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Care for AIDS orphans in Uganda: findings from focus group discussions

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Since 1982 when the first case of AIDS was identified in Rakai district (Serwadda et al. 1985) the disease has moved like a bushfire and killed many people in Uganda. The records of the AIDS Control Programme (ACP) give reports of AIDS cases as 43,825 by December 1993 (ACP 1994). Because this figure is based on official health reports of the disease in a country without a vital registration system and where most people die outside medical units, it is a gross underestimate. Perhaps a close figure is four to five times the ACP report. According to WHO reports, Uganda's number of deaths due to AIDS is second only to that of the United States, a much larger country. In terms of percentages of populations, Uganda is perhaps the worst affected country with an estimate of 8 to 12 per cent HIV positive, although other African countries have not been as open to studies of the disease as Uganda has been. This implies 1.4 to 2.2 million out of a total of 18 million Ugandans may already be infected.

The impact of AIDS on the country has been devastating. The disease has killed many highly educated people, businessmen and economically active people, thus depriving the country of the entrepreneurship, technical and professional persons needed for high economic productivity. Both public and private health systems, working under strained budgets, are overburdened by the high cost of medication and care of AIDS patients. Many babies are born with the virus transmitted from their mothers, thus increasing infant mortality. The 1991 census reported an infant mortality rate for Uganda of 128 per 1,000, higher than in the 1969 census, when it was 120 (Republic of Uganda 1993). The adult mortality rate has also increased: life expectancy at birth went down from 47 years in 1969 to 42 in 1991.

Perhaps the most shaken is the socio-cultural system of the African extended family which hitherto was the foundation of caring for the sick and orphans in the society. Agyeman (1993) observed that in the past extended families in Africa were known to care for the aged, sick, weak, and the helpless. However, a recent dramatic increase in the number of orphans due to the AIDS epidemic in Uganda has threatened to break this major function of the extended family. According to the reports of the 1991 population census of Uganda, the number of children under 18 with one or both parents dead has increased between 1969 and 1991 (Republic of Uganda 1993). Muhumuza (1992) claimed that the orphans in Uganda totalled 1.3 million out of 8 million children, giving a high level of prevalence of 16.2 per cent. In the district of Masaka, which is one of the hardest hit by AIDS, the 1991 census figure of orphans was 102,542, about a quarter of the children in the district (Nampinga 1995).

Studies on HIV and AIDS in Africa have concentrated on behavioural aspects, transmission issues, AIDS progression rates and patient care (Serwadda et al. 1992; McGrath, Rwabukwali, et al. 1993). Even recent work on the impact of AIDS on population is mostly focused on the economy, health system and mortality (Gregson, Garnett and Anderson 1994;

Goldfarb 1991; Hassig et al. 1990; Mulder et al. 1994; Persson 1994; De Cock 1994; Cabral 1993). A few studies have published findings on AIDS orphan care.

Perhaps the pioneering study of orphans in Uganda was by Hunter (1990) who was alarmed by the high proportions of orphans in the population. She found that 23 per cent of the children in Rakai district did not have both parents in comparison to 12 per cent in Hoima; she predicted that the usual coping mechanism of the extended family would not be adequate to handle the problem. Another study, by Barnett and Blaikie (1992) in the Rakai district, narrated the experiences of different groups of orphans. Despite the existence of the extended family system in the area, Barnett and Blaikie found some of the orphans stunted and malnourished because they could not cope with orphanhood. The study concluded that most orphans were deprived of education, parental care, nutrition, shelter, clothing and the legal protection of their parents' property. However, these two studies were limited in the coverage of Uganda to the south and central regions and one district in the western region. This paper reports findings of a recent study of the care of AIDS orphans in several regions of Uganda. It is also the purpose of the paper to investigate how the various societies in Uganda have coped with the orphan problem since the onset of the AIDS epidemic. Changes in past and present coping mechanisms are discussed and recommendations for the future are made.

Methods

A study entitled 'Evolution of Household Composition and Family Structure under the Condition of High Mortality in Uganda' was conducted in 1992 in six districts of Uganda: Hoima in the west, Kabale and Mbarara in the southwest, Masaka in the south and Iganga and Mbale in the east. None of the northern districts was studied because of the political security problems at the time; apart from Gulu, other districts of the north are not as seriously affected by the disease as those in the south, southwest and east. Ethnographic materials on the major tribes in the districts were prepared by anthropologists in Makerere University, providing information on the past. Data were collected from focus group discussions with elders and youth in each of the districts; there were twelve male and twelve female elders' groups totalling 128 males and 104 females, aged between 35 and 92 years. Most of the elders were married, but some were widowed, separated or divorced; although most of them were peasant farmers, the occupations of the rest varied from retired civil servants, such as teachers and clerks, to traders.

