

## **AIDS in Uganda: how has the household coped with the epidemic?**

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### **Abstract**

**This paper examines how households are coping with the AIDS epidemic and is based on data from four studies of six districts in Uganda between 1992 and 1995. Patient care was found to be principally given by the parents and other relatives. A considerable proportion of spouses cared for the male AIDS patients. Orphans were mainly cared for by relatives, especially grandmothers. Upon the death of one parent, the surviving parent was the principal caretaker. A number of orphans cared for themselves. People cope with widowhood by either remarrying or migrating.**

**The effects of HIV and AIDS on traditional norms were reduction in widow inheritance, household management by the widows or relatives after the death of the household head, and resorting to shorter funeral ceremonies. In marriage, people coped by changing their behaviour to sexual abstinence, fidelity, separation or dissolution of marriages, decrease in polygyny, delayed marriage, and careful selection of potential marriage partners, including tests for HIV before marriage.**

AIDS is the most deadly sexually transmitted disease ever to confront humanity (WHO 1994), and in many parts of Africa, the epidemic is a major public health problem. From the beginning of the HIV/AIDS pandemic until 1 January 1996, an estimated 30.6 million people throughout the world have been infected with HIV; it is estimated that in sub-Saharan Africa, 19.2 million people were infected (Mann and Tarantola 1996). The global pandemic which is the most feared of our time has already had profound economic and social effects and has resulted in great population loss in many parts of the world (Feldman 1994).

HIV infection is a serious health and socio-economic problem in Uganda. The virus was probably introduced into Uganda in the 1970s or early 1980s and the first cases of AIDS were diagnosed among traders and prostitutes along the Trans-Africa highway in Rakai in 1982 (Serwadda *et al.* 1985; Statistics Department 1996). AIDS started killing Ugandans in the early 1980s (McKinley 1996). Because of its spread among the heterosexual population, the control of AIDS has become a top government priority. The disease has now become an epidemic, with the central districts having the highest number of AIDS cases and prevalence rates compared to the rest of Uganda (Statistics Department 1996). In some towns, 12-15 per cent of adults are infected with HIV; overall, an estimated 1.2-1.5 million Ugandans have been infected, and 150,000-200,000 die annually from AIDS (McKinley 1996).

This so far incurable disease has had significant economic, psychological and social effects on the household structure and family composition in Uganda. Because of the alarming number of AIDS cases, professionals including physicians, social workers and health workers have had to cope with the consequences. In general, people have to cope daily with a disease for which there is as yet no cure. There is increased mortality and morbidity that demands a great deal of nursing and leads to an increased number of orphans and

widowed parents. Sexual behaviour which risks infection is a hazard and a threat to the institution of marriage.

This paper presents a study of how families and households have coped with the AIDS epidemic in Uganda. Coping mechanisms in general are reviewed and findings from another Ugandan study are presented.

## **Coping mechanisms**

### ***Patient care***

Traditional African society relied on women as principal carers for the sick (Gribble 1992; Caldwell *et al.* 1994; Ntozi 1995a). Treatment was given by traditional healers (Piot *et al.* 1992). However, with the AIDS epidemic, members of the family and clan are expected to assist in nursing and treatment (Ntozi 1995a).

The usual method of AIDS patient care is seeking preventive and curative treatment from health units (Bartlett 1993; Lwihula and Over 1994; Keogh *et al.* 1994; Anarfi 1995; Awusabo-Asare 1995; Mann and Tarantola 1996). In Uganda, AIDS care and treatment is given in selected medical units scattered throughout the country (Tembo *et al.* 1994; STD/AIDS Control Programme 1997). However, with the increasing number of AIDS patients, lack of space for admissions and lack of a cure for AIDS, other means of care and treatment have been sought by the affected families. One means is recourse to traditional healers, who are usually sought when modern medicine has failed. The traditional healers include herbalists who deal with day-to-day treatment of AIDS patients, and diviners who seek the underlying causes of AIDS; they especially work on the supposed supernatural causes (Ntozi 1995a). Most traditional healers claim to know the cure for AIDS and many people believe them.

Home based AIDS care by the patient's relatives, friends, medical personnel and social workers is another way of coping, in which AIDS patients are cared for at home. Health workers (sometimes HIV-positive themselves) who have been trained in basic health care, AIDS education and counselling, visit households with AIDS patients (Piot *et al.* 1992; WHO 1994).

