

## **Impact of AIDS on the family and mortality in Uganda\***



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The world is now in the middle of a second decade since the first cases of AIDS were identified among the homosexuals of United States around 1980 (Grmek 1990). Since then, many more cases of the disease have been observed in ten regions of the world: North America, Western Europe, Oceania, Latin America, sub-Saharan Africa, the Caribbean, Eastern Europe, the Southeast Mediterranean, Northeast Asia and Southeast Asia. Mann, Tarantola and Netter (1992) estimated that between 38 and 110 million people would become HIV-infected and about 25 million would develop AIDS by the year 2000. By 1 January 1992, out of a total 12.9 million HIV-infected cases in the world, 10.9 million or 85 per cent were estimated to be in the developing countries. More serious is that sub-Saharan Africa, with less than 10 per cent of the total world population, contributed 68 per cent of the HIV-infected cases in the world.

The first AIDS case in sub-Saharan Africa was diagnosed in Rakai district of Uganda in 1982 (Serwadda et al. 1985). At present the disease has become an epidemic in many countries of the region, concentrated in the subregions of central, eastern and southern Africa. For instance, by December 1992, the cumulative total of AIDS cases reported through the official AIDS surveillance system was 27,901 (Brunborg, Fylkesner and Msiska 1993). Given the inefficient vital registration systems in these countries, this figure is a gross underestimate.

Perhaps the sub-Saharan African country most affected by HIV and AIDS is Uganda. The profile of the HIV/AIDS epidemic in Uganda can be summarized in the following terms: by December 1993, the cumulative AIDS cases reported by the official health system stood at 43,875 (ACP 1994); with about equal numbers by sex, with 47.7 per cent and 52.3 per cent of male and female cases respectively, the age-sex distribution showing female to male ratios of 4:1 and 2:1 in the age groups 15-19 and 20-24 respectively. This is followed by about equal numbers of both sexes at age-group 25-29 and a slight excess of males in all age groups thereafter. Although all 39 administrative districts had cases reported by that date, there are significant variations in the severity of the epidemic from district to district, with cumulative cases per thousand population in 1993 varying from less than one in some remote districts to more than 144 in Kampala city. The distribution by residence indicates a more severe urban

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than rural epidemic, with trading centres being in between in severity; nationally, the frequency of AIDS-related deaths is increasing and AIDS is touching most people's lives directly or indirectly.

Many researchers have conducted studies of transmission, progression rates, sexual behaviour, patient care and the impact of the disease in Uganda (e.g. Konde-Lule 1992; Serwadda et al. 1992; Barnett and Blaikie 1992; McGrath et al. 1993; Mulder et al. 1994). The findings of these investigations have greatly enhanced the understanding of the disease and its impact on Ugandans. However, most of these studies have been limited in coverage of the country; they have concentrated on Rakai, Masaka and Kampala districts which are most affected by the disease. This paper reports the findings of a study on the impact of AIDS on the family and mortality covering six districts in the west, southwest, south and east of Uganda.

## **Methodology**

Against this background, a study to examine household composition and family structure under the conditions of high AIDS-related mortality was carried out in six districts in Uganda: Hoima, Iganga, Kabale, Masaka, Mbale and Mbarara. The study was in three phases: the first involved the review of ethnographic materials on the populations in the six districts and collecting information from elders and youth through focus-group discussions.

Phase 2 involved administering an individual elders' questionnaire and carrying out a large-scale household survey in the six districts in order to document the recent changes in the household composition and family structure. The third phase will be carried out three years after the second phase. During this phase the areas covered in the second phase will be resurveyed to determine subsequent changes occurring in the communities, especially those due to AIDS.

The data collection for the first two phases is complete and this paper presents the results from the elders' survey which was carried out in the six districts. A total of 143 elders, 109 men and 34 women, were interviewed. The distribution of the respondents according to the six districts was as follows: Hoima, 26; Iganga, 23; Kabale, 24, Masaka, 24; Mbale, 24; and Mbarara, 22. The respondents were aged at least 45 years and all were heads of households which were selected using a combination of purposive and random cluster sample design. Counties in the districts most affected by AIDS were identified, and the most affected subcounties and parishes in these counties were picked. Out of a list of Resistance Councils of villages in the most affected parishes, a random number of the Councils were selected. On the advice of Resistance Councils chairmen and chiefs, households headed by people aged at least 45 from the Councils were included in the final sample. The interviews were conducted by the postgraduate students in demography at Makerere University, all of whom were fluent in both English and the local languages. To ensure that the same questions were asked, the questionnaire was translated from English to the local dialects. The interviews were therefore conducted in local languages and immediately transcribed to the English version of the questionnaire.