Eleven male and eleven female youth groups with 113 males and 114 females participated in the discussions. The male ages ranged from 19 to 34 and the females from 14 to 34. The youth were in various occupations and included a sizeable proportion of students. Among other topics, the discussions were on orphans and orphan care in the community in the past and present as well as how the community was coping with the increasing AIDS orphans and the fostering of them.

In contrast to random sample surveys, focus group discussions do not provide a statistically representative sample of respondents. However, the participants in the discussions were carefully selected to represent all the age groups from 14 to 92 years. The groups in all the six districts were selected on the basis of different levels of HIV/AIDS prevalence. Postgraduate students in population studies, knowledgeable in qualitative data collection techniques, fluent in English and the dialects of the areas and under the supervision of anthropologists, worked as moderators and recorders of the discussions. Field reports show that the discussions achieved an in-depth interaction within the groups on issues and hence brought out explanations that would not have surfaced in the surveys. Another advantage of the focus-group approach to research was the convenience and time saving for the discussion participants and researchers.

However, in comparison with the personal interview method, this technique may have a problem of lack of confidentiality and shyness. The participants may have avoided answering some questions directly for fear of divulging embarrassing information on the community or even people around; others may have been too shy to speak on some issues. All the records on the issues of orphans and orphan care were summarized by research assistants.

Results

Orphan care by a surviving parent

It was reported that in the past one of the parents usually survived. If the father survived, he would have the means to look after the orphans. In fact, in all the six districts, a child with a father was not considered an orphan, because the father would marry other wives who would look after his children using his wealth. For example among the Bakiga of Kabale and Banyankore of Mbarara, the father of the deceased wife would offer the widower another daughter to replace her sister and look after the orphans. Roscoe (1923) wrote of the Banyankore:

> If a wife died leaving children, her sister might come and take charge of them. She was then known as the heir of the dead woman and generally married the husband.

Unfortunately it emerged from most of the discussions that at present many AIDS widowers are already sick with AIDS themselves and are often too weak to fend for the children. Few women now agree to be married to a widower even if he is HIV-negative. Where the men are HIV-negative, the cost of treating the deceased wives would have been very great and would leave them with little to spend on the orphans.

In the case of widows, successors to the deceased husband were in the past selected by the husband before death or by his clan to take care of the family as a guardian. This successor could be a brother, cousin or the eldest son of the deceased. His role was to inherit the wives of the deceased and look after the children. The heir, who was not necessarily the successor, was also expected to use the inherited property to take care of the welfare of his siblings. For instance, he would use the property to pay the school fees and bridewealth of the young siblings. If the widow did not want to be inherited, she would return to her natal home and remarry elsewhere provided her bridewealth was returned to her deceased husband's family. She would surrender all her children to her husband's family who would look after them.

The participants informed us that, since the advent of AIDS epidemics, the widow's situation had deteriorated. At the time of the husband's death, she is probably an AIDS patient, too sick to care for her children. Even if she is HIV-negative, the husband's male relatives would fear to inherit her because of the AIDS scare. If there is no successor to her husband, no relative is obliged to care for the orphans. It is now difficult for women to migrate to other areas to find another man for remarriage. In some instances, the widow is considered by her in-laws a witch who has killed her husband, and they may isolate her and her children. Despite this, some widows have refused to have their children fostered because of fear of relatives who could harm them. The husband would have spent most of his wealth on his treatment and hence little would be left for the widow and children. Additionally, there were many reports of husband's relatives grabbing the deceased's property, especially land, and leaving the widow and children empty-handed. In most cases, men do not have wills to be used in the distribution of their wealth and thus do not protect the orphans' future.

Care by the relatives

All participants agreed that, as in the past, most relatives feel that the extended family is obliged to assist orphans. AIDS orphans are distributed to various relatives to be looked after; unfortunately, in the districts hardest hit by AIDS, such as Masaka and Mbarara, the relatives are complaining of looking after too many orphans. Some of the relatives who would assist are sick themselves, most probably of AIDS, and too weak to help, which reduces the number of relatives able to care. Of the remaining healthy relatives, there are many who are economically unable to look after more than one or two orphans in addition to their own large families. While in the past these orphans needed food which could be produced on abundant land and simple shelter and clothing, today the requirements are far greater and more expensive including payment of exorbitant school fees. In contrast to the past, the government no longer assists most of the foster families to pay the school fees. Other relatives refuse to look after orphans of some people considered to have been rich, educated, arrogant and unfriendly when alive. Because some wills state that the orphans should not be moved out of their homes, the relatives are afraid of evil spirits of the deceased parents and ancestors if they take action contrary to the wills.

