental death. It is widely recognized, across SSA that there is a danger that postponing efforts to address children's psychosocial needs will lead to long term emotional and behavioural disturbances (e.g., Ali, 1998; Foster, 2002; Kezaala & Bataringaya, 1998). For example, Ali (1998) observes, based on her study of orphan care in Malawi, that as long as the emphasis continues to be on physical needs, with little attention to the psychosocial needs of AIDS orphans, this orphan generation will grow to be none other than street children, prostitutes, drug users and be susceptible to abuse, causing yet another crisis.

Apart from the physical and emotional well-being of orphans, another need of orphans is education (Fleshman, 2001; Gilborn et al., 2001). While CBOs may be able to work with families to ensure that orphans receive basic necessities, such as food, clothing, shelter, health and psychosocial support, another key problem is educational

needs (Ali, 1998; Ayieko, 1997; Fleshman, 2001; Harber, 1998; Kezaala & Bataringaya, 1998; UNAIDS, UNICEF, WHO, 2002). A frequent problem is the inability of caregivers to pay various school related expenses, such as school fees, books and uniforms. A study in Kenya found that 52% of children orphaned by HIV/AIDS were not attending primary school compared to 2% of non-orphans (Focus: AIDS and Orphans Report, 2002).

Similarly, in a study by Nyambedha et al. (2003) in Western Kenya, the lack of food in households with orphans was cited as a problem in 48% of 100 households interviewed. According to Nyambedha et al. this was related to poor school attendance because "orphaned children who go hungry do not attend school or shy away because they do not want to face the rigorous academic pursuit of school" (2003, p. 39). In Zimbabwe, Francis (2000) notes that those who manage to stay in school, often have to endure stigma resulting from the rumour or suspicion that their parents died of AIDS. This stigmatization can result in some orphans dropping out of school (Foster, 1998). The plight is even worse for orphans who are themselves HIV positive. Nevertheless, keeping orphans in school is crucial for their future. Education can provide a safety net and perhaps break the cycle of poverty.

The well being of all children affected by AIDS depends in great part on the capacity of the community to support and raise them. Research has focussed on mechanisms to involve the community and give insights of how community home-based care programs can address issues of orphans and vulnerable children, as well as the cost effectiveness of community based care. With increasing numbers, orphans are being supported by the community at-large, a kind of extended family (Foster, 2002).

Given the extent of the orphan crisis and the dramatic increase in orphans because of the HIV/AIDS pandemic, we need to know the sources of stress the orphans are experiencing and whether the stress they are experiencing will create other stressors. We also need to know if and what kind of impact CBOs are having on orphans and informal orphan caregiving, if their needs are being met, as well as challenges facing orphans affected by HIV/AIDS.

Informal Caregivers of Orphans

Although there seem to be numerous studies published on caregiving, most of these were done in developed countries and dealt almost entirely with caregiving for persons with AIDS (PWAs) who were homosexual or bisexual. Furthermore, very little has been documented on the physical and psychological health problems of informal caregivers in developing countries. Also, little research has focussed on informal caregiving for a stigmatized disease in developing countries (e.g., Knowlton, 2003) or in countries where there are different beliefs about the transmission of HIV and AIDS.

Nevertheless, the studies from developed countries may be applicable elsewhere because some of the factors that are related to the caregivers health, such as role overload, financial burden, alienation, duration of caregiving and inadequate social support (e.g., Prachakul & Grant, 2003) can be applied to sub-Saharan Africa. In sub-Saharan Africa, the AIDS epidemic hits primarily young, heterosexual adults. This results in young children and the elderly becoming caretakers of orphans and vulnerable children.

Pearlin et al. (1990) describe informal caregivers as those who provide practical help, assistance and nursing care to those who are unable to help themselves. They are often the lovers, spouses, friends, or family of someone with a disease or illness, such as Alzheimer's, HIV/AIDS, cancer or mental illness, and are not professional care providers. Many caregivers will balance caregiving with other work and responsibilities. While informal caregivers provide an invaluable service, they may confront demands that tax or go beyond their normal capabilities and therefore may face psychological and physical health problems (Aneshensel, 1993; Clipp et al., 1995). Caregivers may also suffer a financial burden as a result of the demands of caregiving, as well as feelings of inadequacy because of their lack of knowledge regarding care and support, their poor access to health care, lack of medicine, food and other basic necessities (Velkoff & Lawson, 1998). Many caregiving tasks are physically demanding, and some caregivers may neglect their own health, making them susceptible to physical health problems (Pavalko & Woodbury, 2000). Furthermore, AIDS caregivers are likely to face other stressors because of the difficult nature of the epidemic. These caregivers are at risk of stressors associated with the stigmatization of the disease which are distinct from other caregiving contexts, such as Alzheimer's, a non-sexually transmitted disease (e.g., Cook et al., 1997; LeBlanc et al., 1995; Pearlin et al., 1988). While these findings come from research in wealthy nations, there is no reason to expect the effect of caregiving on caregivers to be different with respect to these areas in poor nations. If anything, given the lack of economic, health and social resources to help the sick and their caregivers and the generally poorer level of overall health of populations in poorer nations, it is

reasonable to expect that the added physical and emotional stress of caregiving would have an even greater impact on caregivers in poor countries (Misra, 2003).

Joslin (2002) in her study, notes that an understudied aspect of the HIV/AIDS pandemic is, however, the role of informal caregivers in developing countries such as sub-Saharan Africa, particularly elderly caregivers of orphans and vulnerable children (Joslin, 2002). As HIV/AIDS takes the lives of millions of young and middle aged adults in Africa, grandparents assume the care of orphans and the sick. The World Health Organization (WHO) has noted that they endure serious hardship in the caregiving role (WHO, 2002). One study in the Democratic Republic of Congo (formerly Zaire) found that the primary guardians for 35 percent of HIV/AIDS orphans were grandparents (Ryder et al., 1994). Also, in the WHO study of the impact of AIDS on older people in Zimbabwe it was found that a majority of the older persons interviewed were caring for one or more orphans in their household. Furthermore, 86% of the caregivers were aged 60 years or older and 73 percent of the orphans were being cared for by persons in this age group (WHO, 2002). In a study by Nyambedha et al., (2003) on the new role of the elderly as caretakers of orphans in a rural part of Kenya, 20 out of 465 households (randomly sampled) were found to have orphan caregivers aged 55 years or older, most of whom were grandmothers or stepmothers. The age of the caregivers in this study ranged from 57-78 years of age. When it comes to children affected by HIV, the role of grandparents is not unique to sub-Saharan Africa (SSA). Grandmothers are most often the surrogate parents to children of HIV-infected parents in the United States (Nampanya-Serpell, 2003)

Historically, the elderly were cared for by their family, e.g., their children and sometimes grandchildren. However, in disease epidemics and low income countries, this is rapidly changing. The HIV/AIDS pandemic has affected and increased the number of grandparents who are caregivers to their grandchildren (Velkoff & Lawson, 1998). These effects are especially overwhelming in sub-Saharan Africa where HIV/AIDS is known as "grandmother's" disease (Nampanya-Serpell, 2003). Caregiving for the HIV-infected in developing countries can carry an extreme financial burden. In most developing countries, like those in sub-Saharan Africa, medical services are not free of charge. Every clinic, hospital visit or consultation requires a fee. There are also fees for medications, needles and syringes, commodities that are usually covered by medical plans in developed countries such as Canada, England, France, and others. The lack of medical services is further exacerbated by the economic and environmental conditions, as well as the devastating HIV/AIDS pandemic (Nyambedha et al., 2003).

Physical and Psychological Health

Informal caregiving has been widely linked to depression and other psychological problems. Several factors associated with the physical health effects of caregivers that have been documented in developed countries include: employment status of caregiver, relationship between caregiver and care recipient and HIV serostatus of caregiver (Prachakul & Grant, 2003). For example, Pavalko and Woodbury (2000) found that caregivers aged 50-65 in the United States frequently had greater rates of depression than noncaregivers because of the intense pressures and stresses from this role. Also, in a

study by Flaskerud and Lee (2000) of female caregivers aged 23-82 in southern California, depressive symptoms were more common as the result of caregiving in HIV-positive caregivers than HIV-negative caregivers. Similarly, Land et al., (2003) reported that gay and bisexual male HIV-positive caregivers from San Francisco and Los Angeles had higher levels of depressive symptoms than HIV-negative caregivers. HIV-positive caregivers reported higher levels of secondary stress due to financial concerns and lower levels of self-esteem than the HIV-negative caregivers. For the HIV-positive caregivers, poorer health and financial issues predicted greater depressive symptomatology (Land et al., 2003). These results speak to the battle faced by those living with HIV or AIDS, who are also caregivers (Land et al., 2003).

Moreover, in a study by Wight (2000) on HIV-positive and HIV-negative male caregivers in San Francisco and Los Angeles, among HIV-positive caregivers, mental health was influenced by failing health, perceptions of alienation and stigma, internalized homophobia, role overload and financial worry. Caregiving for these men was considered precursive because they were giving care that they may need in the future (Wight, 2000). Over time, these caregivers seemed to be more affected by their own waning health, their homosexuality, and the stigma of AIDS, than by the demands of caregiving (Wight, 2000). Research on the effect of caregiving on physical health was less conclusive. It is clear that several tasks required of caregivers are physically trying which may negatively affect their health. In addition, research on caregivers demonstrates that they may neglect their own health, particularly during phases of critical care (Clipp et al., 1995; LeBlanc et al., 1995; Pavalko & Woodbury, 2000; Pearlin et al, 1988;).

In developing countries such as Africa, informal caregivers experience some of the same physical and psychological effects of caregiving, but for different reasons and under different circumstances. In Nyambedha et al.'s (2003) study of elderly caretakers of orphans, they found that 108 of the 465 households sampled were shelters to one or more orphans. The elderly caregivers' decisions to care for the orphans were guided by affection. In this case, emotionally driven decisions obscured the elderly's lack of economic ability to exercise their decisions, as well as their familial responsibilities or the stigma attached to HIV/AIDS.

Stigma and Cultural Beliefs

For African countries HIV/AIDS continues to be a stigmatized condition, creating stress for infected and affected persons (Akinsola, 2001). Fear of HIV/AIDS-related stigma can lead to secrecy and non-disclosure of HIV status, rendering the epidemic masked and socially hidden (ICASA, 2003). Even caregivers are subjected to the stigma of AIDS. Consequently, their stress is compounded. They experience not only the stress related to caregiving, but also stress related to maintaining secrecy in their communities (ICASA, 2003). While people do not often speak openly about those in their village infected with HIV, the stigmatization is evident in denial of medical services, HIV testing without consent, denial of housing and employment, how families, churches and communities treat those suspected of being infected with or affected by HIV, even to the point of imposing physical violence on them (ICASA, 2003). In the African context, HIV/AIDS-related stigma and discrimination significantly impede and pose barriers to

effective care and support programs. The biomedical explanations of illness and disease also differ from local knowledge. The social construction of a disease such as HIV/AIDS is shaped by cultural, political and economic realities (Bennett, 1997). For example, the Yoruba people of Nigeria believe that any misfortune, disease or death is the work of the enemy, witchcraft or supernatural power (Lambo, 1963). Moreover, a study by Hall & Nokes (1999) found that the Shona culture does not accept the germ theory of disease and many believe that if a person is ill, it is because of witchcraft. Beliefs about the causes of HIV/AIDS in Africa and how these beliefs influence the way people react to the syndrome are very different from the understandings in developed countries. Nevertheless, with the help of community based organizations, informal caregivers in developing countries may be able to combat the effects of stigma, as well as the challenges and problems they and the orphans face.

Community Based Organizations

In order to cope with the increasing numbers of orphans and HIV/AIDS patients in sub Saharan Africa, CBOs have been called upon to get involved in tackling the massive problem of HIV/AIDS. "It has become apparent that community-based efforts at AIDS prevention and care of those affected are in the African context the first line of defence against the disease" (Population Council, 2003, p.1). Community based organizations (CBOs) have developed traditional and modern responses to help meet the urgent needs of people infected or affected by HIV/AIDS and they play a critical role in prevention, care and support. Although there is no one definition of community based

organizations given by existing CBOs, all of the CBOs were started for specific reasons. CBOs were initiated to: eradicate poverty, help orphans and children with needs, to provide home based care and medicine, training and education, and to sensitize their communities on HIV/AIDS (Futures Group Europe, 2003). They provide assistance in the form of medicine, health care, food, basic human necessities, money, counselling, spiritual assistance, visitation, prevention, outreach and education, care and support, social services, school necessities, employment, voluntary counselling and testing and income generating activities. Community based organizations strengthen local communities and provide strong internal roots within communities. CBOs are beneficial because they cost less and are based on local needs and available resources and the mutual understanding of community members.

For the purpose of this thesis, I will be privileging definitions of CBOs developed for another project in Kenya. There are many definitions of CBOs, producing a lack of consensus on what qualifies as a CBO. Community-based organizations in developing countries are very diverse and are funded in many ways. The various types of CBOs include: support groups, civil rights organizations, women's organizations, education groups, lobbying groups, self-help groups, income-generating and credit groups, religious groups and cultural groups. In Kenya, there are two types of CBOs, primary and secondary. The first are the independent primary organizations which are formed and managed by the local members using their own resources for the benefit of their members. Membership in these organizations is voluntary. An example of a primary CBO in Kenya is Kuku Women's Group that was formed in 1978. This CBO started as a

Merry Go Round² group and eventually branched into income generation and urban agriculture (Kairi, 2003).

The secondary CBOs are those which are created by external agencies as vehicles of delivery of community development in the community. External support may come in the form of capacity building, project funds and social capital. The secondary CBOs are a form of social infrastructure started by external agents to manage community activities at the local level (Kairi, 2003). The outstanding strengths of traditional grassroots community responses are that they cost less, are based on local needs and available resources and the mutual understanding of community members. Community based orphan support initiatives have demonstrated their ability to support large numbers of orphan households in greatest need and children in difficult circumstances (Drew et al., 1998; Foster et al., 1996). "Community based orphan support programs are able to support orphans in a way which complements existing coping mechanisms. Such support is cost-effective as it enables large numbers of orphans to be supported within their own communities" (Foster et al., 1998: S13). Orphan care and support programs are designed to enhance communities' abilities to address increasing number of orphans and to create awareness about the challenges these children face (UNAIDS, 1999; UNICEF, 1999).

2

Merry-go-round is a system in which each member of a group contributes a certain amount of money, labor, or goods to a larger "fund" and on a system of rotation each member alternately receives what has been collected from the other group members. This usually starts with the entire group discussing their common problems and identifying the best way to support themselves. Whatever is raised in the group is given to one person at a time. For example, the group may decide to contribute 50 shillings a head, this money is given to a member who then decides the most appropriate way to invest or spend the money.

CBOs (also referred to as grassroots organizations or peoples' organizations) are distinct from other Non-governmental organizations (NGOs). CBOs are different from NGOs in that they are membership organizations striving to further the interests of their own members, while NGOs have a broader scope of activities that may assist CBOs and pursue interests that do not directly benefit their members.

The AIDS Committees of London and Windsor are examples of CBOs. The AIDS Committees bring people together in partnership to provide leadership in education, support and advocacy to meet the challenge of HIV/AIDS. The objectives of the AIDS Committees are to: decrease the number of new infections; improve the quality of life of their service users and increase communities' capacities to support those living with or concerned about HIV/AIDS (AIDS Committee of London, 2003). The AIDS Committees began as small, local organizations, but have since successfully grown into large-scale organizations with many paid staff. Regardless, they still fit the CBO definition, if only in a minimal sense.

Given the lack of literature on community-based organizations, we need to examine the role CBOs play in care and support for orphans and informal caregivers, as well as their impact on the needs of these orphans and informal caregivers. We also need to know how CBOs are working with informal caregivers to provide them with the education they need to care for orphans, as well as themselves.

CHAPTER III THEORY

I believe the Stress Process (Pearlin et al. 1981; 1997) is the most appropriate theory for this study. Given the circumstances that the orphans and informal orphan caregivers face, the fact that their usual patterns of life are disintegrating, this theory will be useful in explaining the stressful situations that they are experiencing. This theory will also help us better understand the stressors orphans experience with the death of their parent(s).

Therefore, this study will be set within the Stress Process theory (Pearlin et al., 1981; 1997). There are various definitions of stress available in the literature. For example, Lazarus (1966) states that stress "as a universal human and animal phenomenon, results in intense and distressing experience and appears to be of tremendous influence in behaviour" (2). Furthermore, according to Lazarus and Folkman (1984) stress "is a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (p. 19). However, for the purpose of this thesis, I will be focussing on the Stress Process from the work of Pearlin et al. (1981).

According to Pearlin et al. (1981; 1997), the stress process incorporates three conceptual realms: the sources of stress, the manifestations of stress and the coping mechanisms of stress. Sources of stress, manifestations of stress and coping mechanisms are all influenced by social context. Stress is a normative experience and can originate from social situations within the context of a society.