## **Results**

The information collected in the elders' survey covered household composition, mortality, morbidity and their causes, impact of AIDS on the family, general health status of the community and migration.

### **AIDS and the family**

The household is the basic unit of subsistence production in Uganda, and its existence within the extended family system has enabled it to weather the many stresses of war and social dislocation which have occurred in the country for over two decades. It is suspected, however, that the increased stress occasioned by AIDS is getting too much for the extended family system to bear in the long run (Mukiza-Gapere and Ntozi 1993).

AIDS is a family matter and has a major impact on all parts of society. It attacks families in a variety of ways. Ankrah (1991) found that, although the virus affects an individual, the impact of the disease is felt by the wider group, the family and the community in which the family lives, either because of the incapacitating effect on the breadwinner or through increasing expenditure at the household level, all of which increase the scarcity of social and material needs. Large sums of money are spent treating the patients, as HIV/AIDS leads to a gradual rather than sudden deterioration of the infected individual. In a study by Davachi et al. (1988) it was reported that a single admission of an infected child costs the equivalent of three months of a father's salary.

They also concluded that a child with AIDS and his death can have an immense economic effect on the immediate and the extended family. In another study by Hassig et al. (1989) it was found that, while the cost of hospitalization was about the same for HIV-positive and HIV-negative patients, the infected persons had spent twice as much for treatment before hospital admission as had the non-infected individuals. Hassig concluded that HIV infection puts a high financial burden on the people with AIDS and their families. The fact that an AIDS sufferer continues to survive for periods of 24 or more months may adversely affect the living standards of a family. The expenditure on medicines and hospital care, as well as on special foods, all takes extra money from the whole household budget.

In populations where the HIV/AIDS epidemic is mainly transmitted heterosexually, the chances are that if one member of a relatively steady union or couple contracts the infection, the other also will. AIDS patients are cared for by their families with most of the burden borne by women including wives, mothers, sisters, daughters, aunts and grandmothers (Orubuloye et al. 1994:241). Some AIDS care is given by the modern medical system, but it is the family that in most cases gives care (Ankrah 1991).

When respondents were asked whether AIDS had affected household composition and family structure in their communities, over 83 per cent responded that it had. The main reasons given were that many families had lost members especially from AIDS, and also in a number of households the members were increasing because of orphans.

AIDS has also had some effect on the traditional way of managing the household when the head dies. For example, 37.8 per cent indicated that there was no more inheritance of widows in their communities. As a consequence new headship structures are emerging. There are now quite a number of households headed by widows, single women who never married, widowers and children under 18 years of age who are orphans.

### **AIDS and mortality**

The AIDS epidemic is unusual in that its chief targets are not the old and the weak. Although AIDS kills people of any age, unlike other major killer diseases in Africa, AIDS deaths are concentrated among the sexually active adult population that is also the most productive. It is selectively killing the generation of adults who are the main breadwinners, leaving large numbers of vulnerable survivors with no means of support (Ainsworth 1991). Fostered AIDS orphans are also different from other children. They are subject to higher mortality than children living with both parents, partly because there is some dispute about who should meet medical costs, and the care they receive in general is inadequate.

There are socio-economic implications in these high levels of mortality: they threaten the functions of household life. The death of parents creates large numbers of orphans; younger family members cannot care for the sick and elderly; and young adults are not present to manage the household, or make income-generating decisions for meeting consumption, education expenses and the provision of an adequate diet. The death of producers has caused a deterioration in the producer-consumer ratio within some farm households, particularly since mortality is concentrated in the most productive cohorts. As a result, the range of crops, the amount of lands cultivated and the marketed surplus tend to decline. The absence of future producers may have a profound effect upon the demography and economy of Uganda. There is increased mortality of young children through paediatric AIDS, there are probably also raised mortality levels among surviving and seronegative children from AIDS-afflicted families through reduced nutrition and poorer care (Barnett, Blaikie and Obbo 1990). Palloni and Lee (1991) point out that adult mortality excesses lead to orphanhood and widowhood. The levels of paternal and maternal orphanhood at young ages (between 0 and 10 or 15) will rise, reflecting the increased mortality of young parents. In a study in Tanzania, it was found that the increase in infant and child mortality due to AIDS infection will probably offset recent successes in lowering childhood mortality. AIDS will also raise child mortality indirectly by throwing into poverty the healthy orphaned children of parents who have died from AIDS (Ainsworth 1991).