Some youth groups reported that the orphans are stigmatized; often relatives suspect that the young orphans are HIV-positive and hence fear for themselves and their own children the danger of infection in the process of caring for them. Further, the children of some of the foster parents also believe that the orphans are infected and hence tend to isolate them to avoid infection.

The problem of food shortage was also mentioned by the discussion group as important. In the past, land was abundant to many families who would use it to produce a lot of food for any size of household. Today, there is a critical shortage of land in two of the six sample districts, namely Kabale and Mbale, with serious consequences for food production.

It was further found out in the discussions that many relatives are either too young or too old to care for the orphans. Additionally, there were complaints from the elders of orphans being too difficult to manage. Some orphans had refused to work; others had decided to run away from relatives and went to towns to fend for themselves as servants or street children, a fast growing problem in Kampala city. Conversely, some relatives were reported by the youth groups to have abused orphans by overworking them and confiscating their parents' properties.

Other assistance to orphans

During the discussions, it was reported that in the past there were few 'Babies Homes' to look after homeless babies; since the AIDS epidemic started, many non-governmental organizations have assisted orphans. These include Uganda Women Efforts to Save the Orphans (UWESO) launched by Janet Museveni, the President's wife, the AIDS Support Organisation (TASO) started by a group of AIDS widows, Orphans Community Based Organisation (OCBO), World Vision, Save the Children Fund, church organizations and individuals. These organizations and individuals have set up institutional orphanages, placed orphans in individual households, paid school fees and provided clothing and other essential commodities of life. In addition, local communities have assisted in building homes for orphans to live in with relatives.

Discussion and conclusions

Orphan care has changed since the onset of the AIDS epidemic in Uganda; the changes have largely been due to the large number of orphans who have overwhelmed the extended family

system. The death of both parents within a short time span has worsened the orphan's situation since there is no parental care. The social stigma on healthy widows and widowers ended the practices of widow inheritance and the marriage of widowers to sisters-in-law which used to ensure efficient orphan care.

However, it is reassuring to find that relatives still care for the orphans despite their own problems. This has led to a heavy financial burden on the carers, leading to their children often being economically deprived. For instance, Muller and Abbas (1990) found that 47 per cent of the households in Kampala supporting orphans did not have enough money to send their own children to school, compared to only 10 per cent of the households without orphans. It is logical to expect that at the same time a much higher percentage of orphans was not going to school since they take second place to the parents' own children in priority for education. Now, five years later, the situation must have deteriorated further. To alleviate the situation, the government and non-government organizations should increase assistance to households caring for orphans.

A further problem arising from the current orphan care situation is the higher mortality of orphans. Apart from the mortality due to perinatal AIDS which has been discussed elsewhere (Goldfarb 1991), the HIV-negative orphans are likely to experience higher mortality than other children because of lack of parental care. Since the extended family system is becoming increasingly strained and some orphans abused, it is expected that the infant and child mortality of these children will rise. Although the practice of fostering of children when their mothers are alive is common in Uganda, most of the children used to be boarded out at ages 4 and above. Where younger children were fostered, reports abound of their reacting with appetite loss leading to kwashiorkor (Gaber and Dean 1955). In Sierra Leone, Bledsoe, Ewbank and Isiugo-Abanihe (1988) found evidence that, among the Mende, fostered children were apt to be nutritionally disadvantaged and had reduced access to modern medicine when they were sick; consequently their mortality was higher than average. As Uganda privatizes the medical services and health care, it will be necessary for the government and non-government organizations to support these services for all the orphans. This may encourage the foster parents to seek medical care for the orphans whenever they are sick and hence keep their mortality in check.

Another interesting finding is that many orphans' carers are too old or too young to meet the responsibility. Most of the old carers are grandparents and the young ones are siblings who are still children themselves. Hunter (1990) reported that 43 per cent of the guardians in Rakai were over age 50, and 31 per cent of the orphans were under the care of their grandfathers and grandmothers. Since the grandparents may be too weak to create the wealth needed to cater for the orphans' requirements, orphans under their care receive little material assistance which puts their future welfare in doubt.

For the orphans under the care of fellow-children, it is a double tragedy. In their study of Rakai district, Barnett and Blaikie (1992) found many orphans aged below 18 looking after their younger siblings and living in their deceased parents' homes. The reasons for this situation are threefold. First, the orphans fear that if they left their parents' homes, their land could be seized by greedy landlords, neighbours or relatives. Their relatives therefore advised them to stay and defend their land rights. Secondly, because of much internal (rural-rural) migration in many parts of Uganda, often close relatives of orphans are too far away to help them: for instance, among the Baganda, newly married sons migrate from their parents' village to another village to ensure independent living (McGrath, Ankrah et al. 1993). The third reason is that the wills of some parents insist that their children do not leave their ancestral homes. Unfortunately, the older children themselves need the care which they no longer have and the young ones may not get the psychological and material support from

them that they need to grow up properly. If not properly guided, these young children are bound to have health, psychological, emotional and economic problems in future.