Non-government organizations such as The AIDS Support Organization (TASO), foreign NGOs and religious missions also give support to AIDS patients. In Uganda, TASO was established by HIV-infected individuals and partners, relatives and friends of people who had died of AIDS, to provide counselling and treatment in a culturally appropriate manner (Piot *et al.* 1992).

### ***Orphan care***

The extended family had an obligation to assist orphans in the old days: various relatives, mostly from the paternal side, would take care of them (Ntozi and Mukiza-Gapere 1995; Ntozi 1995b; Nampinga 1995; Foster 1996; Urassa *et al.* 1997). If one parent survived, he or she could take care of the children. In the case of widows, successors to the deceased husband, if they came from the husband's family, were the ones responsible for the care of orphans. 'Babies' Homes' also used to look after homeless children. But now, these homes cannot meet all their objectives through lack of funds and overcrowding.

Recent studies show that the carers of orphans are mainly relatives from the extended family (Foster 1996; Urassa *et al.* 1997; Aspaas 1997). In Zimbabwe, the obligation of caring for AIDS orphans has now shifted to maternal relatives, away from the paternal relatives

whose responsibility it was in the past (Foster 1996). In Rwanda, the support for orphans depended on the marital status of the mother. Upon death of the married mothers, the paternal extended family would generally take care of the children. For the children of single or separated mothers who had died, it was mainly the maternal grandparents (Mody 1993).

The extended family cannot cope with the increasing number of AIDS orphans (Mashumba 1994; Kelso 1994). The adult survivors within the extended family are either too old or too young to look after the children and other survivors are too sick with AIDS to care for their own or their dead relatives' children. In order to overcome this problem, families are assisted with food, clothes, school fees and community education on AIDS. Local communities have also assisted in building homes where orphans can live with relatives (Ntozi and Mukiza-Gapere 1995). With the AIDS epidemic, the *Munno Mukabi* (friend in need) spirit, responsible for community fund raising to help with funeral expenses, has evolved into a support group for AIDS families and orphans in Rakai district (Obbo 1995). In addition, there is a new situation in which the burden of orphan care falls on the orphans themselves. This is confirmed by studies in Uganda by UNICEF (1994) and Konde-Lule *et al.* (1995) and in Zimbabwe by Foster (1997).

The orphanhood problem due to the AIDS epidemic is crucial and therefore, individuals and NGOs have set up institutional orphanages as supporting mechanisms for AIDS care (Chevallier 1994; Ntozi and Mukiza-Gapere 1995; Foster 1996). However, evidence from Zimbabwe shows that orphanages can absorb only a small proportion of orphans (Mashumba 1994; Kelso 1994). A similar situation exists in Uganda.

### **Widowhood**

Traditionally, the problem of widowhood in many African societies was solved by inheritance of widows by the man's relatives (Okeyo and Allen 1994; Olowo-Freers and Barton 1992). Among the Fulani of Mali, the Burkinabe, the Kuranko of Sierra Leone, the Zimbabweans, the Zambians, the Namibians, the Luo and Gusii of Kenya and the Rwandese, widows were expected to remarry within the husband's extended family (Ntozi 1996).

In Uganda, widow inheritance is common among the Alur (Southall 1970), the Acholi, Sebei and Bakonjo (Standing and Kisekka 1989), the Banyankore (Ntozi and Kabera 1991), the Bakiga (Yeld 1973), the Jie (Lamphear 1973; Novelli 1988), the Karimojong (Novelli 1988), the Baganda (Obbo 1986) and the Lango (Harley 1940). Widow inheritance is regarded as a social obligation to ensure that care is given to the widow and orphans (Kirumira 1992). The successor to a deceased married man inherited the deceased's wives so that they would continue producing children for the clan, and he would look after all their children as his own to ensure effective orphan care (Mukiza-Gapere and Ntozi 1995).

Recently, the levels of widowhood have increased in countries of sub-Saharan Africa that are afflicted by the AIDS epidemic (Ntozi 1996). Sexual intercourse is an essential component of widow inheritance (Okeyo and Allen 1994; Butlerys *et al.* 1994; Mukiza-Gapere and Ntozi 1995; Ntozi 1996); in the AIDS era, the custom of widow inheritance is declining because of the risk to the inheritor of HIV infection. No relative has the obligation of looking after the orphans and the widows, and households are headed by widows themselves (Nampinga 1995; Mukiza-Gapere and Ntozi 1995).