Stressors can be divided into primary and secondary stressors. The primary stressors originate from the stressful event or situation itself and secondary stressors are the result of the primary stressors. The perceptions and experiences that children have with stressors may be very different from adults. The impact of stressors on children may be somewhat cushioned by the protection of their family and by their inadequate comprehension of the consequences of certain events (Field and Prinz, 1997). Children and adolescents usually experience more than one stressor at a time. Current research indicates that when more than one stressor is combined, the effects are more apt to increase (Brenner, 1984). The most extensively used life stress measurement for young age groups is the Life Events Record developed by Coddington (1972a). The Life Events Record contains a list of events judged to be frequently experienced by children and adolescents. The number of events included in the scale varies depending on the age of the child (Brenner, 1984). According to Coddington's Life Events Record, the number one stressful life event that a child or adolescent can experience is the death of a parent(s). Other life events that are stressful for children and adolescents include separation or divorce of parents, jail sentence for a parent, birth or adoption of a new sibling, death of a brother or sister, change to a different school, separation from a sibling(s) and the marriage of a parent to a stepparent.

At the simple end of the life events are events which occur to most children in our society and for which there are good coping patterns, for example, children jealous of newborn siblings. Also along this line are the stresses which occur when children have only one parent in the home or when they live in multiple-parent, multiple-dwelling

households. Along the severe end is the stress caused by separation of children from their parents or siblings. In this case, some children are well cared for and others are ignored when the separation is caused by death or illness. Also at the severe end are the children who live in situations of abuse, neglect, and parental alcoholism (Brenner, 1984).

A contextual factor that has been found to effect post-traumatic consequences is secondary stressors, or stressful events that may occur after a primary stressor is experienced (e.g., Sandler et al., 1988; Thompson et al., 1998). Children or adolescents who experience the death of a parent may experience more secondary stressors compared to non-bereaved peers (e.g., Sandler et al., 1988; Thompson et al., 1998). Sandler and colleagues (1988) found in their study of 91 youths, each of whom lost a parent to death, and 16 non-bereaved youths, that the death of a parent was associated with a decrease in positive family events for the surviving child, and that both negative and positive changes were related to increased distress. Similarly, Silverman and Worden (1992) found that many bereaved children experienced changes in their daily lives, especially in their home, and that children with the greatest changes in their daily lives had the most difficulty coping with the death of their parent(s). Furthermore, in a study by Thompson et al. (1998) of 116 youths aged 9-17 (26 youths lost a parent to homicide and 45 youths lost a parent to natural death and 45 non-bereave youths), not only was the death of a parent related to increased stressors and distress, but examination disclosed that the link between parental death and child distress could be attributed to the role of secondary stressors (Thompson et al., 1998).

Primary stressors associated with caregiving of those infected or affected by HIV/AIDS, then, are situated in the actual activities of caregiving. These stressors may be objective (e.g., assistance provided with personal care), or subjective (e.g., feelings of burden or overload that flow from these activities) in nature (Pearlin et al., 1990; 1997). Secondary stressors, in contrast, are no less significant than primary stressors but they are secondary in the sense that they are effects of the primary stressors (Pearlin et al., 1990; 1997). Secondary stressors associated with AIDS caregiving are located in other realms of the caregiver's life. For example, care may put a financial strain on the caregiver's resources (Wight, 2000).

The manifestations of stress affect an individual's health and emotional well-being. According to Pearlin et al. (1990), "caregiving is potentially a fertile ground for persistent stress" (583). Therefore, stress increases as the demands of caregiving increase (Aneshensel et al., 1995). Nevertheless, according to Pavalko and Woodbury (2000), even though levels of emotional distress are invariably higher for caregivers than noncaregivers, some research suggests that distress levels reach a levelling off and stay balanced or even decrease as caregiving continues (e.g., Whitlatch et al., 1997), therefore suggesting a process of adaptation to caregiving. In contrast, other research has found that health problems continue to amass during caregiving, suggesting a process of stress proliferation or "wear and tear" (e.g., Pearlin et al., 1997).

The stress process not only provides a framework for understanding stress and coping, but, in its conceptualization of stress proliferation it also provides an understanding of how some stressful life experiences create more stress. This stress

comes from different places within stress proliferation, putting in motion a course of events that fuse the original source of stress and lead to distress (Pearlin et al., 1997). Therefore, stressors beget stressors. Even though proliferation can develop in various types of stressful circumstances, the manifestation of stress can vary from one context to the next (Pearlin et al., 1997). For example, AIDS caregivers, in contrast to Alzheimer's caregivers, tend to encounter death "at an age that violates normative life-course expectations" (Pearlin et al., 1997: 376). Also, AIDS is one of the most highly stigmatized illnesses/diseases. Therefore because of the stigma and the association with sexuality and deviance and because in sub-Saharan Africa there are often children left behind, there is a greater diversity of points of stress. Stress proliferation is not universally experienced by all caregivers and the magnitude of stress proliferation depends on the resources and social supports available and the coping mechanisms employed by the caregivers (Pearlin et al., 1997). Through the conceptualization of stress proliferation, we can also see how the multiple roles of the caregivers can create more stress or in some cases, maintain a certain level of stress.

Much of the research on multiple roles has conceptualized the additional roles as demands for the caregiver's time (see Brody, 1981; 1985). Contrary to the premise that multiple roles produce strains (see Good, 1960; Marks, 1977), an increasing body of literature from developed countries has shown that holding multiple roles is generally associated with better physical health, lower psychological stress, higher self-esteem, and greater well-being (see Stoller and Pugliesi, 1989; Thoits, 1983).

Recent research suggests that negative effects of caregiving are generally reduced by other roles (e.g., Stoller and Pugliesi, 1989). Scharlach (1994), in a study of employed caregivers in Los Angeles, California, also found caregivers who were employed to be less stressed than those who were not employed. Within this perspective, the other roles of caregivers may be perceived to increase well-being or provide support that could cushion the blow of stresses related to the caregiving role (Stoller and Pugliesi, 1989).

Providing care can also have positive effects on the caregiver's psychosocial health and well-being. Wardlaw (1994) found that caregivers felt a sense of usefulness, compassion and fulfilment from their roles as caregivers. Similarly, Stajduhar and Davies (1998), in a study of family caregivers aged 31-65, also found that informal caregivers felt a sense of pride in their role as caregiver, found meaning in their experiences, as well as renewed inner strength and spirituality. Also, in a study of informal helpers in northeastern New York, Stoller and Pugliesi (1989) found that occupying additional roles was positively associated to caregiver well-being. Similarly, Stephens et al. (1994) found that caregiving daughters and daughters-in-law experience both stress and benefits in their multiple roles as caregivers, wives and mothers. Furthermore, Moen et al. (1995), found that for caregiving wives and daughters, certain role combinations, such as caregiving and employment, had positive effects whereas other role combinations, such as caregiving and marriage, had adverse effects for well-being

In a study by Reynolds and Alonzo (1998), of informal caregivers in a mid-western urban community in the United States, becoming an HIV caregiver entailed

acquiring skills that were formerly unknown and, in doing so, the caregiver uncovered new, positive outlooks that enhanced his or her existence. Reynolds and Alonzo (1998) concluded that when the challenges of caregiving were met with triumph, the caregiver could experience an increased sense of cohesion, mastery, and personal growth (Reynolds & Alonzo, 1998).

While the research just cited reviews the beneficial effects of multiple roles for caregivers, there is other research that demonstrates that the effects of multiple roles may also be damaging, increasing the magnitude of stress (Aneshensel, 1993; Aneshensel et al., 1995; LeBlanc et al., 1997; Pearlin et al., 1990; Pearlin et al., 1997). Parallel with role strain, multiple roles are perceived as fighting for the time and energy of the caregiver, thereby generating psychological distress (Brody, 1981; Penning, 1998). Also, Stoller and Pugliesi (1989), indicated that among nonspousal primary caregivers of elderly, multiple roles can render feelings of burden among caregivers providing high levels of assistance, thereby giving support to the view those multiple roles can have negative consequences for caregivers.

Turner and Catania (1997) found that caregivers in cities in the United States who had sparse resources, little income and minority social status have more health problems because they lack resources to get support with the objective demands of caregiving. Furthermore, lower income caregivers also reported more burden compared to caregivers with higher incomes. This is also similar in developing countries where caregivers have little or no access to financial resources. For example, an elderly grandparent, who was once supported by his/her son or daughter who is now prematurely deceased because of

HIV/AIDS, is now trying to support his/her grandchild(ren) and possibly other orphans in the community with little or no resources. People experience stress in different ways and with a variety of behaviours, perceptions and conditions that can alter the impact of stress (Pearlin et al., 1981). For example, Blackman and Bolden (1999), in their study of Caribbean health care professionals who work with HIV/AIDS patients, found that the stress of caregiving, especially with limited resources, may be magnified by interpersonal factors (e.g., 'young people dying' and 'fear of getting the disease', and external factors, such as 'staff turnover', 'insufficient staff' and 'lack of training') prominent to the caregiver. Also, Land et al. (2003) found that role captivity, role overload and low self-esteem were common predictors of stress and depression in both HIV-negative and HIV-positive caregivers of persons with HIV/AIDS. Furthermore, Moen et al. (1995) in their study of women's caregiving among wives and mothers aged 23-50 from upstate New York, hypothesized that younger caregivers would experience more stress than older ones. They expected that caregiving would be more stressful earlier in life than later, given the potential for role strain and overload as well as the unexpectedness of the role disruption in early life. Caregiving in earlier life could have greater effects because younger caregivers may not be financially, emotionally or physically able to provide adequate caregiving needs. In addition, caregiving in later life could be viewed as a more normative role change. However, the opposite occurred in their results. In their study, older caregivers are worried about their own health and their future abilities and experience more stress than younger caregivers, given unexpected role disruptions. This is important in the context of HIV/AIDS in sub-Saharan Africa when caregivers, usually

the elderly, are caring for their grandchildren or other orphans, as a result of the untimely death of their children or that of other relatives due to HIV or AIDS. These role disruptions may have dramatic consequences for the lives of the orphans and the caregivers. This is also evident in the study by Hunter (1990), where orphans in Uganda were cared for by grandparents who were less able than younger relatives to provide adequate care and basic needs, such as food, clothing, shelter and health.

In the study by Moore (2001) in Togo, caregivers (n=30) of PWAs also experienced emotional stress, anxiety, fear of death and being contaminated. In this study, 60% of the caregivers were overwhelmed when they thought about the problems of HIV/AIDS and 56% were anxious because of the increasingly young population of people with HIV/AIDS. Also, 29% were anxious about the increasing rate of the epidemic and their fear of contamination because of their caregiving role to PWAs. Furthermore, 41% of caregivers reported that since they became involved with the PWAs, they have become emotionally stressed out and 69% reported that because of their compassion and empathy for their patients, they felt emotionally stressed because they did not have the means to make them well. Moreover, 32% reported their fear of death and anxiety about death had increased since they began working with PWAs (Moore, 2001). Therefore, the role of caregiving can have dramatic consequences for informal caregivers. Social support that an individual has access to which can help in their time of need can alter the impact of stress. Social support can be in the form of individual, group or organizational support. For example, consistent with previous conceptual and empirical work on caregiving, social support may strengthen caregiver well-being directly or it may cushion the effects

of stressful circumstances (e.g., Pearlin, 1981). In a study by Moore (2001) of PWA caregivers in Togo, 48 % of caregivers relied on prayers, 57% relied on their faith to keep their sanity, and 83% shared with other caregivers to get support and ease their stress. Social supports and coping mechanisms "can intervene at different points along this [stress] process, thereby mediating the outcomes" (Pearlin et al., 1981, p.342). Also, Turner and Catania (1997), in a study on informal caregivers to PWAs in cities in the United States, found that support for AIDS caregivers assists in buffering the effect of caregiver burden and has positive effects on well-being. Therefore, receiving social support with caregiving is necessary in decreasing perceptions of strain for caregivers with the highest caregiving demands.

Accessing social support can also be a contributing factor in psychological stress for caregivers who are constrained by health problems, for example, individuals who are stigmatized by the role of AIDS caregiver, or who are too sick to access social support services. According to Flaskerud and Lee (2000), support groups may not be easily attainable because of many factors such as lack of transportation and respite care, as well as other factors such as stigma and isolation.

Coping mechanisms, which are the strategies people use to prevent or control events or situations they encounter in their different roles, also play a prominent role in mediating or altering the impact of stress. Coping refers to any kind of response to stressors or events that facilitate or inhibit, evade, or control emotional distress (Pearlin & Schooler, 1978). Lazarus and Folkman (1984) define coping as behaviours and cognitions that individuals employ to manage stressful situations and negative emotions.

According to Lazarus and Folkman (1984) there are two types of coping strategies: problem-focussed coping and emotion-focussed coping. Problem focussed coping are actions or strategies directed towards managing the problem or stressor and emotional focussed coping are strategies used to regulate emotional responses to the problem or stressor. Until recently, coping theories had only been developed for and focussed on adults. Although studies on children and coping strategies are beginning to emerge in the literature, there is very little knowledge concerning the ways young children cope with stress and stressors in their lives. Therefore, the conceptualization of children's coping emerged from the theoretical models of adult coping. Nevertheless, evidence suggests that children's coping abilities may differ from adult coping strategies (e.g., Arnold, 1990; Compas, Banez, Malcarne, & Worsham, 1991; Elias, Gara, & Ubriac, 1985; Fields & Prinz, 1997). Coping is tied to stress, because coping can only be examined in the context of responses to stressors. Children are faced with numerous stressful situations or environments that require coping responses (Fields & Prinz, 1997). Children and adolescents may be limited in their coping strategies by cognitive, affective, expressive, or social facets of development and by lack of experience. Children have very different environments from adults, primarily because children have little or no control over their situations or circumstances (Fields & Prinz, 1997).

There are various patterns of coping that children use to avoid stress. Brenner (1984) lists four ways used by children to avoid stress: denial, regression, withdrawal, and impulsive acting out. Denial is evident when children act as though the stress or stressors do not exist. Regression is evident when children act younger than their age, resulting in

more attention and therefore easing their stress. Withdrawal is evident when children take themselves out of the picture by running away from the stressors or stressful environments, or simply become invisible. Impulsive acting out is evident when children are trying to avoid the past or the consequences of the current situation by making others angry at them (Brenner, 1984).

There are also five other coping mechanisms that children use to accept and face stress (Brenner, 1984). Vaillant (1977) provides us with these five coping mechanisms: altruism, humour, suppression, anticipation, and sublimation. Altruism is used when children forget about their problems by helping others, especially family. Humour is used by children to joke about their challenges and problems, or to express pain and anger. Suppression allows children to put aside their problems temporarily. Anticipation is used by children to foresee and plan for another stressful event. Sublimation is used by children who find ways to release their anger, fears and sadness by becoming preoccupied with other things such as games or sports (Vaillant, 1977).

Research studies linking the stress process, caregiving and orphanhood are beneficial because they provide us with an understanding of the impact of stress on orphans and caregivers. Given that the stress process is a theory that originated from North America, its usefulness may be different in various contexts and especially in sub-Saharan Africa.

CHAPTER IV METHODOLOGY

This thesis used data collected as part of an evaluation of home based care (HBC) programmes that were part of the larger HIV/AIDS Prevention and Care Programme (HAPAC) in Kenya. Data were collected for the larger project using focus group discussions (FGDs) and in-depth interviews (IDIs) with members of a sample of CBOs that were selected for the evaluation and their clientele.

HIV/AIDS Prevention & Care Project (HAPAC) managed by Futures group Europe, is the major provider of home-based care and support (HBC) in Nyanza province of Kenya. The programme is implemented in Migori and Rachuonyo districts by Catholic Relief Services (CRS) and Nyanza-wide by a network of 126 Community-Based Organizations (CBOs), which receive training and support supervision from MajorStep Consultants. In addition, Mildmay International provided training for provincial and district Ministry of Health staff in home based care to build the capacity of health care systems in Nyanza.

Futures Group Europe contracted Steadman Research Services (SRS) and Dr. Isaac Luginaah at the University of Windsor to conduct an evaluation study of the HAPAC HBC programme in Nyanza, to determine impact levels, especially on the lives of those infected and affected by HIV/AIDS, and also to explore the success of the programme in terms of its responsiveness to local needs (see also Futures Group Europe, 2003). The study was carried out between Sept 2002 - August 2003.

Study area and population

The HBC programme and its evaluation were conducted in Nyanza Province, Kenya. Nyanza province is in the western region of Kenya bordering the northern and eastern shores of Lake Victoria. This region is primarily inhabited by the Luo and Kisii people. The Luo are concentrated in the southwest of the province and the Kisii people occupy the Kisii Highlands, 50km east of Lake Victoria. The Kisii comprise the country's sixth largest ethnic group and the Luo comprise the third largest group, with approximately 6.3% and 13% respectively of the national population. They are the second largest ethnic group in Nyanza, after the Luo, with approximately 13% (Urgent Africa, 2003).