There is a growing number of orphans on the streets of Kampala. Some of them ran away from their relatives' homes but others were forced by economic conditions to leave and fend for themselves. Of the latter group, some may have been dispossessed of their parents' property. Some unscrupulous successors to dead fathers no longer use the deceased property for the advancement of orphans and then distribute it when the children are adults as is expected of them; instead, they sell off the property and throw out the orphans. Under the *Mailo* land tenure system operating in Buganda where most peasants are tenants of the landlords, the legal rights of orphans on their parents' land have caused a serious situation. Heartless landlords have evicted orphans from the land because the latter are not able to pay rents (*busulu* and *nvujjo*) in time (Barnett and Blaikie 1992). In other cases, landlords have argued that the tenancy of land was between themselves and the deceased parents and not the orphans. Land-hungry neighbours have also tried to take advantage of the orphans' youth to take their father's land; as a result, many cases on the land rights of orphans are now in courts of law. The village civic leaders (Resistance Council Officials) have helped to protect the legal rights to land of orphans but their powers under the law are limited. A law to protect orphans and widows' rights to their father's or husband's property is urgently needed to deal with the problem. It is also imperative for the AIDS patients to be made aware of the value of making wills to prevent their children being dispossessed after the patients' death. Such wills would strengthen the law against the culprits in the land and property seizure. Equally important is a law to keep children out of the streets of cities before they become thugs.

The cost of treating an AIDS patient is also a problem to the orphans. It has been conservatively estimated by Berkley (1992) that between US$150 and US$1,700 is spent in the public and private clinics per patient, and US$15 per day for health care is spent. Some patients have sold their properties such as land and cows to pay for treatment, so that, by the time of death, even the rich patients have spent a lot of their riches on treatment and very little is left for the care of orphans.

In the past, orphans in Africa were absorbed by the extended family system without much trouble. Because of the recent increase in numbers and lack of external support, the extended family can no longer cope with the problem.

Reports by the discussion groups that the government and organizations are unable to assist foster families, and that in some cases they discriminate against them, are disappointing. At this stage of the problem it is important that government and non-government organizations consider offering incentives to families that foster orphans, which would greatly strengthen the extended family system. If the government and these organizations could pay school fees and provide clothing and food subsidies to all orphans irrespective of their backgrounds, it would greatly encourage the relatives and friends to accommodate the orphans. In addition to this assistance, incentives to foster-parents in the form of school fees and clothing for their own children could motivate more people to accept orphans. This proposal may be considered too expensive at present but it could save much more money later, which will be necessary to deal with the psychological stress of these orphans as adults.

The problem of stigmatization of widows, widowers and orphans should be faced squarely. The widowers and widows who are willing to be tested should be officially encouraged to do so at reputable testing centres. After testing several times for about two years following the death of the spouse, the widows and widowers should be given a certificate showing them to be HIV-negative and their community leaders should be informed. This may assist them to be accepted by the community as harmless and hence able to remarry. Combined with this policy, government and non-government organizations, social

workers, church leaders and counsellors can enlighten the public about the stigmatization of AIDS widows and widowers. The success of this policy would greatly improve the care of orphans.

Stigmatization of orphans can also be tackled by government and other organizations. The orphans can be tested and retested for HIV seropositivity. Those who are negative can then be declared so by the testing centres and distributed by the social workers and relatives to the foster-parents who are more likely to accept them than when they are untested. Those seropositive can be distributed to those willing to care for them in that status until death. Stigmatization apart, the foster families are entitled to know the sero-status of the orphans in order to safeguard themselves against infection.

Another suggestion is for investment in the social work system. At present in Uganda there is a lack of organized social work: a few government departments and organizations employ social workers whose activities are not co-ordinated to maximize the impact of their services to the community. For instance, during the focus group discussions there was no mention of the activities of social workers as a solution to orphans' problems because the respondents were not aware of such services. With the increased seriousness of the orphan problem it is imperative for the government and non-government organizations to set up a strong social service system which would complement and enhance the extended family system's efficiency in handling orphans. Social workers can work with and help extended family members to make the correct decisions on the distribution of orphans to relatives and friends. The expertise of the social workers can be used when inspecting the prospective foster-homes of orphans; then the social workers can follow up the foster-homes and advise members of the family on how to cope with the orphans and their problems. The conditions of the orphans at the foster-homes can be regularly monitored by social workers in conjunction with extended family representatives. In this way, the abuse of these orphans by the foster-families can be detected and dealt with before they become out of control. The social workers can also be an additional source of information to government and courts of law when handling the land question.

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