In the present study we tried to identify the deaths that had occurred in the households ever since they were formed. Respondents were asked about the relationship of the deceased to the head of the household, sex, age at death, year of death, cause of death and changes the death caused in the household. A total of 442 deaths had occurred in the study households with a slight majority (51.1%) being females. One-quarter of all deaths had occurred under age 15. About three-quarters of all deaths had occurred after 1985.

On the question of cause of death, AIDS was found to account for 32.8 per cent of the deaths, AIDS-related diseases (including malaria and fevers) accounted for 12.3 per cent and 'other diseases' for 54.9 per cent. More females than males had died of AIDS: 52.2 per cent of AIDS deaths were of females.

On the effects the deaths of these members had on the households, 25 per cent of respondents said that they miss the advice and company of the deceased, 25 per cent said they lost financial assistance, and about 10 per cent said they had been left with the problem of orphans to care for. Other reasons, like loss of support in labour and home deterioration and home management problems, were also given.

Respondents were also asked what they thought were the major causes of death for the different groups of the population. For the under-ones the causes were given as diarrhoea, measles and fever in that order. AIDS was mentioned by about five per cent of the respondents. Of the infants who were identified as having died of AIDS, 98.5 per cent had died before the age of five months. The major causes of death among children aged one to five years were given as 'measles and fever' and diarrhoea and vomiting in that order. The major cause of death at ages 18 to 35 years was given as AIDS by 85 per cent of respondents; AIDS was also given as the major cause of death among adults aged 35 and over. Other diseases such as tuberculosis and diarrhoea, which have symptoms related to those of AIDS, were reported by about 15 per cent of the respondents. These findings are similar to those reported by the health information system (ACP 1994).

The respondents were asked their opinions as to who was dying most from AIDS and the majority thought that it was males in the age group 18-35 years; the major reason given was that this group was sexually active. Respondents were also asked about people's response to death. About 20 per cent said that they worried about it and an almost equal percentage said that people no longer fear death, that they are now used to it, since it is too frequent. They

were asked how people are now treating the ceremonies relating to death. The majority suggested that the ceremonies are not as much respected as they used to be in the past; there is a lot of haste involved. Concerning burial, the biggest percentage said the ceremony used to take some days in the past, and the dead body was wrapped in traditional materials like bark cloth; these days, burial is immediate and the body is put in a coffin. As for mourning, it was noticed that it is given less time because of so many deaths; in the past, mourning lasted a long time. The ceremony of the last funeral rites now takes only a short time, usually on the same day as the burial; in the past, people would come in advance to prepare for the rites; the ceremony took many days and was held several months after the burial. On the issue of inheritance most respondents noted that now property is left to the orphans and widow; and men no longer inherit widows for fear of AIDS. In the past, women were taken over and the clan members used to share property with orphans.

## **Discussion**

### ***Family composition and structure***

This survey shows that a new structure is emerging for households in Uganda. Households are headed by widows, widowers, single women and even children under 18 years of age as well as orphans. Widows are heading the households because the old practice of widow inheritance by brothers-in-law is disappearing since they fear contracting HIV from the widow. Widowers are also finding it difficult to get remarried because women are afraid of being infected by them.

With a few experiences of their relatives and friends who married, contracted HIV and died, many single women prefer to stay unmarried for fear of death. A more serious household structure is that headed by children who are orphans under age 18. These are children whose parents have both died and who either are unwilling to be looked after by extended family members or have no close relatives to assist (Barnett and Blaikie 1992). In a study of a group of HIV-positive women in Kigali, Rwanda in 1988-91, Keogh et al. (1994) found that 30 per cent of the women and 44 per cent of their partners had no relatives nearby. Almost a third of the women had no partner willing or able to care for the children when the woman died. McGrath et al. (1993) report that in Buganda newly married couples migrate away from their parents' village to other villages to ensure independent living. It is therefore probable that with high internal (rural-rural) migration in Uganda, some orphans find themselves without close relatives nearby to help. The implications of this on the development and growth of these children and those under their care are serious for psychological, economic, social and health reasons.