Study Sample

Selection of the CBOs for this study was done in two phases. The initial phase involved grouping the CBOs (Nyamoyo, Omeko, Yofak, Konyango, Ruma, Ndere, Spring Ministry, Chungni Kimiyi, New Hope and Orongo) into categories based on their main objectives, target groups and their activity focus (see also Futures Group Europe, 2003). In the second phase, the two CBOs (New Hope and Orongo) that were involved in the study were ranked by MajorStep Consultants who had been involved in the HAPAC-HBC project from the onset (see also Futures Group Europe, 2003), based on key indicators (see Table 1) that were used to evaluate the performance. Each CBO was then given a score for each of the listed indicators. Individual scores were then summed up to come up with a final score and rank. It was found that all the top performing CBOs involved

with orphans and their caregivers were Luo, with the best performing CBO being Orongo. However, in order to represent the Kisii people in the study, the highest ranking Kisii CBO - New Hope was also included in the study. Hence, the Orongo and New Hope CBOs were the ones contacted for data collection.

Sampling Strategy and Sample Selection

Table 2 provides a summary of the number of FGDs and IDIs that were conducted. There were 2 FGDs with 16 CBO members (13 females and 3 males) who were chosen by their respective CBOs to participate, and 6 FGDS (3 each for boys and girls) with a total of 31 orphans (15 males and 16 females) who participated in the discussions. Six IDIs were conducted, 2 with CBO leaders (2 females) and 4 with informal caregivers (3 females and 1 male).

The sampling of orphans and caregivers was done by Steadman Research Services (SRS). This was done by using references (membership/beneficiary list) from respective CBOs. For the caregivers, the inclusion criteria was that participants must have been involved with their respective CBO for at least six months. Based on the broader interest, only children who were “total” orphans (lost both parents) for no more than two years, aged 11-14, and registered with a CBO for at least six months were included in the FGDs for boys and girls. Two years was used as the cut off for children who had been orphaned in order to minimize recall bias from the children. MajorStep Consultants facilitated the selection of the CBO leaders for face-to-face interviews, trained the CBOs on all aspects and monitored their performance. The District AIDS

Control Council (DACC) are the link between CBOs and government/institutions/hospitals and were responsible for supervising all such groups involved in health matters, as well as taking part in training.

Table 1 Indicators for CBO Evaluation and Ranking Indicators
1. Background and Experience
2. Institutional Capacity
3. Mobilization
4. Training
5. Meeting targets
6. Provision of quality care
7. Number of clients reached
8. Participatory monitoring and self evaluation
9. Use of resources
10. Ability to scale up

Table 2 Number of Focus Group Discussions and In depth Interviews		
Activity	Group	Number of Participants
Focus Group Discussion	CBO Members	16
	Orphans	31
In Depth Interview	CBO Leaders	2
	Caregivers	4
Total		53

Data Collection

Data collection was carried out by Steadman Research Services between September and November 2002. Steadman Research Services is a private research company with multilingual staff that has been involved in survey and interview-based data collection for evaluation of various HIV/AIDS programmes for over 5 years. Qualitative data were collected using in-depth interviews and focus group discussions with orphans, caregivers, and community-based organizations.

Data from in-depth interviews (IDIs) consisted of views, opinions, attitudes and knowledge about the situation of orphans and informal caregiving. Focus group discussions were used to collect data on various themes that would enable the contextualization of orphanhood, orphan caregiving and the impact of community-based organizations within the study area.

Focus Groups

Focus groups were used for the orphans and for CBO members because it was felt that within the sociocultural context, participants such as orphans would be more responsive and spontaneous in informal, semi structured group settings. For orphans, a focus group setting can provide a forum where the children can generate their own questions, and answer these questions freely in their own terminology. FGDs are beneficial for the orphans in this study because they allow the orphans to communicate with each other and share thoughts and experiences regarding the stressors they are experiencing. For CBOs, a focus group setting allows each member to talk openly and

share perspectives on the impact of the support they provide with other members who may not have encountered the same obstacles. FGDs tend to facilitate considerable interaction on given topics in a limited span of time (Kidd & Parshall, 2000). Lunt and Livingston (1996) characterize the focus group as a microcosm of 'the thinking society', capable of revealing the processes whereby social norms are collectively shaped through debate and argument. Focus groups reveal the way in which particular individuals' opinions are accommodated or assimilated within an evolving group process (Kidd & Parshall, 2000). Individual inputs weave and clash through the process of dialogue and argument between individual participants as group members ask one another questions, exchange anecdotes, and comment on one another's experiences and points of view.

In Depth Interviews

In-depth interviewing is one of the most commonly used data collection methods in qualitative research. Qualitative in-depth interviewers are trained to explore issues in depth from an unbiased perspective. In-depth interviews are not as structured as quantitative questionnaires. Questions tend to be open ended and allow flexibility in probing areas of particular interest and relevance to the client. The in-depth interview (IDI) takes seriously the notion that people are authorities on their own experience and are therefore best able to report those experiences.

Face to face, in-depth interviews are valuable for exploring the impact and perceptions of informal caregivers and community-based organizations. In this case face to face conversations, semi structured by a checklist of general topics, were used for

interpreting issues related to home based care in the context of HIV/AIDS. In this study, the strength of using in-depth interviews provided a forum for caregivers and CBO leaders to share their own experiences and perceptions on a deeper level than FGDs. In-depth interviews were conducted with participants to help go beyond expressed concerns to begin to understand the role of deeper issues like quality of life, the challenges facing caregivers and also CBOs in their attempts to provide care to their clients. This method of inquiry allows the meanings attached to what presents itself as a complex issue to be understood in the context of everyday life rather than just in the context of the HIV/AIDS epidemic alone.

The Research Instruments FGD and IDI Checklists

The research instruments for this study (See Appendix A) consisted of checklists of topics to be discussed in each group and interview. Checklists went through several stages of review and revision by the researchers from Futures Group Europe, Steadman Research Services and the consultant from the University of Windsor. These were pre tested by Steadman researchers for clarity, organizational flow and length.

Checklists probed several different topics related to orphans, caregivers, CBOs and home based care in the context of HIV/AIDS including: nature of care and support provided by CBOs to their clients (orphans and caregivers), psychological problems, quality of life, need assessments and challenges. In addition, the checklists were designed to be flexible, allowing the interviewer to follow up issues raised by participants that were not on the checklist. To maintain consistency, all FGDs and IDIs were

conducted by the Steadman researchers. Except for the interviews with DACCs and Majorstep which were in English, the two FGDs and remaining IDIs were conducted in the local languages (Luo or Kisii).

Prior consent was obtained for participation of the orphans from their respective CBOs, caregivers and from other caregivers taking part in the discussions. No attempt was made to distinguish households where children were orphaned as a result of AIDS or to determine whether children or caregivers were HIV infected. Counsellors were also provided for orphans at the end of each focus group discussion. All discussions were tape recorded and transcribed verbatim in the Luo and Kisii languages in order to accurately represent respondents views and later translated into English. The nature of the study was explained to each participant and each was informed that it was their own choice whether or not they participated.

Ethics

Ethical consent was obtained through Steadman Researchers in Kenya. Steadman Researchers did the data collection and solicited participants consent by reading out a letter and explaining to the participants what the study was about and what their rights were. The nature of the study was explained to each participant and each was informed that it was their own choice whether they participated. Ethical clearance was also obtained from the Research Ethics Board (REB) at the University of Windsor. REB helps to ensure that ethical principles are applied to research involving human subjects.

Data Analysis

The analysis for this thesis was guided by themes coming out of the stress process theory (sources of stress, manifestations of stress, coping mechanisms) related to orphans, informal orphan caregiving and community based organizations in the context of HIV/AIDS. For this thesis, I analysed the data by looking for the primary and secondary stressors that affected the daily lives of the orphans and informal orphan caregivers. I also looked for other stressors that manifested or proliferated from the original primary and secondary stressors experienced by the orphans and informal orphan caregivers. Furthermore, I looked for the coping mechanisms that the orphans and informal orphan caregivers used to mediate or moderate the stressors they experienced. Finally, I looked for the social support and resources provided by the CBOs and the impact that they had on the orphans and informal caregivers.

The key categories of responses for questions asked in the interviews were created prior to coding of interviews. Line-by-line coding was used (see Strauss & Corbin, 1990). FGD transcripts from CBO members and orphans were coded using different coding schemes. However, a different coding scheme was used for the IDIs from individual groups (CBO Leaders, Caregivers). The transcripts were read and reread in order to generate explanations as to the impact of CBOs on orphans and caregivers, as well as the different perspectives of orphans and caregivers, in the Nyanza province of Kenya. Key categories were reviewed several times in order to ensure that concepts pertaining to the same phenomena were placed in the same category.

A number of steps were taken to ensure consistent analysis of the data (see Baxter & Eyles, 1999; Kidd & Parshall, 2000; Krefting, 1991; Patton, 1987). A code-recode procedure was conducted. In qualitative research, "coding is an integral part of the analysis, involving sifting through the data, making sense of it and categorizing it in various ways. The analytic choices made here about what to code and how will influence every stage of the research from here on" (Darlington & Scott 2002, p. 145). Further, considering that the transcripts were translated from Luo and Kisii into English, member checking was used as a technique to ensure the validity of the findings. Participants were asked whether what had been translated was what they meant in the discussions in order to reduce misrepresentation (see Baxter & Eyles, 1999; Krefting, 1991). N5 (Scolari) qualitative software was used to facilitate coding and data analysis.

CHAPTER V RESULTS

Introduction

The main purpose of this study was to explore the perspective of orphans, informal orphan caregivers and the impact of community-based organizations, in the context of HIV/AIDS in Nyanza, Kenya. The study is informed by the Stress Process Theory (Pearlin et al., 1981; 1997) and focuses on how the three conceptual realms of the stress process can help us understand the stressors affecting the lives of the orphans and the informal orphan caregivers, the manifestations of these stressors and the coping mechanisms employed by the orphans and caregivers, as well as the social support provided by the community based organizations.

Sample Profile

Orphans

There were six focus group discussions with orphans (3 each for boys and girls). The number of orphan participants in each focus discussion ranged from 4-7 children. There were 31 orphans in total (15 boys and 16 girls) who participated in the discussions, of these 17 orphans ages were specified in the transcripts and 14 were not. There were 7 orphans aged 11 years, 3 orphans aged 12 years, 3 orphans aged 13 years and 4 orphans aged 14 years old. The other fourteen orphans' ages were not specified, however, 5 orphans were 13-14, 7 orphans were 11-14 and 2 orphans were 11-12. All participants were "total orphans" (those who had lost both parents) for no more than two years (in order to minimize recall bias).

Informal Orphan Caregivers

There were four in-depth interviews with informal orphan caregivers (3 females and 1 male). The caregivers ranged in age from 32-56 years. One female caregiver, who was 50 years of age, was a widow who took care of 15 children, 6 of which were her own children and 9 of which were orphans. Another female caregiver, who was 56 years of age, had a sick husband and took care of her five grandchildren. Another female caregiver, who was 35 years old, was also a widow who took care of 10 children, 6 of which were her own children and 4 of which were orphans. The final caregiver, a male who was 32 years old, was an orphan himself who took care of 5 children, 3 of which were his own children and 2 of which were orphans.

Community-Based Organizations

There were two focus group discussions with the CBO members (13 women and 3 men) and two in-depth interviews with CBO leaders (2 females). The members of the New Hope Children's Centre and Orongo Widows and Orphans group were all farmers and small business owners. However, the members of Orongo Widows and Orphans group were all widows. The CBO leader from New Hope Children's Centre is a preacher, evangelist and the co-ordinator of the centre and the CBO leader from Orongo Widows and Orphans is the chairperson and co-ordinator of the group.

The major themes that emerged in this study through the analysis of the FGDs with orphans and CBOs members and IDIs with caregivers and CBO leaders are provided on Tables 3 and 4. These themes are: sources of stress, manifestation of stress and coping mechanisms. These themes are further categorized into sub-themes.

Table 3 Stress Process Themes for the Orphans			
Primary Stressor	Secondary Stressor	Manifestations of Stress	Coping Mechanisms
Death of Their Parent(s)	Concern Over Who Would Take Care of Them	Orphan's Emotional Distress	Withdrawal Sublimation Altruism
	Their Relationship With the New Caregiver and Moving to a New Residence	Orphans are Treated Differently in Their New Home	
	A Change in Responsibilities/ Duties	Orphans are Forced to Work	
	The Separation from Their Sibling(s)	Not Allowed to Visit Sibling(s)	
	Problems at School	Absent From School	

Table 4 Stress Process Themes for the Informal Orphan Caregivers			
Primary Stressor	Secondary Stressor	Manifestations of Stress	Coping Mechanisms
Caring for Orphans	Lack of Community Support	Challenges of Caregiving and Multiple Roles	Spirituality and Religion Income Generating Activities CBO Membership CBO Training and Education CBO Care and Support
	Not Being Able to Work	Providing Basic Necessities and School Fees to Orphans	
	Treatment of Orphans	Effects of Problem Children	

Sources of Stress-Primary and Secondary Stressors

ORPHANS

Primary Stressor

The Death of the Parent(s)

According to Pearlin et al. (1981) primary stressors originate from the stressful event or situation itself. All research supports the conclusion that the death of a parent is traumatizing in a child's life. Given that the literature on childhood stressors is consistent with the death of a parent being the number one stressful event in a child's life (see Brenner, 1984; Coddington, 1972), I am assuming that the primary stressor for the orphans in this study is the death of their parent(s). For the majority of the children, parents are the most important people in their lives, so that when a parent dies, life as the child knows it, is upset and irrevocably changed. Children orphaned by HIV/AIDS are acutely affected as their parents become sick and die. The illness and loss of one or both parents sets orphans on a long path of painful and distressing experiences (Worldvision UK, 2004).

Orphans in this study miss their parents and the life they used to have with them. They think about the good things that their parents used to do for them and how much they loved them. Some orphans explain how, if their parents were still alive, they would not suffer and be emotionally abused. They would also not lack necessities, such as books, clothing and shoes:

Sometimes when the person I stay with scolds and quarrels with me I feel so bad and ask myself could I be suffering the way I am suffering if I had my parents (Female Orphan).

Where I stay other children are bought clothes for Christmas but I am not bought any. There are things that can be done to other children while you will be neglected because your parents are dead (Female Orphan).

Secondary Stressors

Secondary stressors are those which result from the primary stressors. In this research, the secondary stressors presumably resulting from the death of the parent(s) for the orphans included: concern over who would take care of them; their relationship with the new caregiver and moving to a new residence; a change in responsibilities/duties; the separation from their siblings; and problems in school.

Concern Over Who Would Take Care of Them

Emerging from this analysis as a secondary stressors to affect the orphans' lives is the concern over who would take care of them after the death of their parents. Most of the orphans were never told by their parents who will be taking care of them and very few of the orphans indicated any awareness of arrangements their parents made before their death. Some orphans were too young to remember, while others were away with other relations when their parents died. Therefore, existing arrangements were made with the extended family members. The majority of orphans were sent to live with their grandmothers because there was no one else to stay with. However, as depicted by the following statement, a few orphans did not know of any or have concrete plans as to who would take care of them now that their parents are dead:

I was told my uncle would take care of me... then I was told that my grandmother would take care of me... Before my mother died she told me that I would be staying with my grandmother (Female Orphan).

Most of the orphans reported still living with the family they were sent to live with. For those who changed homes, a few were taken in by 'good Samaritans'. One orphan indicated that:

I lacked money for school, one day at the bus stop, one woman asked me if I could help her carry some tomatoes to her house. In the house she asked me some questions about my life and I explained my situation to her. So she said that there was no point of going out again because she will think of a way to help me. So I started staying with her (Male Orphan).

Not knowing where you would live or who would take care of you can be a very stressful and worrisome experience for these orphans. However, one major obstacle that prevents parents from making adequate arrangements for their children before their death is the culturally rooted hindrance on the discussion of succession issues while parents are still alive (Nyandiya-Bundy and Bundy, 2002). Aside from not knowing who will take care of them, these orphans also faced the acclimation of a new life with a new caregiver and moving to a new residence.

Their Relationship with the New Caregiver and Moving to a New Residence

Also emerging from the analysis as a secondary stressor is living with a new caregiver in a new residence. Consistent with Gilborn et al. (2001), orphans live with and are being taken care of mostly by extended family such as aunts, uncles, stepmothers, brothers and sisters, and grandmothers, while a few orphans are in the care of their pastor

or another community member. The majority of orphans stated that they were staying with their grandmother, however, some of the orphans were now living with a stepmother, an aunt or an uncle, since their parent(s) death. When there was no where else to turn and no extended family members left to stay with, a few orphans found themselves living with members of their community, including pastors.

The stress of living with a 'new' caregiver is mostly compounded/aggravated by the fact that orphans have to move to join their caregivers in new places of residences. Almost all of the orphans had to move to a 'new place' to live. They had to move to join their caregivers.

We were staying in Kisii town but when my parents died our grandmother who is taking care of us brought us here (Male Orphan).

We were staying in Nairobi but when our father and mother died we were brought back to stay with our grandmother (Male Orphan).