An increasing proportion of the household is orphaned; this means a heavy burden on the households looking after the orphans. For instance it has been found by Muller and Abbas (1990) that 47 per cent of the children of fostering parents in Kampala do not go to school in comparison to ten per cent of children of non-fostering parents. The foster parents' own children have to share with orphans other facilities in their homes, such as food, clothing, rooms and beds, which may worsen their welfare and particularly health. It is possible these children will grow up resenting the fostered children and perhaps the system of child fosterage. The situation is likely to be worse for the orphans who may have little right of protest in their foster-parents' homes. Although the relatives are still willing to help it seems the problem of orphans has gone beyond the capacity of extended families and outside assistance is urgently needed.

### **AIDS deaths**

The study showed that three quarters of the deaths in respondents' households occurred after 1985: this is an important finding in two respects. First, although the respondents' households had been formed at least fifteen years ago, three-quarters of the deaths had taken place in the seven-year period 1985-1992 when AIDS had gained momentum in Uganda. Secondly, the data reveal the large impact of AIDS on mortality. This is consistent with the reports of elders that AIDS-related diseases had caused 45.1 per cent of deaths, and close to the findings of Mulder et al. (1994) that 50 per cent of mortality in Masaka district is due to HIV-1 infection.

Another interesting result of the study is the female-male ratio of deaths. It is now known that, because of biological, behavioural, cultural, demographic and economic factors, the rate of HIV transmission is higher in women than in men (Persson 1994). We found that 52.2 per cent of the AIDS-related deaths were of females, and 47.8 per cent were of males. This finding is close to what other researchers have found in Uganda using the national serosurvey data. Berkley et al. (1990) concluded that women were 1.3 times more likely to be infected with the virus than men. Mulder et al. (1994) reported that while 53 per cent of female deaths were attributed to AIDS, the corresponding percentage for males was 47. Much closer is the December 1993 report of the National AIDS Surveillance System which found 52.3 per cent of AIDS cases were females and 47.7 per cent were males.

As expected the age pattern of AIDS deaths shows that ages 18-35 were reported to have suffered most from AIDS mortality, reflecting the high rate of sexual activity in this age span. The disease accounted for 85 per cent of deaths in this age group. This finding agrees with results from earlier studies in Uganda showing that young adults were most affected by the disease. For instance, Konde-Lule (1992) claimed that because of a high rate of sexual activity, adolescents in Rakai had 11.2 per cent seroprevalence. A two-year HIV-1 study of a Masaka area by Mulder et al. (1994) found that mortality due to AIDS among those aged 13-44 was at least 80 per cent.

On the causes of deaths, the results indicate the re-emergence of old killer diseases in the population. Owing to major health campaigns, diseases such as diarrhoea, measles, malaria and tuberculosis had subsided. Unfortunately, the advent of HIV infection means reduced bodily immunity against disease: this has encouraged diarrhoea, measles and malaria to kill children and tuberculosis to claim a heavy toll on adults.

The elders claimed that of the infants identified as AIDS cases, 98.5 per cent died in the first five months of their life; although it is true that babies born with HIV die very fast, the percentage given seems too high. Goldfarb (1991) reported that most children born with HIV in Africa die by the age of 18 months and 80-90 per cent by five years. It appears the elders failed to give a good estimate of the period of survival for children who are HIV-infected because they could not easily separate other causes of death from AIDS-related diseases. In any case, most major killers of infants in Uganda are malaria, measles and diarrhoea which are AIDS-related.

### **Feelings of loss by elders**

It is important to know about the loss suffered by the elders and how they feel. Their major concerns are the physical loss, financial problems and coping with orphans. They feel the physical loss because most of those dead are their children and grandchildren whom they loved and expected to be their heirs and descendants of their family or clan line (Ntozi et al. 1990). Now that they are gone the elders have an empty life without kinship links. Barnett and Blaikie (1992) describe a Rakai man who had lost a wife and eight sons and daughters as destitute, isolated and much older than his age. It is an extremely bad situation, and beyond description.

An equally important effect of AIDS on the elders was the financial loss. Most of those who had died belonged to the economically active segment of the society. As Barnett et al. (1990) schematically demonstrated about Rakai, the financial loss to households in Uganda due to AIDS is enormous. AIDS deaths mean loss of farm and business labour from children, family income from members employed outside the home and other resources contributed by family or clan members during emergencies. Consequently AIDS-afflicted family farms have become bush, businesses have collapsed, family incomes have dwindled and family resources have declined. In the long run, the national economy will be greatly affected.