When orphans were taken by a new caregiver and moved to a new home either in the same village or in a new village far from home, in most cases, they were confronted with new roles and responsibilities.

Change in Responsibilities/Duties

The orphans in this study reported that their responsibilities involved a variety of tasks or household chores, which included: washing clothes, farming, cooking, planting, fetching water, washing utensils, collecting firewood, sweeping the house, slashing the homestead, looking after the cattle. Describing their normal daily lives, one orphan

commented that her duties had increased since her parents died:

In the morning when I wake up, I go to fetch water, from fetching water I wash dishes and then I make breakfast. After making breakfast I wait for lunchtime. I prepare lunch after which I clean the dishes then I have a bath. My work is to go to the farm and work and then I help in household chores like fetching water, washing utensils, then I go to school (Female Orphan).

For those living in financially constrained situations, their tasks sometimes included doing casual jobs to pay for school fees, going to the shamba³, caring for children and selling sugarcane. One orphan stated how he would work to pay the school fees for the children in the household:

I am the one taking care of the children. When they are sent out of school because of money, I do casual jobs to earn money and pay for them. I also teach them about preparing the farm for planting and farming in general. I also sell sugarcane to get money to buy soap, cooking oil and other necessary things (Female Orphan).

While most orphans reported doing their chores on the weekend, they also reported that the irregular nature of their daily tasks only helped to further complicate their lives. These orphans frequently talked about how sometimes they were told to “do the chores alone” or that the other children were told “not to help them” (see also Makame et al., 2002).

Others do not even fetch water, they abuse me and send me to go and fetch water alone and collect firewood (Female Orphan).

³ A Shamba is a small subsistence farm/garden

When my brother is not around, their mother tells them not to work...there are other children in our home but the don't assist me (Female Orphan).

Apart from the tasks they are required to do alone, some of the orphans are forced to live away from their sibling(s).

The Separation from Their Siblings

When the issue of finding extended family caregivers for orphans is difficult, the associated problem that emerged in this analysis is the separation of orphans from their siblings. Most of the orphans in this study have at least one brother or sister, or both. Although most separation of orphans was to facilitate caregiving. Some of the orphans were separated so that their brother(s) or sister(s) could attend boarding school:

I have not stayed together with them [since our parents passed away] (Female Orphan).

I have two grandmothers. I am staying with my paternal grandmother and my brother is staying with my maternal grandmother. My grandmother took him so that he can go to school (Male Orphan).

Other orphans' siblings who have been separated from them were living with other relatives. Almost all of the orphans were separated from the sibling(s) since the death of their parents in order to share the economic burden of orphan care. For the most part, grandmothers were the primary caregiver.

Orphans who have been separated from their siblings and not allowed to visit them may also feel isolated, particularly when their brother(s) or sister(s) have been taken away from them to live somewhere else or attend boarding school. This is further

heightened when the orphans themselves are not able to attend school or have been absent from school for a long period of time.

Problems at School

Another emerging secondary stressor in this analysis to affect the orphans' lives' is the problems they face at school. Most of the orphans have remained in the same school since before their parent(s) died, however, a few changed or were away from school for financial reasons, because of the death of their parents, when their school closed or when they were too sick to attend school. One orphan stated that she "had been stayed away from school for two years because she was sick". Another orphan indicated that he "took some time off before going to school after his father's death".

As expected, the death of the parent(s) resulted in financial constraints which further reinforced the absenteeism from school. This is evident in the following quotes:

And at times you are told to miss school by the person paying the fees. Maybe she does not have the money, or you have to do work for her, so she will tell you to just miss [school]
(Male Orphan).

It was a long time before I went back to school. There was nobody to pay school fees for me...(Male Orphan).

When orphans have to work to either pay for their own school fees or help support themselves, this puts stress on them and their lives and lowers their self-esteem, especially when their caregiver is helping to pay for school fees for their own children.

The orphans in this study experienced numerous stressors and difficulties in their daily lives since the death of their parent(s). Therefore, I believe that the secondary

stressors they experienced are the result of the death of their parent(s). Hence, the death of their parent(s) is the primary stressor to affect these orphans lives. Nevertheless, their caregivers tried to provide the care and support the orphans need.

INFORMAL ORPHAN CAREGIVERS

In some cases, what is viewed as a situation in which the elderly provide childcare is actually more akin to a situation of mutual support with increasingly frail grandparents becoming the care recipients of grandchildren.

Informal orphan caregivers are mostly extended family, predominantly stepmothers and grandmothers. Most caregivers are women and care is provided in the home. Caregivers also have children of their own ranging in age from 2-17 years old. With respect to the informal orphan caregivers, the primary stressor identified was caring for the orphans. Three secondary stressors were identified as a result of the role of caring for orphans: lack of community support; not being able to work; and the treatment of the orphans.

Primary Stressor

Caring for Orphans

Emerging as the primary stressor in this study affecting the caregivers' lives is the role of caring for orphans. With the caring for orphans on top of their normal, everyday duties, as well as their own families, puts tremendous stress and demand on the lives of the caregivers. Commenting on the difficulties caregivers face in taking care of orphans, one participant observed that:

It is a very hard task. It is very difficult especially when the child happens to be a boy. He reaches a stage where he becomes stubborn, such that for instance even if you send him he won't come back on time. This is a difficult task (Female Caregiver).

The challenges of caring for orphans is further aggravated by the health problems and age of caregivers. The caregivers in this context can be referred to as the 'hidden victims' of HIV/AIDS. The burden of caregiving produced psychosocial health problems for caregivers such as: fatigue, lack of sleep and eating problems. Other psychological problems experienced by caregivers are: stress, loneliness, anger and frustration, isolation and stigma. The key worry, however, is the future of the orphans. As evidenced in the following quote, this is more disturbing when the caregiver is a grandparent:

In fact there is a problem taking care of these orphans because I am getting old and cannot do a lot for them (Female Caregiver).

Almost all of the caregivers in this study are sick and therefore have trouble feeding and caring for the orphans, as stated in the following quote:

I became sick, that is the reason why I do not have enough food to eat even though I have a big farm (Female Caregiver).

As indicated in the following quotes, caregivers have been caring for the orphans since the death of their parents:

Their parents passed away and I had no where to take them. I was left with all these children to take care of...I have stayed with them for 2 years (Female Caregiver).

Since their father died in 1997, yes, I am now with them because there is no where I can take them since both their parents died. I am the only grown up alive (Female Caregiver).

In some cases, other extended family members are able to help. Grandfathers and daughters-in-laws sometimes take over caregiving when the primary caregivers are unavailable.

When I am not around, there is the wife of their elder brother who takes care of them and my wife is here at home, they share this burden of taking care of them (Female Caregiver).

I have never been away. I am always there I don't go anywhere (Female Caregiver).

Caring for their own children is a full-time job for these caregivers. Therefore, taking care of orphans as well can be considered the equivalent of 'over time' work. Caregivers stated that they have numerous daily tasks and responsibilities which include providing food and basic necessities, farming, fetching water, ploughing and household chores:

When it is ploughing season, I wake up, sweep the floor, make porridge or even if it is tea. Even if it is going to the market, I go and buy vegetables or omena fingerlings and prepare so that when children come for lunch they find food ready. I then have a slight rest, I can rest up to around three, then I wake up, wash the dishes, fetch water then take a bath. I can prepare for them or they can do it on their own when they come back from school after I have organized everything (Female Caregiver).

Emerging from this study is a development in caregiving whereby certain individuals can be referred to as "Good Samaritans". These are grown up orphans who are beginning to take care of other orphans, the advantages of which need to be overemphasized in the current context. One orphan explained how he takes care of other orphans because they are just like him:

I am an orphan, with this experience I decided to take care of them because they are orphans like me. I told them that my parents also passed away and left us when we were younger

than they are. Help the orphans because they are supposed to be helped and remember you will be blessed. If an orphan wrongs you please never revenge just correct him or her (Male Caregiver).

Caregivers face numerous obstacles when they take on the role of caregiving for these orphans. These obstacles turn into secondary stressors that stem from the primary role of orphan caregiver.

Secondary Stressors

Lack of Community Support

A secondary stressor affecting caregivers' lives is the lack of community support in caring for the orphans. Considering the overwhelming number of orphans, one could argue that community resources are already over-stretched. Nevertheless, the help the caregivers did receive was very little and it was in the form of counselling. One caregiver explained how a community helped her by providing counselling on orphan care:

The Mwamasarore village is the one that helped me through... the child was accepted to school and I was told to be close to the child so she does not feel that her parents are away (Female Caregiver).

Another caregiver stated how she wanted the community to help with fund raising to buy farming essentials when she was sick, however, the community did not support her:

No, I wanted the community to contribute in a fund raising but nobody came. I wanted to use the money to hire a tractor for digging and buying fertilizers. That is the time I had a stomach problem but nobody turned up. That is the time I started experiencing stomach problems such that I was unable to work. My neighbours, they did not come. No, in this area people do not give any support. I do not know whether it

is because of poverty maybe they are not used to assisting children like orphans (Female Caregiver).

However, caregivers believed that the community should be providing them with more assistance to care and support orphans. They felt that the community should offer to take one child each, instead of one person caring for a dozen children.

As evidenced by the following quotes, a few caregivers felt that the community should pitch in and share in the care of the orphans, school fees, and help donate funds to build a hospital, especially when some of the caregivers are sick:

They do not help me, they do not even know the (children's) names. They could have sat down and decided someone to take one child another one takes another child for them to help me...If they wanted to help me, they would have done so since there are more than 12 children left behind. Each one should have offered to take in at least one child. This would have helped a great deal but they didn't do this (Female Caregiver).

It could be better for me if they can help me in paying school fees and by providing these children with food. The problem I have is school fees and farming because I am sick, there is nobody to support them... There are so many problems in our community because even if you want to be helped, the other person is also sick. You know that tomorrow somebody will die, who will help you then? (Female Caregiver).

The lack of community support is further complicated when the caregivers are unable to work anymore.

Not Being Able to Work

Another secondary stressor in this analysis that affects the caregivers' lives is not being able to work anymore. Some caregivers cannot work or farm their land because of

illness and therefore have trouble supporting orphans, as evidenced by the following quote:

Before I got sick I was a farmer and I used to harvest more than we need for food. Therefore the surplus, I used to sell and get some 20/-shillings, when their parents died things changed. I used to harvest 22 sacks of maize, one sack of sorghum, so part of it we could sell to get money and buy some soap. This year getting food is a problem in this house (Female Caregiver).

The problem I have is school fees and farming because I am sick, there is nobody to support them I am always in bed just the way you found me if I get well I will be able to support them (Female Caregiver).

Other caregivers try to work when they are well, but they are still troubled by the fact that they are the only breadwinner in the family and are unable to fulfill the needs of the orphans, as evidenced by the following quote:

I am the sole breadwinner so I have to look for food for them, If there is anyone who is sick I take him or her to hospital. Those are the only things I can do for them (Female Caregiver).

While the caregivers battle to try to provide for the orphans they still manage to treat the orphans fairly, even though they have problems caring for them.

Treatment of Orphans

Another emerging secondary stressor to affect the caregivers' lives is the treatment of orphans. Some caregivers try to be honest with the orphans and not be cruel to them when they make mistakes. As indicated by the comments below, caregivers try to be open and understanding with the orphans:

In fact when taking care of these orphans, you must have a problem. You do not need to be harsh on them. You need to be open to them in a way that they understand that they are orphans and make them know that you are ready to help them as they are (orphan) (Male Caregiver).

When the child has been given bad advice the child becomes nervous and edgy. So you have to talk to the child. You don't have to be harsh, be polite, it will reach a time that the child will open up and tell you what he feels is wrong. You must just monitor the child closely and try to understand him or her and know what is in his/her mind. There are many people who are staying with orphans and are too busy to even know what the orphans have in mind (Female Caregiver).

Some of the caregivers explained how they try to treat orphans equally and not separate them from the other children:

In this case, for example when we are eating, I do not separate them. I just treat them like my children. I just make them feel that they are loved. We stay together, eat together and they feel at home (Male Caregiver).

I have many responsibilities like now if anyone has any problems with these children I should know why. And if these children misbehave by, for example, destroying peoples properties, I should be the one to solve that problem and settle it (Male Caregiver).

Other caregivers try to help the orphans the best they can so that “the orphans feel that they are well taken care of and do not think about their parents so much”. As indicated by the following quotes, caregivers sometimes turn to God to help them:

I can feed them the way it is required, it is only through God's help that they have been able to survive. They grow up because of God's power, even if it is difficult there is nothing we can do... I know how to handle them, I do not humiliate them in any way. I tell them this is what God has provided for us to eat. Like you know when you abuse the child that is when they start getting confused on what to do. So I pray to God to

take care of us the whole day and actually he does that. He feeds us both spiritually and physically...(Female Caregiver).

I need money for school fees, books and farm workers, then I will not have much problems because the children will go to school and because I have a big farm, I will get enough food. Also if God can touch anybody's heart so they assist the orphans with things they need like beddings, clothes and other things. You know when you provide everything like paying school fees and providing food they do not think much about their parents (Female Caregiver).

However, some caregivers simply do not know how to help the orphans because they need things the caregivers are unable to provide.

Caring for orphans, providing basic necessities, and paying for school fees is a lot for these caregivers to handle, especially when the caregivers are sick, unable to work, have little or no community support, or have families of their own to care for. The primary and secondary stressors the orphans and informal orphan caregivers experience in this study can manifest and create other stressors within the realm of their lives.

Manifestations of Stress

Some stressful life experiences create more stress (Pearlin et al., 1997), putting in motion a course of events that lead to distress. Emerging from the analysis of the sources of stress are manifestations of the primary and secondary stressors experienced by the orphans and informal orphan caregivers.

ORPHANS

Many of the challenges faced by orphans since the death of their parent(s) are escalated by a lack of financial resources. Orphans have encountered problems such as a

lack of free time to study because of their responsibilities, lack of food and clothing, new caregiver and residence, sibling separation, lack of money which prevents education, doing household chores alone, being humiliated by other children who do not help with responsibilities, abusive caregivers and denial of food. As a result of the stressors experienced by orphans (discussed above), they have also experienced other stressors that are manifest or were created from the primary and secondary stressors originally experienced. These manifestations are: emotional distress, absenteeism from school, being forced to do work, being treated differently at home and not being allowed to visit siblings.

The orphans in this study feel that they would not have these problems if their parents were still alive to care for them. Consistent with Gilborn et al. (2001) who found that compared to children who have parents to care for them, AIDS orphans often face a greater risk of lacking basic necessities, physical and emotional abuse, malnutrition and mistreatment.

Death of the Parent(s)-Orphan's Emotional Distress

The resulting impact of the death of an orphan's parents is the manifestation of emotional distress, whereby orphans constantly worry about their parents and wonder what their lives would be like if they were still alive. When orphans think about their parents they tend to worry about many things including why their parents died, the difficulties they have faced since their death, and the lack of support and assistance that they receive.

You wonder what killed your parents. Sometimes when I sit and think, I just feel that if my parents were alive I could get things I need, this is mostly when I lack something (Male Orphan).

Maybe I do not have a book so I think that if my father were alive he would have bought for me some things. I think that if my father were alive I would not ask for things. Maybe I do not think about those...(Male Orphan)

Orphans have encountered many problems since the death of their parents. Associated with these findings is the notion that orphans are treated differently in their new homes.

New Caregiver and New Residence-Orphans are Treated Differently at Their New Home

A new caregiver and the move to a new residence manifests in the orphan's lives because in their new homes, most orphans are treated very differently from the life they used to lead when their parents were still alive. Orphans are faced with such issues as less care than other children in the home, neglect, abused by caregivers or by other children in the home, denied visitation, refusal of education, and denial of food and basic necessities. A few of the orphans explain how they are abused by those who live in the home, are denied food and are then sent to work:

A good person or parent will take us like orphans and will not scold us but most people scold us or give us more work to do than their own children... Sometimes they beat us for nothing even when we have made a mistake together with their children the blame is put on you and may be the other children did it (Male Orphan).

Orphans are just left alone, they wander house to house looking for food and they are even abused to stop eating like gluttons... There are people who like begging for food in other people's homes. They should not come to disturb us to give them food.

Even when we don't have vegetables they still insist that they need food (Male Orphan).

Other orphans state how the caregiver's children in the home are bought clothes and shoes, but they are ignored because their parents are dead. They also explain how they are abused by the other children in the home:

Where I stay other children are bought clothes for Christmas but I am not bought any... There are things that can be done to other children while you will be neglected because your parents are dead (Female Orphan).

Sometimes when you are meant to go somewhere far, you are told to go on foot. When you refuse to go, they say you are rude... They buy shoes for other children while you are left without shoes... The other children mistreat them when their mothers are not around (Female Orphan).

Orphans are treated differently because they do not have parents and because the caregivers have their own children.

The caregivers like their own children but they don't want children without parents... Maybe they don't have any sympathy for them (Male Orphan).

You might find one child is liked more than the other is and he is abused all the time (Male Orphan).

Aside from being treated differently at their new home, orphans are also separated from their siblings and are not permitted to visit them.

Sibling Separation-Not Allowed to Visit Siblings

The separation of siblings manifests in the orphans' lives because orphans are not able to visit their siblings. With some orphans living in different villages from their siblings, it is not surprising that some siblings "do not come to visit"; most likely because

of the difficulties in travelling there. Very few orphans have stayed together with their siblings. Most of the orphans have very little contact with their living relatives and therefore are at risk of losing the entire extended family roots. Orphans' relatives rarely visit to check on their well-being, which isolates the orphans from the outside world. Therefore, it is reasonable to anticipate that separation of sibling(s) will be disturbing, especially when other stressful life events play a factor in that separation. Despite the fact that orphans are not allowed to visit their sibling(s), another stressor the majority of orphans face is being forced to do things they do not like or want to do.

Change in Responsibilities/Duties-Orphans are Forced to Work

Change in responsibilities manifests in the orphans' lives because in their new homes, they are forced to do things such as fetching firewood and water, cutting the grass and doing casual work to pay their own school fees. Sometimes if the orphans ignore what they are forced to do, they are punished:

I am forced to fetch firewood and fetch water from the river... Taking maize to the posho mill and cutting grass for the cows. If I ignore doing that I will be beaten and sent away (Female Orphan).

Another orphan states how she is forced to fetch water and carry heavy sacks and is chastised if she refuses:

There are times when the person you are staying with wants you to go and fetch water when you say you are not willing to do that, she scolds you. You can be told to go to the posho mill with a heavy sack of grains, but when you say it is heavy and you are not willing to go to the posho mill, you are reprimanded or even caned and denied food (Female Orphan).

Aside from the findings that orphans are forced to do things they do not want to do is the notion that while orphans are trying to obtain an education they are unable to because of the problems they face at school.

Problems at School-Absent From School

The problems orphans face at school manifest in the orphans' lives because they are often forced to be absent from school. Orphans are absent from school for a variety of reasons, these include lack of school resources, lack of financial resources to attend school, lack of activity fees, building and equipment fees, uniforms and books. A few orphans explained how they are kicked out of school because they don't have fees and therefore are unable to finish their school work:

The biggest problem is lack of pens and exercise books to write and when I don't have them the teacher usually tells me to get out of class because of sitting idle in the classroom ...I don't have a textbook to use at home...When we are given homework, I don't do it properly because I don't have anybody to buy me a mathematics textbook (Male Orphan).

Sometimes when I am sent away from school I sit down and start wondering where I will get the money that is needed at school... We lack books and if we tell the people we are staying with they don't respond (Male Orphan).

Levies like when there is a funeral, death of a teacher or student and you are asked to bring money. Uniforms also, at times when your uniform is too torn you may be sent out of school so you just go home and that is when you think that if your father were alive he would have bought for you (Male Orphan).

One orphan explains how he is sent away and forced to buy books while others continue to learn:

Sometimes one is forced to do some hard work like English. One is forced to buy a book he doesn't have and you are sent to bring one while others continue learning. Even though I can promise to buy one textbook within a few days, when I go back to school they always send me home...
(Male Orphan).

The lower enrollment of orphans is primarily explained by the greater tendency of orphans to live with distant or unrelated relatives or other caregivers.

Orphans are not the only ones who experience the manifestation of their primary and secondary stressors. The informal orphan caregivers also experience the manifestation of their daily stressors.

INFORMAL ORPHAN CAREGIVERS

The caregivers in this study experienced numerous stressors associated with the role of caring for orphans which manifested into other stressors. These manifestations are: challenges of caregiving and multiple roles, providing basic necessities and school fees to orphans, and problem children.

Caring for Orphans-Challenges of Caregiving and Multiple Roles

Caring for orphans manifests in the caregivers' lives because they constantly face numerous challenges and multiple roles. Some caregivers had no choice but to keep orphans who lost both parents. Some of the challenges that caregivers encounter include: meeting needs for orphans; lack of resources; problem children; little or no help and confinement to their homes because of the orphans. These added responsibilities often necessitated other major life changes. One caregiver explained how she tries to give the

orphans everything, but she is constrained by other roles:

I try but I cannot satisfy them with everything. Sometimes when I am well I go to work then I hear that one child has been sent home from school to buy a pen or a book you see, I cannot work. If you think of preparing lunch and supper then you cannot work (Female Caregiver).

At the time of this study one of the key problems caregivers faced was the provision of school fees. However, with the new education policy of free basic education in Kenya, one expects that this will be a welcome relief at least to caregivers. Of course, there is still the outstanding issue of providing books, school supplies and clothes to these orphans. How to make sure the orphans know that you are really there to help them is another key challenge-the difficulty then becomes drawing the line between discipline and harsh punishment. One caregiver explains how she cannot provide food, clothing and education fees to these orphans because she is sick and there is no one to help her with her farming:

The biggest problem is that these children go to school, they need food, clothes and there is nobody who can help them buy clothes, pay their school fees or even providing them with food. There is a very big problem because those who could provide for them died and left them as orphans. I have a big farm that needs to be fertilized and prepared for farming but nobody can help me. But I keep crying day and night for God to help me about my worries and I put all my trust in him that he will provide. The problem I have is that I am sick, I have stomach problems so going to the farm and getting something to eat is a problem (Female Caregiver).

Older caregivers worried about what the children will do without them because other relatives are unwilling to help. Also, the challenge of taking care of orphans is more complicated when the caregiver is HIV positive, as evidenced by the following quote:

People even ask me how I manage to take care of these orphans because there is nobody who is working. I usually tell them that it is not me, but it is God who takes care of them. I struggle alone everyday and God provides for the day. There used to be food but there is no sugar. But now since I become sick, we do not get enough to eat (Female Caregiver).

For the most part, caregivers seemed satisfied with the care and support they provide for the orphans, however, they strongly believe that it is difficult to satisfy all needs. As evidenced in the following quotes, some caregivers reported that they attend to the child's needs before their own because they feel it is their duty:

You know it is hard to satisfy all human needs. I can do for them something but it does not please them but they just have to take it because there is nowhere else they can go...Even when I have nothing I still help them...That cannot be enough for them since they are orphans and they are so many (Female Caregiver).

So you cannot just do your own things, you must attend to the child. Sometimes you might want to knit but you cannot buy thread to knit. You cannot knit while the child you are taking care of doesn't have a pen or doesn't have a book...I am happy, had I been unhappy with it, I could not be staying with them. It is not something that has been forced on me. I am doing it willingly...There are so many things that I desire to do but I cannot. How they can have their own school, teachers and how they can dress, how they can feed properly (Female Caregiver).

Caregivers are still constrained by their lack of economic and financial resources and by the number of orphans they have to care for. This is subsequently heightened when the caregivers do not receive help from their community.

Lack of Community Support-Providing Basic Necessities and School Fees to Orphans

Lack of community support manifests in the caregivers' lives because these caregivers have had difficulties providing basic necessities and school fees to orphans because they did not receive financial support or help from their communities.

Caregivers find it difficult to provide for orphans because they often have their own families or extended families to take care of as well. As stated by one caregiver, caring for orphans is difficult because she has numerous children to care for and they have so many needs:

In my family the problem I have is that I am left with orphans. The biggest problem is that these children go to school, they need food, clothes and there is nobody who can help them buy clothes, paying their school fees or even providing them with food (Female Caregiver).

Some caregivers have problems providing for orphans because they are not able to farm their land. One caregiver explained how she was stressed about providing for the orphans:

There is a very big problem because those who could provide for them died and left them as orphans. There is none who has come to my home to help them. I have a big farm that needs to be fertilized and prepared for farming but nobody can help me. I used to be stressed about where I can get someone to help me (Female Caregiver).

Other caregivers are unable to provide the orphans with beddings, blankets or clothes. As noted by a few caregivers, the necessities the parents left when they died are all gone now:

What their parents left them, things they need like beddings, clothes and other things, is now finished (Female Caregiver).

They are so many, sometimes they do not have blankets so the children sleep in the cold, sometimes they are sent away from school and you do not have anywhere to turn to (Female Caregiver).

Not only are caregivers unable to provide the basic necessities that orphans need, they also find it difficult to pay for orphans' school fees.

What I do to assist them is providing them with things like clothing, food and school fees and also school uniforms when they get old. This, however is a very difficult task (Female Caregiver).

Other caregivers are simply not financially able to provide these fees, as evidenced by the following quotes:

The problem is that most of the time when the second born needs school fees, sometimes it becomes hard for me because I am not financially stable all the time. But for the third born, there is no problem because there is no money needed it is only minor things that are needed like pens, exercise books (Female Caregiver).

Some caregivers find it hard to tackle all of their responsibilities because of the little or no support they have received, because they have other children to care for, or they are aging and find multi-tasking difficult to handle. The challenges of taking care of orphans is further exacerbated by problem children.

Treatment of Orphans-Effects of Problem Children

There is an added stress manifested in the lives of caregivers who have to deal with the effects of problem children. Some of these children are reported to be taking drugs, smoking cigarettes and drinking alcohol. One caregiver explained how trying it is

to care for orphans who are involved in illicit behaviour, especially when the orphans are boys:

They [orphans] have many problems. Taking care of them is very difficult, you must just pray to God. It is difficult because there are some people who advise them, when they get advised the children become very bad. There are problems like taking drugs, cigarettes.... You are surprised when you find out that the child is smoking or drinking alcohol. Being an orphan there are many bad ideas he gets from the places he goes to... (Female Caregiver).

The orphans and informal orphan caregivers in this study encounter and experience multiple stressors in their daily lives. Even though the orphans and informal orphan caregivers have experienced numerous stressors, they have been able to combat some of these by using various coping mechanisms available to them, as well as the social support and resources from the CBOs.

Coping Mechanisms

The orphans, informal orphan caregivers and community based organizations used various methods to cope or combat the numerous stressors they experience every day.

ORPHANS

Coping Mechanisms

The results in this study show that these orphans have very limited coping abilities and generally focus on finding things that make them happy. Despite the death of their parents and the challenges and problems they face, the orphans do try to cope with the

daily stressors they encounter and the situations they are faced with by using methods such as withdrawal, sublimation and altruism. Some orphans used withdrawal as a coping mechanism by emotionally ‘running away’ from the stressors they faced and only thinking about the good things that their parents used to do for them and how much they loved them. Other orphans used sublimation as a coping mechanism by finding various ways to release their anger, fears, and sadness and doing things that made them happy. These things included singing and praying to God, playing ball, playing with friends, playing games, respecting other children, visiting friends, schoolwork, studying and telling stories.

I usually play Obiti with my friends. Obiti is a game where we draw lines on the ground and then you can jump across those lines. A game known as Natabu. This is a game of hide and seek. I will close my eyes and my friends will go and hide... (Male Orphan)

I usually play football with my friends and at times I usually play Onyuro with my friends. Onyuro is a game where we tie a rope between two trees and one person stands in the middle of these ropes... Draft is a game where we use bottle tops to play on a piece of board (Male Orphan).

When I am studying I feel happy... I feel happy when we are telling stories with a friend who is my neighbour (Female Orphan).

The ability of an orphan to cope is reinforced by the treatment they receive from their caregivers. As expected, the results indicate that some caregivers take good care of orphans:

She is taking good care of me, she does not quarrel me, she is good and I have lived long with her... She pays my fees for me when I can't, and even clothes she is the one who buys for me

when I don't have to...She teaches me...She only tells me to do a few jobs like washing utensils, fetching water, firewood (Male Orphan).

In fact, male orphans were more likely to talk about receiving good treatment, as compared to female orphans. The female orphans shared no positive aspects of their experiences with their caregiver. Instead, female orphans stated that their caregivers “disturbed them”, “scolded and quarrelled” with them continuously when they wanted to study.

Also emerging from this study is the orphans' reliance on altruism (see also Vaillant, 1977), whereby the orphans forget about their problems and concentrate on helping others. Many orphans feel that if they could just finish school, get a job, help their siblings, stay happy without suffering, buy books, uniforms and schoolbags and stay in school they would be able to cope with the death of their parents and the various stressors they have encountered since that time:

...finish school and further my education, get employed and stay a comfortable life... To get a good education and employment and to help my brothers in future... To be a good person in future like a pastor... To be a doctor (Male Orphan).

As expected, informal orphan caregivers are able to cope with their stressors in more ways than the orphans. These caregivers have advantages over the orphans, such as knowledge and age, which enable them to find more ways to manage their daily stressors.

INFORMAL ORPHAN CAREGIVERS

Coping Mechanisms

Consistent with the literature, several emotion-focussed and problem-focussed (e.g., Lazarus & Folkman, 1984) coping strategies have been employed by the caregivers in this study. These caregivers have used such emotion-focussed coping strategies as spirituality and religion to manage the stressors they experience.

Spirituality and Religion

Spirituality and religion were widely employed among the respondents, with some typically saying "I have left everything to God" or "It is God's will":

I have left my problems to God because there is nothing I can do given the state I am in...When I have a need and I cannot meet it, I just pray to God. I just leave it to God because I always know that God is able...Through God's power I will succeed. Others will finally wonder whether I am the one who has taken care of them until they have completed their education (Female Caregiver).

They have taught me God's will. When I lack anything I have to rest assure that God is going to provide for the children. This makes me relax (Female Caregiver).

I can feed them the way it is required, it is only through God's help that they have been able to survive. They grow up because of God's power, even if it is difficult there is nothing we can do (Female Caregiver).

Aside from using spirituality and religion as a way to cope with the stressors they experience, caregivers also engaged in problem-focussed coping strategies such as income generating activities, CBO membership, CBO training and education, and care and support.

“Merry-Go-Round” Activities

People who engage these types of coping strategies may be able to confront their problems more positively and experience better quality of life. Caregivers believed that merry-go-round activities gave them the help and support they needed to help provide for the orphans:

The most outstanding help is that recently they gave me something small, so now I am able to do a small business and to help myself. It helped me to do a small business, at least now I can have peace of mind. I leave home in the morning and when I come back I come with food (Female Caregiver).

They taught me how to make mats, they also taught me how to do business and all this is helping me now. The training is good because now if someone gives you something small instead of misusing it you put it to good business to generate more (Female Caregiver).

“Merry-Go-Round” activities are directly linked to the benefits of CBO membership that the informal orphan caregivers’ experience.

CBO Membership Benefits

Caregivers felt that being a member of a CBO was very beneficial because they were assisted in a variety of ways. CBO members shared and worked together, as well as provided assistance to caregivers and the orphans. As evidenced by the following quotes, the caregivers stated that CBO’s helped the orphans with school fees, medicine, food and clothing:

The advantages are that we are together, we share stories together and work together. Another advantage is that the organization is so helpful to these children when a problem arises, they contribute for their school fees (Male Caregiver).

Being a member of Orongo? When I am in a fix I can approach them and ask them for money to buy food for the children. I can say they help me because were it not for them my children would not get medicine (Female Caregiver).

Apart from the support with food, clothing, school fees, medicine and small businesses that caregivers received from CBO's, they also received training and education.

Training and Education

A few caregivers explained how the CBOs taught them how to take care of orphans, how to teach them about the world and not discriminate against them:

How I came to take the responsibility of taking care of the orphans...this is one of the teachings that was brought to us by HAPAC, about Home Based Care. It taught us how to handle orphans and stay with them with mutual understanding. It was difficult but it is also good because somebody who has been trained is able to handle the orphans who if not taken care of, become street children (Female Caregiver).

The AIDS people are the ones who came here to train us on how to take care of children, to teach them how to take care of themselves especially during this time of the deadly disease... They taught how I can handle them and talk with them politely. You should not be tough and harsh with your children. When you become harsh and you are not their real mother, the child is disturbed and thinks a lot. I don't discriminate that they are not my own children, I love them all equally (Female Caregiver).

Another caregiver stated that the CBO's taught her how to take care of herself and her body. CBO's also sponsored her to take health courses:

They have taught me how I can take care of my own body, how I can be the leader of my home and my children without any misunderstanding. They have sponsored me to attend courses on health that have been organized (Female Caregiver).

Caregivers felt that the training and education they received was very relevant to their tasks and responsibilities of caring for orphans. A few caregivers explained how the training they received from the CBO's helped them understand how to talk to and treat orphans:

I was told that someone as such should be treated gently, if she wants something you should never say it is not there. Talk sweet words to her to give her hope and its even better to deny someone healthy something and give to someone sick (Female Caregiver).

The teachings have helped me with the kids and I have not seen any child becoming rude or abusing to me. There is a stage when a child reaches, he can stand before you and abuse you that you are not his mother. I have not seen that. Then, don't you think the teachings have assisted me? (Female Caregiver).

The training and education that the informal orphan caregivers received from the CBOs enable them to cope with the stressors of caring for orphans. Nevertheless, the care and support provided by the CBOs afforded the informal orphan caregivers with another way to cope with their daily lives.