Another growing concern to elders arising from AIDS is the problem of orphan care. Thirty years ago Richards's study of Buganda household composition did not mention orphans at all because they were not a problem (Richards 1966). Since the onset of AIDS, the increasing magnitude of the problem of orphans in Uganda society has alarmed researchers. Hunter (1990) estimated the number of orphans in Rakai alone in 1989 to be 25,364: 12.8 per cent of the number of children under the age of 18 in the district; and the proportion was increasing fast. It is therefore no surprise that ten per cent of the elders were concerned with orphan care as a problem created by the disease. Perhaps the ten per cent reflects the proportion of the people already overwhelmed by this problem.

### ***Changes in funeral rites and inheritance***

In the past, mourning for the dead, burials and last funeral rites lasted long periods because few deaths occurred. From the elders' survey, it was clear that this had changed to shorter periods. Owing to the need to keep economic production going, the almost daily deaths are no longer mourned by the whole village in the form of stopping economic production, especially farming. If this past practice were followed strictly, some villages would spend months without working on the farms and hence have nothing to harvest, which would be a disaster. Instead close relatives of the deceased and those involved in the burial arrangement are the only ones who do not work in the fields. Even for the close relatives the period of mourning before and after burial has been shortened to 2-3 days instead of the previous 1-2 weeks.

The burials have also changed: in the past, they were elaborate, involving wrapping the dead in many traditional materials such as bark cloth in Buganda, and making many long speeches. This practice has given way to hasty ceremonies, the use of coffins and a few short speeches. Often two or three burials take place in the same village according to a tight time schedule; long speeches would delay the arrangements.

A new development in the burials is that in some parts of Uganda there is advance raising of funds to ensure successful ceremonies. This new practice, known in Mbarara as *bataka kweziika* (association for self burials), has been occasioned by the frequent burials which have overburdened individual households. In order to reduce the financial burden, the communities have formed these associations and set up a fund contributed to by all members who would be assisted with the basic needs at a burial. For instance these associations provide a coffin, a cloth for wrapping the deceased and food on the burial day, as well as digging the grave. The associations own some facilities such as those for cooking and saucepans which are hired out when they are not needed by members, and the money generated is added to the association's fund.

It is worth mentioning that the whole idea of burial associations is alien to the culture of Ugandans. In the past, death was feared, unexpected even by the sick and never planned for. Anyone who tried to plan for their own death or that of relatives or friends was referred to as *enkunguzi* (prophet of doom) and never tolerated by the society. The formation of burial associations is therefore a reflection of the realities of the AIDS epidemic and a mechanism to cope with it. It is also evident that the Uganda community is fully aware of the epidemic.

The last funeral rites have also undergone major changes. In the past, it took a long time to prepare the last rites. Several months after the burial in Buganda, many relatives and friends would arrive at the home of the deceased several days in advance to prepare for the ceremony. Sexual intercourse with non-relatives attending the rites was encouraged by custom to ensure replacement of the dead. In the face of the AIDS epidemic, all this has changed. Funeral rites take place soon after burial for short periods and are attended by the close relatives of the bereaved family. The sexual orgies are disappearing and are discouraged by the elders.

A custom related to the funeral rites is widow inheritance, which was common in many societies of Uganda (Roscoe 1911, 1915, 1923; Kagwa 1934; Edel 1957; Southwold 1965). The successor to a deceased married man inherited his wives so that they would continue producing children for the clan and he would look after all their children as his. The major advantage of this custom was to ensure the care of orphans. Unfortunately, because of the fear of HIV infection, this custom is fast disappearing. No man can risk marrying widows even if they are HIV-negative. This has meant that at present no relative of the deceased is solely and culturally obliged to look after the orphans and the widows. The suffering of the widows, widowers and orphans has therefore increased through the change of the custom.

## Conclusion

Although the method of study of questioning 143 opinion leaders who were not completely randomly selected is less than statistical, it is reassuring that the findings of the study are remarkably close to the results of other studies on the subject in Uganda. The effect on the household composition and structure is dramatic. Infant, childhood, adolescent and adult mortality rates have increased substantially. The study is revealing a major change of customs in order to cope with the epidemic. This may result in a future Ugandan society with new values, customs and practices.

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