CBO Care and Support

Caregivers felt that CBO's were doing their best to provide assistance to them as well as the orphans they care for. One caregiver explained how, with the CBO's assistance, she can now provide the basic necessities to orphans that she was unable to provide before:

Since I joined I have attended courses that have helped me. When my husband passed away the group really assisted me, they are the ones who clothed me. When my husband's body

was in the mortuary for two weeks, they provided food and means to get me to the mortuary. I am very grateful to the group. They provide everything, the clothes they wear, and the group caters for fees, books and food...They should continue taking the responsibility of educating the children and my mind will be at ease and I will not be worried about the children being chased away from school for lack of paying school fees (Female Caregiver).

These findings are consistent with Pearlin (1981), who found that the role of caregiving can have dramatic consequences for informal caregivers. For example, previous work on caregiving, indicates that social support may strengthen caregiver well-being directly or it may cushion the effects of stressful circumstances. The help and support that CBOs have provided to the orphans and informal orphan caregivers has had a tremendous effect on their lives and well-being. This was further illustrated by the community based organizations themselves.

COMMUNITY BASED ORGANIZATIONS

Social Support and Resources

CBOs in this study were initiated to: eradicate poverty, help orphans and children with needs, to provide home based care and medicine, training and education, and to sensitize their communities on HIV/AIDS. They provide assistance in the form of medicine, health care, food, basic human necessities, money, spiritual assistance, visitation, prevention, outreach and education, care and support, social services, school necessities, employment, voluntary counselling and testing, and income generating activities.

The CBOs in this study were formed because of the HIV/AIDS pandemic and each began with different objectives. They were started by people coming together to form social networks, others for income generation and caring for orphans. The CBO members stated that helping one another through their groups enabled them to cope with stressful times:

... when you are alone you think too much and get stressed. So when we come together you can meet somebody who can give you good advice or even my suggestion might help somebody (CBO Member).

...if someone's house is leaking we can all work together to repair the house. When we get casual work to do then we can also do it much faster as a group (CBO Member).

CBO members reported that from the outset, their main focus was caring for orphans:

When that Home Based Care Programme started, we realized that orphans are suffering. So we decided to assist them because since both their parents have died, we started this children's centre so that we could help them (CBO Member).

The first and foremost reason for starting this group was from the way we saw the orphans suffer. They didn't have places to live. You would find some just loitering... That is the main reason - to help these young unfortunate people. We wanted to help orphans, the community was getting orphans at a high rate, and then later we also thought of helping the sick (CBO Member).

Counselling services in Kenya, such as spirituality and emotional healing are also provided by the CBOs. One CBO member explained how counselling each other helped to avoid stress:

We encourage them with the word of God. We encourage them so that they don't think too much and we visit them very regularly. We can do it three times in a week because

we rotate. This makes them relax and avoid stress (CBO Member).

We do a lot of counselling. Every Friday we pray as a group and then we have a prayer group that goes round on Saturday (CBO Member).

With a holistic view of the health and well-being of the orphans, CBOs also go to the extent of providing shelter, helping in the repair of houses and helping their members during the farming season:

We visit their homesteads to carry out minor repairs and house chores. We even assist them in weeding or harvesting their farms if they have no strength to do so. We also take to them some of their daily necessities such as food, soap, flour and cooking fat (CBO Leader).

Apart from that we also decided on farming to sustain them because they have to take care of themselves, we cannot afford to take care of them. So through farming they can at least get their sukumawiki (kale) sell some and the maize, that can take care of them (CBO Leader).

Caring for Orphans

The main focus of CBO involvement in orphan care is in the provision of education, food and shelter. One CBO leader stated that their main objective was educating orphans:

We started the nursery school and admitted the orphans who are being educated here free of charge (CBO Leader).

Our main reason for assembling these orphans was to educate them because you could find some left with their grandparents who cannot take them to school. We decided to take them to one school where they could be taught because nowadays education is the greatest thing (CBO Leader).

Another CBO leader believed that the orphans also needed to have emotional needs met:

These orphans are not happy and that is why we thought of helping them. These children lack confidence and even when they play with their friends they don't play with a lot of enthusiasm, so that is why we thought of helping them (CBO Leader).

A CBO member stated that their assistance is provided even when a family member is caring for the orphan, especially when that person is an aging grandmother:

... some have lost both parents and some of them have only their grandmother who is very old... this grandmother cannot do anything to help the children even buying soap. So we can buy them soap so that they can go out with their friends full of confidence. Some of them live with their grandmothers who are still strong but some cases are so bad such that even the children don't go to school because if a child did not eat then he cannot go to school. There are some who have nobody at all to take care of them. At times we take them in. What we sometimes do in such extreme cases is to take the land and plough it as your own and then take the children to live with you (CBO Member).

Helping Caregivers

The CBOs are involved in various forms of income generating activities, with the most common activity being micro businesses (buying and selling). One of the CBO members stated that their activities include brick making, and farming:

We make bricks, we plant vegetables, we used to grow sugar cane but we discouraged growing it because it uses up much land and we encountered a lot of difficulties in terms of machines, cattle for processing it and transporting the cane to the sugar mill... We also do cooking during funerals, when we are invited to offer the service. Yes. We usually go with all the cooking equipment including plates, sufurias, drums for water and other things, then we do the cooking (CBO Member).

Another CBO member stated that their activity is home based care, where they contribute money to provide food, clothing and school fees for families in need:

We do Home Based Care. We also talk to them about God, we encourage them and we are always with them showing them love. We give them with food. There are foods they want and the family might not afford so we can contribute money then we go and buy food because this is part of Home Based Care (CBO Member).

We buy clothes for them (orphans), provide them with places to live, give them food and also send them to school. These orphans have been distributed to members who volunteer to stay with them. Some have up to three or five children. There is one lady who is currently living with thirteen, mostly because these kids are related to her in one way or the other. So the group at times help her like in paying for their education (CBO Member).

This CBO member also explained how they sell various items, such as water and art and then divide the profits among each member to take care of their families:

We sell water, we have seven rental houses, we have a hotel, art and design, we do battery charging and we have a welding machine... We have employed people. Even though they are members we pay them... The members do benefit because every month we divide the money amongst the members. Each member is given as per his contribution to the organization. That is as per his share in the organization. In the recent past we received some aid from HAPAC. It was a good thing so we decided to call a meeting where all the seventy two members attended. In the meeting we decided to give each member one thousand shillings each. This money was for each person to invest in any way she liked so as to help them. Since we gave them that, we decided not to give them that commission we were giving them before. What we give them now is that flour and mostly we give it to very deserving cases. That is how we help our members (CBO Member).

Even though CBOs provide social support and resources such as home based care, income generation activities, the provision of food, clothing, medicine and school fees,

these CBOs are still constrained by the various challenges they face while trying to help the orphans and informal caregivers.

Challenges Facing CBOs

As expected, CBO members identified several challenges facing their various organizations. The most frequently mentioned challenges included the growing number of orphans in all the communities, lack of funds, and the inability to expand the coverage of their services.

Growing Number of Orphans

The growing number of orphans was identified by both the members and leaders of CBOs as the toughest challenge confronting them. The CBO members stated because there are so few members in each organization and so many orphans, there is little money to pay for the orphans school fees:

There are many problems, at times the children go to school but they do not have books at times they do not have uniforms ... At times the child is sent out of school because of textbooks, or he does not have a school bag and you also do not have the means to buy these things (CBO Member).

These are many problems because right now there are too many orphans who even if you take them in, they will not be very happy as they are always thinking of their parents ... They are so many that it is so difficult to help them and when they see one being helped..., they will definitely not feel happy. Some of them look for us and ask us to help them and at times we ourselves are not in a position to help. So these children go away with the knowledge that you have just refused to help them... We also ask God to give us more resources so that we can improve the quality of life for these children (CBO Member).

We are few members and if we continue taking more orphans to take care of, we are not going to be able to. So we are forced not to increase the number of orphans we are currently taking care of. So we cannot grow because we cannot take more orphans to take care of (CBO Member).

Similar views concerning the increasing number of orphans in these communities were expressed by the CBO leaders, who explained how so many orphans are being left by those infected with HIV and this is putting a strain on education and school fees:

The main problem is the orphans because even if we maintain these sick people, in the long run they die and they leave the children. When parents die and most of them are young people we will automatically take the children. So the major problem is the school fees for these kids.... To top all these problems, the major one is orphans, in my opinion (CBO Leader).

Right now we have so many orphans that we cannot sponsor. It is so difficult such that at times, when we go to the school and call these orphans, other orphans also join them and truly they are also orphans so you just sympathize with them (CBO Leader).

Consistent with the increasing number of orphans is the challenge of trying to education all of these children.

Education of Children

It is encouraging that the children in this area are eager to go to school amidst all the suffering and problems they encounter daily. Even though the issue of children's education was extensively talked about through the study (see quotations below), the new government policy on basic education may have brought significant changes such that the problems related to the education of children and orphans will become a future problem.

... we find some children are frustrated because they cannot get quality education since they do not have support. We therefore need the children to get quality education... We were thinking of starting a small school and then putting all these children and then we employ form fours leavers who are jobless. It will be cheaper since the school demands a lot of money from us (CBO Leader).

Education is the main thing I don't think there is anything as important as education... The kids need education, as a group we have some who have done their form four so as a group we thought they need some training so that we can have a workshop say for carpentry or computer because we have some in that training. In future we were thinking that if we get tools or computers these young people can just be employed there. It is important to get them to earn because there is one who is earning and now he has taken five orphans to help. He is living with them and they are going to school, so I think it is important to get them something to do because they could be our saviours in future (CBO Leader).

When it comes to the orphans they need school uniforms, schoolbooks, school levies, small monies like examination fees, tuition fees and these small things. People will tell you their children are going to school but they are really not going to school because of such small things as watchmen's fees etc. You go to the village and find an orphan going to school barefoot, without proper uniform and wearing tattered clothes (CBO Leader).

While the CBOs have been able to help support orphans in elementary school, the emerging issue is now how to support these children when they go to college.

Financing Children's Future Education

The problem that remains with the education of orphans is being able to send them to college. CBOs, as evidenced by the following quote, find it difficult to send their own children to college, let alone orphans they are taking care of:

We have worked in collaboration with the community to try and solve the problems that have proved to be difficult for us to solve alone. The one that we were unable to solve was the case of a child who was to go to college. We have a problem of lack of enough funds to send even our children, let alone the orphans to college. The number of orphans in primary and secondary schools is also big and our income keeps on fluctuating, sometimes it is good and sometimes it is not good enough (CBO Member).

While the payment of school fees for orphans will be a lesser problem at this point in time, there is no doubt that as these orphans make progress from elementary school through secondary school to college, this problem will likely never go away. Based on the recent education policy and what the future holds for orphan education in Kenya, it is imperative that these CBOs beginning to find ways to "save" towards the future education of the orphans who are currently in school. Consistent with trying to provide education and fees for orphans, CBOs also face the challenge of the lack of funds and resources for care and support of orphans and informal orphan caregivers.

Lack of Funds and Resources

It was not surprising that in this setting the lack of funds and resources was consistently identified as a major challenge to CBOs. There was agreement between members and leaders on this fact as indicated by the following quotations:

The key problem is in terms of money. We try but the resources are not enough and even for the work we do, money does not come in so readily. Money is therefore a big problem... The main problem is just money because all the things we do need money (CBO Member).

Poverty, how to take their children to school, most of their children cannot go to school ... I think the whole problem boils down to lack of resources (CBO Member).

One CBO member stated that they have resorted to sewing together old clothes just to make bed sheets to cover the orphans. It is encouraging, however, to learn that some communities have joined in CBOs efforts to raise funds to take care of orphans and those who in critical need:

What I can say is that the community sometimes organizes a fund raising for the children we are supporting to assist them in their education if we are unable. We also attend the fund raising and donate some money together with everyone else. By doing this we also benefit because some of our responsibility as a group is taken away (CBO Member).

The lack of funds and resources faced by CBOs is further complicated by the persistent lack of belief by some people, communities and cultures about HIV/AIDS.

Beliefs About HIV/AIDS

The beliefs that HIV/AIDS is not a medical disease can be explained in one way through the belief in witchcraft (Kisii) and 'chira' (Luo). In these communities, the belief that HIV/AIDS is not a biological phenomena prevents CBOs from being able to provide the necessary care and support to those affected by HIV and AIDS. As evidenced by the following quotes, the CBO members stated that some people do not accept that HIV or AIDS has a biological existence in their community and believe that any disease is the result of witchcraft or a curse:

It (witchcraft) has actually become a problem because this is a mixed area we have Luo's and Kisii's...In Luo it is called 'Chira'... in Kisii they say this is witchcraft (CBO Member).

In this community, the Abagusii community, people don't believe that there is AIDS...I don't know if they get embarrassed or what. Many Kisii people do not believe AIDS is real, they believe it is witchcraft... So this is one problem we have faced (CBO Member).

These findings are disturbing considering the efforts by CBOs, NGOs and government to create an awareness of HIV/AIDS in this context. The implication is that there is still a need for more work in communities with orphans and informal caregivers, who are affected by HIV or AIDS, where traditional beliefs about health and illness, witchcraft and chira(curse) are persistent. Meanwhile some communities now see CBOs as outlets for all sorts of assistance. What is disturbing is when some community members attempt to fake illness in order to receive assistance. Furthermore, some extended family members of orphans who are very capable of maintaining and caring for these orphans still insist on leaving these children with CBOs. This is evident in the following quote:

So now we have people bringing children and the kids they bring are orphans but sometimes these people bringing them are working and earning a living and at times their wives are also earning. The child could be a very close relative of theirs at times their nieces and nephews. Yet they insist to leave these orphans with us... It is hard to explain to them that we only help those who have no other means. So there is a bad blood because some feel we have a lot of money and are not willing to help them. Fortunately for us our chief is very understanding and she supports us (CBO Member).

The CBOs in this study face numerous challenges in the care and support of orphans and informal orphan caregivers. Even though some of these challenges are more than the CBOs can handle, they are still trying to overcome them to the best of their ability.

The efforts being made by CBOs to address the challenges outlined above should be viewed with the socioeconomic and environmental influences in mind. Most of the communities within which these CBOs are operating are resource poor settings and poverty alone may be a major limiting factor to CBO's efforts. Nevertheless, the CBOs have made numerous attempts to address the challenges they face trying to provide care and support for the orphans and the informal orphan caregivers on a daily basis.

SUMMARY

The stress process theory aided in the understanding of the impact of stress on orphans and informal orphan caregivers. The focus of this study was to examine the primary and secondary stressors experienced by orphans and informal orphan caregivers, the manifestations of these stressors, the coping mechanisms employed by the orphans and informal orphan caregivers, and the social support and resources provided by the community based organizations, in the context of the HIV/AIDS pandemic.

Based on the stress process, three conceptual realms: sources of stress, manifestations of stress, and coping mechanisms emerged as the major themes of this study. From these themes, various sub-themes emerged. Consistent with the first theme of the stress process, in sources of stress for the orphans, the primary stressor identified was the death of the parent(s). The secondary stressors identified were: concern over

who would take care of them, their relationship with the new caregiver and moving to a new residence, change in responsibilities/duties, the separation from their siblings, and problems at school. In the sources of stress for the informal orphan caregivers, the primary stressor identified was caring for orphans. The secondary stressors identified were: lack of community support, not being able to work and the treatment of orphans. As expected, the primary stressor for the orphans and the informal orphan caregivers created the secondary stressors. The secondary stressors were the direct result of the primary stressors. The orphans and the informal orphan caregivers felt that they would not be facing these difficulties or experiencing these stressors if the parents were still alive.

The primary and secondary stressors further manifested and created other stressors. The manifestations of stressors for the orphans were: emotional distress, absenteeism from school, being forced to do work, being treated differently at home and not being allowed to visit siblings. The manifestations of stress for the informal orphan caregivers were: challenges of caregiving and multiple roles, providing basic necessities and school fees to orphans, and problem children. Even though they have experienced numerous stressors, what the orphans and informal orphan caregivers say in this study contradicts one another. This will be explored further in the discussion and conclusion chapter.

The findings show that both the orphans and informal orphan caregivers used various coping mechanisms to combat the various stressors they have experienced. The orphans reported very limited coping abilities. The orphans used coping strategies such

as withdrawal, sublimation, and altruism to cope with their stressors. The informal orphan caregivers, however, were able to find more ways to cope, such as relying on the emotion-focussed coping strategies spirituality and religion, and the problem-focussed coping strategies income generating activities, CBO membership, training and education and CBO care and support. The community based organizations in this study provided various aspects of social support and resources to the orphans and informal orphan caregivers. CBOs provided care for orphans and help to caregivers, however, they also faced many problems in trying to provide support. CBOs faced the growing number of orphans, educating the children, financing children's future, lack of funds and resources and lack of belief about HIV/AIDS.

CHAPTER VI DISCUSSION AND CONCLUSION

This thesis examined the stressors affecting the lives of the orphans and informal orphan caregivers, as well as the social support and resources provided by the CBOs, in the context of HIV/AIDS, in Nyanza, Kenya. This study was set within the Stress Process theory, using the work of Pearlin et al. (1981; 1997), with the following objectives, to examine: the primary and secondary stressors affecting the lives of the orphans and informal orphan caregivers affected by HIV/AIDS; the manifestations of stress to see if the stress they experience manifests or creates other stressors; and the coping mechanisms employed by the orphans and the informal orphan caregivers and the resource available to them, as well as the social support provided by the CBOs. The three conceptual realms of the Stress Process theory helped to clarify the objectives and guided in the analysis of this study. My goal was to examine the thoughts and opinions of the orphans, informal orphan caregivers about the stressors they experienced and the community based organizations perceptions and the situation in Kenya. Based on the objectives listed above, this study produced the following results.

Sources of Stress-Primary and Secondary Stressors

According to Pearlin et al. (1981), primary stressors originate from the stressful event or situation itself and secondary stressors are the results of the primary stressors. This theoretical premise enabled the researcher to understand the stressors affecting the orphans and informal orphan caregivers. From the data, it was found that the orphans experienced the death of their parent(s) as a stressor affecting their lives. At the start of

this analysis, it was assumed from the literature (e.g., Brenner, 1984; Coddington, 1972a) that the death of their parent(s) was the primary stressor in the orphan's lives. However, after further analysis of the data and the secondary stressors, the death of their parent(s) was viewed as the only logical primary stressor to affect the orphan's lives. According to Coddington's Life Events Record, the number one stressful event that a child or adolescent can experience is the death of their parent(s). Other stressful events include change to a different school and separation from a sibling(s).

From the primary stressor, six secondary stressors emerged through the analysis of the focus group discussions with the orphans: concern over who would take care of them; their relationship with the new caregiver and moving to a new residence; a change in responsibilities/duties; the separation from their siblings; and problems at school. As indicated earlier secondary stressors occur after the primary stressor is experienced. For a child, the death of the parent(s) (as a primary stressor) produces a high level of stress in itself and is accompanied by multiple secondary stressors not experienced by children with parents (see Sandler et al., 1988; Silverman & Worden, 1992; Thompson et al., 1998). The orphans in this study felt that if their parent(s) were still alive they would not be suffering, emotionally abused or having any of the daily problems and difficulties they were experiencing. Since the death of their parent(s), most of these orphan have been living with extended family members, particularly their grandmothers. These findings are similar to those of Foster (2000) who reported that traditional first choice substitute caregivers are becoming seemingly more unavailable, paving the way to overburdened caregivers. Nevertheless, these orphans continue to worry about who will take care of

them now that their parents are dead and their grandmothers are aging and frail and will soon no longer be able to care for them. Orphans also worried about the acclimation of a new life with a new caregiver and moving to a new residence because of their new caregiver arrangements. With this change in lifestyle, these orphans found that their responsibilities/duties increased and they were doing more household work than other children in the home and more casual jobs to pay for school fees. These orphans also reported doing this work alone while the other children in the home did nothing.

The orphans also experienced the stress of being separated from their sibling(s). Some orphans were separated so their sibling(s) could attend boarding school, while others were separated in order to share the economic burden of care. According to Brenner (1984), “every separation brings with it change, pain, and dislocation” (p. 43). Permanent losses may be slightly less stressful than temporary losses, since they ordinarily require only one primary change in their life. Nevertheless, loss or separation may also result in other stressors. When a parent or sibling has been lost, it may be quite a few years before grieving is finished. Children’s reactions to separation or loss also depend on their ages and stages of cognitive functioning (Brenner, 1984).

Many orphans experienced absenteeism from school for some time because of the death of their parent(s), while others stated that they had been absent from school as a result of financial constraints. These findings are similar to those found in the AIDS and Orphans Report (2002), which reports that over 50% of orphaned children were not attending school, compared to 2% of non-orphans. These results are also consistent with Makame et al. (2002) who found that orphans in Tanzania were frequently absent from

school due to work duties at home or other work to pay for school fees, were often separated from their siblings, and had to do more work than other children in the household.

For the informal orphan caregivers in this study, it was found that the role of caring for orphans was the primary stressor to affect their lives. Consistent with Pearlin et al. (1981), primary stressors originate from the caregiving role itself. The informal orphan caregivers found taking care of orphans to be very hard and have encountered many difficulties. For these caregivers, the difficulties in caring for orphans was further exacerbated by their age and health problems. These findings are also consistent with Pearlin et al. (1997) who found that some health problems continue to increase during caregiving, suggesting a process of stress proliferation. Caregivers found that the burden of caring for orphans produced problems such as fatigue, lack of sleep, eating problems, stress, anger and frustration, isolation and stigma. These problems were further aggravated by the fact that the majority of caregivers were over the age of 50. The burden of caregiving also means many caregivers may neglect their own health, making them susceptible to health problems (Palvalko & Woodbury, 2000). Given the lack of economic, financial, health and social resources, it is reasonable to expect the added stress of caregiving would have a greater impact on the caregivers in this study, and in other similar contexts.

The obstacles that these informal orphan caregivers faced in caring for orphans turned into secondary stressors to affect their lives. These secondary stressors were: lack of community support; not being able to work; and treatment of orphans. These findings

are similar to Wight (2000), who found that secondary stressors associated with caregiving are located in other realms of the caregiver's life, for example, a financial strain on caregiver's resources. Caregivers felt that the community should share in the support of orphans by helping in fundraising to pay for school fees and by sharing in the care of orphans. Caregivers found that they were unable to provide the basic necessities that orphans require either because they were too old and could not do a lot for the orphans, or because they were too sick to work and provide for the orphans. These caregivers also have their own children to care for and many struggle to provide for both. These findings are consistent with several studies (Forsythe & Rau, 1996; Nyambedha, 2000) who found that as HIV/AIDS and the number of orphans increases, extended families are no longer able to meet the needs of orphans. Caregivers also found it difficult to pay for orphans' school fees as well. Paying for school fees was difficult for some caregivers who were not financially stable or who were simply not able to work anymore because of illness. Other caregivers that could work were still unable to fulfill the orphans needs because they are the only breadwinner in the family. As the informal orphan caregivers struggled to provide for the orphans, they still felt as though they treated the orphans fairly. These caregivers felt that they tried to be open and honest with the orphans and not disrespect them when they made mistakes. They also believed that they treated the orphans equally and did not separate them from the other children in the home. The caregivers in this study simply wanted to help the orphans as best they could so the orphans felt loved and well taken care of in the absence of their parents. These findings contribute to the stress process literature and the literature on caregiving by

providing evidence of the effects of caring for orphans in a developing country in the context of HIV/AIDS.

Manifestations of Stress

According to Pearlin et al. (1997) some stressful life events create more stress, which can vary from one context to the next. This theoretical premise helped the researcher understand which of the primary and secondary stressors manifested into other stressors for the orphans and informal orphan caregivers in this study.

For the orphans, five stressors manifested from the primary and secondary stressors they experienced. These manifestations were: Orphan's emotional distress; absenteeism from school; being forced to do work; being treated differently at home and not being allowed to visit siblings. Based on the stress process framework, this analysis contributes to this literature by showing that the primary and secondary stressors experienced by orphans manifested into other stressors.

The death of the parent(s) manifested into orphan's emotional distress because the orphans constantly worried about their parents, why they died and what their lives would be like if they were still alive. These orphans also worried about the difficulties they have faced since their parent(s) death and the lack of support and assistance they have received. A new caregiver and a new residence manifested because the orphans were treated differently in their new homes. These orphans experienced less care than other children, neglect, abusive caregivers, abuse by other children in the home, refused education and denial of food and basic necessities.

Sibling separation manifested because the orphans were not allowed to visit their siblings. The orphans rarely had visits from their relatives so they had very little contact with them. This lack of family connection isolates the orphans from their extended family roots. Change in responsibilities/duties manifested because the orphans were forced to do work in their new homes and if they refused or ignored their work, they were beaten or chastised. Problems at school manifested because the orphans were frequently absent due to lack of resources. Some orphans were also kicked out of school because they didn't have the fees. These findings are similar to those of Case, Paxson and Ableidinger (2004) who found that orphans are less likely to be enrolled in school than are non-orphans with whom they live.

For the informal orphan caregivers, three stressors manifested from the primary and secondary stressors they experienced. These manifestations were: challenges of caregiving and multiple roles; providing basic necessities and school fees to orphans and the effects of problem children. These findings are consistent with Pearlin et al. (1990) who found that caregiving is a fertile ground for persistent stress. Caring for orphans manifested for these caregivers because they constantly faced numerous challenges. Caregivers had difficulties meeting the needs of orphans, such as food and school fees. Some caregivers were inhibited by multiple roles in their family. These findings are similar to several studies (Aneshensel et al., 1993; 1995, LeBlanc et al., 1997; Pearlin et al., 1990; 1997), that found multiple roles may be damaging, increasing the magnitude of stress. Nevertheless, these caregivers felt that they were doing their best to provide for the orphan(s) in their care. The lack of community support the caregivers received

manifested because these caregivers had difficulties providing basic necessities and school fees to orphans. The treatment of orphans manifested for these caregivers because they had difficulties in caring for problem children, some of whom were involved in illicit behaviour such as taking drugs, smoking cigarettes and drinking alcohol.

Nevertheless, a point of interest in this analysis is the discrepancy between what the orphans report and what the informal orphan caregivers report. For example, the orphans reported that they are neglected, scolded and beaten by their caregivers and given more work to do than the caregivers' own children. While the caregivers report that they are not harsh on the orphans, they treat them like their own children and make them feel loved. What the orphans and informal orphan caregivers say in this study is contradictory and I can only offer possibilities as to the reasons why this occurred. For the orphans, a focus group discussion setting where the orphans could share thoughts and experiences with each other regarding the stressors they are experiencing may have provided them with the opportunity to believe that they also experienced some of the same stressors as other orphans. For the informal orphan caregivers, the in-depth interviews may have provided them with an avenue to share thoughts, opinions and experiences that were not necessarily accurate. Also, given that the interview questions were different for the orphans and for the informal orphan caregivers, the types of questions asked together with the notion of social desirability, may have influenced the answers or responses. To go beyond socially desirable responses from both orphans and informal orphan caregivers, what is needed are specific interview questions that would provide more objective data on the views and actions of orphans and informal orphan caregivers.

Coping Mechanisms

The orphans and informal orphan caregivers in this study used various methods to cope with the stressors they experienced. The CBOs in this study provided social support and resources to help the orphans and informal orphan caregivers. According to Pearlin et al. (1981), social supports and coping mechanisms "can intervene at different points along this [stress] process, thereby mediating the outcomes" (p. 342). This theoretical premise helped the researcher understand the methods the orphans and informal orphan caregivers used to cope with the stressors they were experiencing, as well as the impact of the social support and resources provided by the CBOs to the orphans and informal orphan caregivers.

Fields and Prinz (1997), who looked at research published in the last 10 years on coping and stressors in childhood and adolescence in nonclinical populations, suggest that children and adolescents may be limited in their coping strategies by cognitive, affective, expressive, or social facets of development and by lack of experience. In this study context, it was found that the orphans used coping mechanisms such as withdrawal, sublimation and altruism to combat some of the stressors they were experiencing. Some orphans used withdrawal as a way of 'emotionally running away' from their stressors and only thinking about how much they love their parents. These findings are consistent with Brenner (1984) who stated that withdrawal is evident when children take themselves out of the picture by running away from the stressors or stressful environments, or simply becoming invisible. Orphans used sublimation as a coping strategy by finding various ways to release their anger, fears, and sadness and doing this that made them happy,

which included singing, praying to God, playing with their friends, studying and telling stories. These findings are similar to those of Vaillant (1977), who found that one of the coping strategies that children use is to accept and face stress is sublimation, which occurs when children find ways to release their anger, fears and sadness by becoming preoccupied with other things such as games or sports. Orphans also relied on altruism as a coping mechanism that they used to forget about their troubles and focus on helping others. Some orphans believed that if they stayed in school so they could get a good job afterwards, they could help their siblings. These findings support those of Vaillant (1977) who stated that altruism is used when children forget about their problems by helping others, especially family.

How an orphan copes with the stressors affecting their daily lives is strengthened or weakened by the treatment they received from their caregivers. It was noted in this study that the male orphans were more likely to receive good treatment from their caregivers, as compared to female orphans. Female orphans did not recalled experiencing any positive treatment from their caregivers. They noted, however, that their caregivers scolded and quarrelled with them continuously. This could be the result of a gender-bias on the part of the caregivers', where female orphans are likely more involved in household chores. However, more research is needed to explore this area. These findings contribute to the stress process literature by providing evidence of coping strategies used by orphans in a developing country in the context of HIV/AIDS.

As expected, the informal orphan caregivers in this study were able to find more ways to cope with their stressors than the orphans. Caregivers used emotion-focussed

coping strategies such as spirituality and religion, and problem-focussed coping strategies such as income generating activities, CBO membership, CBO training and education and CBO care and support to deal with their stressors. The caregivers used spirituality and religion as a coping mechanism by leaving everything to God. These findings are consistent with Moore (2001) who found that 48 % of PWA caregivers in Togo relied on prayers, 57% relied on their faith to keep their sanity, and 83% shared with other caregivers to get support and ease their stress. With HIV/AIDS, new challenges will continue to present themselves to caregivers. Their lives, and for that matter their quality of life, in many respects, will be changing from the known to the unexpected. This changing situation will present an enormous challenge for intervention. It was encouraging, however, to notice that some of the caregivers have adopted very positive coping strategies by involving themselves in various activities such as "Merry-Go-Round", an income generating activity where everyone shares in the profits to help support each other, especially with the help of the CBOs. These caregivers felt that their CBO membership was very beneficial and used it as a way to cope by sharing and working together to provide assistance to orphans. The caregivers also believed that the training and education they received from their CBOs helped them cope with caring for the orphans and taught them to take care of themselves. Finally, the caregivers felt that the care and support provided by the CBOs helped them cope with providing the basic necessities that the orphans required. These findings are also similar to those of Turner and Catania (1997), who found that in a study on informal caregivers to PWAs in cities in the United States, support for AIDS caregivers assists in buffering the effect of caregiver

burden and has positive effects on well-being.

The CBOs in this study provided various avenues of social support and resources to help the orphans and informal orphan caregivers. CBOs provided assistance such as medicine, health care, food and basic necessities, spiritual assistance and counselling, prevention, outreach and education, care and support, social services, school fees, employment and income generating activities. CBO members believed that helping one another through their groups allowed them to cope with their stressors.

The main focus of the CBOs in this study was to care for orphans. CBOs provided education, food, shelter, and emotional healing to the orphans. These findings are similar to several studies (Drew et al., 1998; Foster et al., 1996), who found that community based orphan support initiatives have demonstrated their ability to provide support to large numbers of orphan households in greatest need and children in difficult circumstances. "Community based orphan support programs are able to support orphans in a way which complements existing coping mechanisms. Such support is cost-effective as it enables large numbers of orphans to be supported within their own communities" (Foster et al., 1998, p. S13). Orphan care and support programs are designed to enhance communities' abilities to address the increasing number of orphans and to create awareness about the challenges these children face (UNAIDS, 1999; UNICEF, 1999).

CBOs in this study were also involved in providing various forms of income generating activities, spirituality and emotional healing to the informal orphan caregivers. Some of the income generating activities included brick making and farming. CBOs explained how they would sell various items, such as water and then divide the profits

among the members to care for their families. CBOs also provided spiritual and emotional healing and believed that this counselling helped one another avoid stress. These findings contribute to the stress process literature and the literature on community based organizations by providing evidence of the role CBOs play in the care and support of orphans and informal orphan caregivers and the impact of that support in the context of HIV/AIDS and the orphan crisis.

The well-being of children affected by AIDS depends in great part on the capacity of the community to support and raise them. With an ever increasing number of orphans, CBOs are increasingly supporting orphans but they are still challenged as to how to establish substitute mechanisms that can provide children not only with physical care, but with the emotional, psychological, and social support they need. Supporting and strengthening community efforts to meet orphaned children's needs will contribute to their human development and eliminate the need for "survival sex", primarily in females, in exchange for food or money. In this way, prevention of future HIV infection is also strengthened. The efforts of NGOs, CBOs and donors are significant largely to the extent that they help children, families, and communities cope more easily with the associated problems. Unfortunately, few programs have focussed on preparing and supporting willing guardians to take on additional child care responsibilities.

Nevertheless, CBOs still find themselves constrained by the various challenges they face such as the growing number of orphans, the lack of funds, lack of belief about HIV/AIDS and the inability to expand coverage of services. CBOs in this study found that the growing number of orphans was their biggest challenge. CBOs also explained

how the increase in orphans being left by those who died of HIV or AIDS is putting a strain on providing education and school fees. The problem that CBOs encountered in this study was not providing support to orphans in elementary school, but supporting those children in post-secondary education.

CBOs also found that a lack of funds and resources was constantly a challenge to them. However, they were trying to find new ways to support each other, such as joining together to raise funds to take care of orphans and those in crucial need. Finally, CBOs found that the lack of belief about HIV/AIDS prevented them from being able to provide essential care and support to those in need. Although CBOs have tried to create an awareness of HIV/AIDS, they are still constrained by traditional beliefs about health, illness witchcraft and curses.

The stress process theory has been rarely used in developing countries to understand the complex issues of stress and coping as a result of the HIV/AIDS pandemic. This gap may be because of the difficulties in applying the theory in developing countries usually with multiple cultural contexts. In developing countries, the impact of stress, the coping mechanisms and the social support and resources may be very different than developed countries, since the impact of stress and abilities to cope are influenced by socio-cultural and other factors. Nonetheless, the stress process theory is beneficial in that it helps to understand the various primary and secondary stressors that are experienced and their manifestations, as well as the coping mechanisms used to combat these stressors. This theory also helps to understand how social support and resources provided can have an impact on the stressors experienced.

Limitations of this Study

The benefits to using secondary data is that there was no expense or time constraints on the data collection. However, it inhibited me from being able to explore contradictions and discrepancies that were found between the orphans and the informal orphan caregivers. In the study context, the notion of social desirability (social norms and expectations) may have influenced the responses that were given by both orphans and caregivers. To remove the effect of social desirability from the responses, specific questions aimed at eliciting objective data would provide a more accurate representation of the experiences of orphans and caregivers.

Given that I did not collect the data personally, I was not able to experience the various cultural aspects of Kenya. Therefore, I cannot fully understand the reality of the experiences and lives of the orphans, the informal orphan caregivers and the community based organizations, in the context of HIV/AIDS.

Future Research

This study calls for more research to be done specifically on the stressors experienced in the context of HIV/AIDS in developing countries. Research on the Stress Process has been neglected in developing countries. Various cultures, especially in developing countries will have different experiences than those in developed countries. Therefore, we need to look at how cultures in developing countries are experiencing various stressors related to HIV/AIDS. This can be achieved through more objective gathering of the data used in the studies.

We also need to look at the effects of these stressors across cohorts and among those infected or affected by HIV/AIDS to see if there are differences in the way these stressors are experienced. It would also be very beneficial to individuals who will be working within community based organizations to know the kinds of stressors, challenges and problems their clients are facing, as well as possible solutions.

This study provided a foundation for future research and contributed to our knowledge of the stressors that orphans and informal orphan caregivers can experience, their manifestations and the impact of community based organizations, in the context of HIV/AIDS in Nyanza, Kenya.

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APPENDIX A

RESEARCH INSTRUMENTS USED FOR THIS STUDY

IN DEPTH INTERVIEW GUIDE --CBO LEADERS.

Final Draft

To be labelled clearly

Name of CBO

Name of Interviewer

Date of interview

Position of person interviewed

Gender of person interviewed

Introduction

My name is from Steadman Research Services, a research company that conducts both market and social research in services and products offered by different companies, organisations and agencies.

I am here today to discuss with you issues of common interest. Please feel free to express your views and opinions, as there are no wrong answers. Remember all views/ opinions and answers you express are contributory to the discussion and are therefore respected and treated with utmost confidentiality. It is okay to speak in the language you are comfortable in.

- Please tell me a little bit about yourself, who you are, what you do (occupation) and how you spend your normal days and leisure time (Interviewer Probe how he/she became the ----- (mention his/her position)
- Please tell me a little bit about your organization (Interviewer probe: why/when/ how it was started, its membership base, criteria for recruiting members, its structure, its activities and its target group)

Objective and Activities

- What were the objectives/goals for starting this organization?
And how did the organization determine/arrive at these objectives/goals?
- As an organization, what are your main activities and how do you identify/determine these activities? (Interviewer probe; criteria for determining activities to be done by the CBO/its members)
- What other activities/services does your organization do/offer to support/help ----- in your community? (PLWHAs/Orphans/widows -Interviewer: mention the group they work with)
- Does your organization also work with ----- (PLWHAs/Orphans/widows)

Interviewer: mention the group(s) they DON'T work with)

- If yes please briefly describe how you work with them/what do you do for them?
- If no do you intend to integrate them in your programme in the future, how?
- How do members of the organization get involved in its activities and how do they benefit from it.

Challenges

- What are the main challenges you face in implementing project/programme in this community? (Interviewer probe: Socio-cultural practices, administrative problems, lack of resources -specify, lack of community support, interference from local leaders, lack of trust from clients, irresponsible members, etc
- How have you tried to overcome these challenges?

Needs of the target group

- What are the main needs of ----- in this community? (Interviewer: mention the group they work with)
- Of the needs you have mentioned, which are the most important ones?
- What makes you say that (Moderator probe: how did you come to think these were the most important needs i.e. did you ask the beneficiaries what their needs were?)
- What does your organization do to address these needs?
- What are some of the needs you have been unable to tackle and why?

Funding and Sustainability

- How does your organization currently fund its activities/projects?
- (Interviewer: If not mentioned above)ask - Is your organization or its members or both currently engaged in any income generating activity?
- If yes which one(s) are they, and how do the members/organization carry them out?
- (Interviewer: If the CBO receives external funds) ask -Assuming the external funds you currently receive are stopped/withdrawn, how do you intend to continue running the CBO/funding the projects?
- Would you say your organization is meeting its objectives, why do you say so? (Moderator probe for the reasons)
- Considering all that you have told us (challenges, needs) which areas do you think your organization has achieved most success? What makes you say so? (Interviewer: probe how they judged success); Is it from the perspective of the beneficiaries, the CBO, the local administration, the response from major step, DACC, Futures etc)
- What do you think are the factors/reasons contributing to your success as an

organization?

- Do you think you are receiving enough support from the community in your work? (Please explain your answer) if yes in which areas do you receive community support?
If no what areas do feel the community should offer support and by doing what?

Perceptions on Majorstep/DACC

- Have you received any form of training/education to help you in your /projects programmes?
- If yes, from where did you receive the training and in which areas were you trained on?
- How long ago was this training?
- Who in the CBO was trained (Interviewer: if individuals- probe why specific individuals)
- In your own opinion do you consider this training relevant and useful (If yes or no, please explain in what ways)
- If relevant and useful, how has this training/education been beneficial to your CBO?
- As a CBO, I know you have worked with both DACC and Majorstep in your projects, what exactly have they done for you i.e. how have you worked together?
- And have you been satisfied with the level of their involvement with your CBO? (Please explain)
- What do you perceive to be the main roles of ----- in working with CBOs?
 1. DACC
 2. Major step
- Do you think these roles are important for the success of your CBO? (Please explain)
- What do you consider to be the strengths and weakness of DAAC? (Interviewer: start with the strengths then weakness)
- What do you consider to be the strengths and weakness of Majorstep? (Interviewer: start with the strengths then weakness)
- As an organization, what are your future plans regarding growth/expansion i.e. t reach and increased quality of care/support.
- What kind of additional help/support do you think your organization need in order to facilitate/expand on its activities in the community?

Interviewer:

Please end the interview and thank the respondent

IN-DEPTH INTERVIEWS GUIDE: CAREGIVERS (Orphans)
Final Draft

Introduction

My name is from Steadman Research Services, a research company that conducts both market and social research in services and products offered by different companies, organisations and agencies.

I am here today to discuss with you issues of common interest. Please feel free to express your views and opinions, as there are no wrong answers. Remember all views/ opinions and answers you express are contributory to the discussion and are therefore respected and treated with utmost confidentiality. It is okay to speak in the language you are comfortable in.

Caregiver Profile

Caregiver's Gender

- Please tell me a little bit about yourself (Interviewer probe: how she/he spends her days both with the kids and on her own, how old he/she is, how she/he came to be the care giver of these orphans, about her spouse)
- Do you have your own children (: if they stay with him/her, how many they are, if they go to school if no why not)
- Please tell me a little bit about these children (Interviewer probe how many they are, if they go to school, what do they normally do when they are not in school, their age range)
- How long have you been the caregiver of these children?
- Apart from you, who else takes care of the children, say when you are not there?
- Do you know if some of them are HIV positive? If yes, how did you come to know?
- How does this affect your help/support/care-giving?

Care and support for the orphans

- Please briefly explain to me what kinds of help/care/support you provide to these children (Interviewer probe for: all sorts of help/care/support e.g. food, shelter, school fees, day today care etc)
- Please briefly describe to me your typical normal day, what do you do from the time you wake up to the time you go to bed?
- Are you satisfied with the kind of care you give the orphans you stay with (if yes or no please explain)
- Would you say the care you give to the orphans is quality care? (Please explain your answer)

CBO Support/Impact:

- Are you a member of any CBO working with orphans?
- If yes what is the name, and what does it do? (how does it help/support you in taking care of the orphans?)
- Which other organizations/groups assist you in taking care of the orphans? How does it assist you in taking care of the orphans?
- What are some of the advantages and disadvantages of being associated/member of this CBO? Interviewer: Please ensure advantages are listed separately from the disadvantages Of all the help/support you receive/have received, which ones are most important/relevant to you in helping you give better care to orphans and why?
- Have you received any training/education from any organization/group on how to take care of the orphans, especially kids whose parents have died from HIV/AIDS?
- If yes please tell me who trained you and some of the things you were trained on.
- Do you think the training/education you received is relevant/important (if yes or no please explain)
- How has this training/education helped you in taking good care of the orphans?

Needs Assessment

- As a caregiver/taker for orphans, what are your main needs?
Why do you think these are the most important needs for the orphans?
- How do you strive to meet these needs?
- Would you say the CBO you are a member of/working with help you meet some of these needs? (If yes or no please explain how. - Interviewer: probe for specific needs met by the CBO)
- If no what do you feel they (CBO) should do to help you meet these needs?

Challenges faced

- Normally people feel it is hard to take care of orphans, the way you are doing, what are some of the challenges you face in your taking care of orphans in this community? (Interviewer probe for: lack of food, space, kids getting sick, time constraints, lack, integrating kids from different backgrounds, psycho-emotional challenges etc)
- Apart from taking care of the orphans, what other responsibilities do you have in the family? (Interviewer probe for: ability to combine taking care of orphans and doing personal, problems integrating her/his kids with the orphans)
- What are some of the negative effects you are experiencing as a result of taking care of orphans? And how has this impacted on you and your family?

Community support

- Have you ever sought any help from your community for help/support in taking care of the orphans? (Probe nature of help sought, reasons for seeking help, when help was sought, where it was sought etc)
- When you sought help/support did you receive any?
- If yes, please briefly describe to me the various kinds of help you have received from the community (leaders, org/groups, friends, relatives, etc). Please be very specific as to who gave you the said help/support.
- Do you think your community is doing enough in helping take care of its orphans? If no, what are they not doing/should be doing?
- How could the community be more involved in the provision of care and support for the sick?

FOCUS GROUPS DISCUSSION GUIDE -ORPHANS

Final Draft

Introduction

My name is from Steadman Research Services, a research company that conducts both market and social research in services and products offered by different companies, organisations and agencies.

Today we are here to discuss about services of common interest. Please feel free to express your views and opinions, as there are no wrong answers. Remember all views/ opinions and answers expressed are contributory to the discussion and are therefore respected.

It is important that everyone contributes to the discussion to make it more lively and meaningful, again it is important that we speak one at a time to enable accurate recording and note taking. It is okay to speak in the language you are comfortable in.

Ice breaker

- Moderator: Please tell a short but funny/interesting story or ask the kids to sing their favourite song.

Residency

- How old are you?
- Please tell me about the people you live with currently
- For how long have you been staying with them?
- Is this where you have always lived? If no where were you living before (Moderator Probe for: for number of times residency has been changed, possible reasons for changing, who the people they stayed with before are)
- Is where you are living now near where you used to live before?
- Do you have any brothers and sisters?
- How old are they?
- Where are they now (Moderator Probe for: those in school/just at home /working/married)
- Do you live with them?
- If no, where do they live, with whom do they live?

Education

- Are you currently in school?
- Were you going to school before you moved to the place you are currently living in?
- If you are currently in school, is it the same school you used to go to or you have changed to a new school?

- Is the school you are in currently far or near where you are staying
- If you are not in school why not?
- Are your brothers/sisters also going to school, if no why?
- Is there a period when you never use to go to school, before you came where you are staying now? If yes why?
- How about now, are there times when you are not going to school? When and why?

Situational Status

- What are some of the responsibilities you have in the home where you live now?
- Do you share these responsibilities with other children?
- When do you do these responsibilities? (Moderator Probe for: for time: after school, during the day when others are in school, in the evening/late at night, during weekends)
- Do other people come to visit your family? Moderator Probe for:
- who are they and what do they normally do when come?
- what do they bring when they come?
- how regularly do they visit?
- who come regularly among those who normally come?
- What do you think are some of the problems faced by children whose parents have died?
- Have some of the things you have mentioned happened to you or other children/orphans you know?
- What are some of the things they worry about?
- What about school, what are some of the problems such children face in school?
- Do you think these children are forced to do things they don't like?
- Are they given everything they need?
- Do you think children whose parents have died are treated differently at home?
- How are they treated differently?
- Why are these things done to them?
(Moderator repeat for school)
- Do you think children whose parents have died are treated differently in school?
- What are some of the things that are done to them?
- Why are these things done to them?
- Did your parents (mum/dad) tell you who would take care of you?
- Is she/he the one you are staying with now?
- If no how come you are not living with him/her (how did you come to live with the people you are living with now)
- What are some of the things you do at home that make you happy?
- Do you do these things alone or with your friends?
- Are these friends the other children you stay with at home?
- What are some of the things you do in school that make you happy?
- Do you do these things alone or with your friends?

- Are these friends other children you stay with at home?
- What are some of the changes you would like to see in your life?
- What are your most important needs?

Moderator: End discussion and thank respondents, tell the kids you are now handing them over to the CBO member/official

Criteria for selecting Orphans for the FGDs

1. "Total orphans" i.e. children that have lost both parents
2. Currently age between 11 and 14 years old
3. Living in the new home for no less than 6 months and no more than 2 yrs.
4. Orphans taking part in the FGDs should come from different homes

**CBO MEMBERS FOCUS GROUP DISCUSSION GUIDE:
Final Draft**

Introduction

My name is from Steadman Research Services, a research company that conducts both market and social research in services and products offered by different companies, organisations and agencies.

Today we are here to discuss about services of common interest. Please feel free to express your views and opinions, as there are no wrong answers. Remember all views/ opinions and answers expressed are contributory to the discussion and are therefore respected.

It is important that everyone contributes to the discussion to make it more lively and meaningful, again it is important that we speak one at a time to enable accurate recording and note taking. It is okay to speak in the language you are comfortable in.

- Please tell me a little bit about yourself, who you are, what you do (occupation) and how you spend your normal days and leisure time
- How did you come to know and be a member of this i.e. the criteria for recruiting (new) members. (Moderator Probe: for awareness and reasons for joining the organization)

Activities

- What were the main reasons for starting this organization?
- If more than one reason, which one do you do most, and why?
- What are the main activities your organization do to help (Moderator identify appropriately, -Widows, Orphans, PLWHAs or a combination of these
- How did you decide on these activities? (Moderator Probe: for clients seeking help, suggestion from community leaders, arising as a community problem etc)
- What other activities/services does your organization do to help ----- in your community? (Moderator Probe for: counselling, spiritual, emotional, materials needs etc)
- Please tell me some of the challenges you face in doing this, and how you go about these challenges
- How many members are there in your organization?

Needs of the target group

- What are the needs of ----- in this community?
- Of the needs mentioned, which are the most important ones?
- What makes you say that (Moderator probe: how did you come to think these

were the most important needs i.e. did you ask the beneficiaries what their needs were?)

- What does your organization do to address these needs?
- How often do you provide these services?

Challenges

- What are the challenges/problems your organization face in providing these services? (Moderator Probe for: Outreach/recruiting new clients, Participation/apathy, Lack of trust from clients/community, Resources, Irresponsible care givers, socio-cultural practices, administrative problems etc)
- How have you tried to overcome these challenges?
- What are some of the needs you have been unable to tackle and why?
- Considering all that you have told us (challenges, needs) which areas do you think your organization has achieved most success? What makes you say so? (Moderator probe how success is actually judged: Is it from the perspective of the beneficiaries, the CBO, the local administration, the response from major step, DACC, Futures etc)

Funding and Sustainability

- How does your organization currently fund its activities/projects and how does your organization plan to sustain the work of the CBO?
- Assuming the external funds you currently receive are withdrawn, how do you intend to continue running the CBO/funding the projects?
- Do you think you are receiving enough support from the community for your work? (Please explain your answer)
- Apart from working with ----- (orphans/widows/PLWHAS Moderator: mention as appropriate), is your organization also involved with (orphans/widows/PLWHAS)? If no do you intend to integrate them?
- What kind of care/help/services are you currently providing to the orphans/widows/PLWHAS in your community?
- Would you say your organization is meeting its objectives, why do you say so? (Moderator probe for the reasons)
- What are the factors/reasons contributing to your success as an organization
- What kind of support does you as an organization need in order to facilitate/expand your services to the community?
- What are your future plans as an organization with regard to growth/expansion i.e. beneficiary out reach and increased quality of care/support.

Moderator:

Please end discussion and thank the respondents.

VITA AUCTORIS

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