The alternative solution to widowhood is remarrying. This is common practice in many parts of sub-Saharan Africa, among the Luo of Kenya (Okeyo and Allen 1994), the Rwandese (Butlerys *et al.* 1994) and the Zambians. In Malawi, Zaire and Zambia, widows are supposed to marry shortly after the spouse's death (Kirkpatrick 1993), as are widowers.

Migration as a response to widowhood has also been noted by several studies. A study by Ntozi (1996) shows that more widowers than widows are migrating. In Zambia, through

fear of AIDS, some AIDS widows and their children are evicted from their homes and forced to go elsewhere (Kirkpatrick 1993). Similar studies in USA found that AIDS patients moved from one area to another to obtain better or closer services, find knowledgeable physicians, participate in chemical drug trials and escape discrimination, rather than die at home (Tatum and Schoech 1992). Thus migration has become a risky behaviour which facilitates the spread of AIDS.

### ***Burial and funeral ceremonies***

In many African societies, burials and mourning for the dead took several days among the affected families (Lwihula and Over 1994). Preparation and performance of funeral rites lasted for long periods. Sexual intercourse with non-relatives attending the funeral rites took place so as to ensure replacement of the dead (Mukiza-Gapere and Ntozi 1995). In Buganda, *Munno Mukabi* as a community fund-raising practice was re-invented during the 1970s to help families pay for funerals (Obbo 1995). According to Mukiza-Gapere and Ntozi (1995), a similar practice known as *Bataka Kwezika* (people burying themselves) is currently used in Ankole.

The AIDS epidemic has brought many deaths in the Ugandan population. This has changed ceremonies relating to deaths, burials and last rites. These ceremonies are shorter because the frequency of burials has meant they must be less costly and be followed by shorter mourning periods (Lwihula and Over 1994; Anarfi 1995; Obbo 1995; Mukiza-Gapere and Ntozi 1995). Women in Rakai district changed the period of mourning from 3-4 days to one day in order to tend their crops (Obbo 1995).

All these changes related to death reflect the realities of the AIDS epidemic.

### ***Sexual behaviour***

During the pre-AIDS times, men and women were free to have several sexual partners. Among the Baganda, sex was used as a ritual on occasions like weddings, funeral rites and the birth of twins. The Banyankore were free to have sex with their brothers' wives; the Bagishu had sexual orgies at the circumcision ceremonies (Mukiza-Gapere and Ntozi 1995). In the AIDS era, this kind of sexual behaviour puts people at high risk of contracting HIV infection.

Though HIV infection and AIDS have no cure, they are preventable. With no successful treatment in sight, primary prevention is the only way to control infection. As a result of AIDS health education, individuals have changed their sexual behaviour in an effort to prevent AIDS or reduce its spread. AIDS in Africa is mainly spread by heterosexual intercourse so male-female relationships are the ones most in need of behavioural change (McGrath *et al.* 1993; WHO 1994; Leonard and Khan 1994). People are adopting safer sex practices by reducing the number of their sexual partners or staying with one partner (Washington 1993; Lwihula and Over 1994). Others, especially the youth, are discouraged from having premarital sex and instead opt for abstinence. HIV-infected people are counselled to abstain from sex. Among some couples where one spouse is unfaithful, usually the male, the female usually opts for sexual abstinence (Blanc *et al.* 1996). In casual and extramarital affairs, people are practising safer sex through the use of condoms (McGrath *et al.* 1993; Washington 1993; WHO 1994; Rwabukwali *et al.* 1994; Bond and Dover 1997). Condom use is the primary defence against the transmission of HIV infection; and the technique of 'social marketing' has been used to promote condom use in Uganda (Miller 1993). This project is called SOMARC (Social Marketing of Condoms) and is financed by DISH (Delivery of Improved Services for Health)/USAID. For partners who are both seropositive, use of condoms is encouraged to prevent reinfection. Where just one partner is

infected, safer sex through the use of condoms is emphasized to protect the seronegative partner from infection.

It is now well-known that pregnant women with HIV or AIDS have an increased risk of spontaneous abortions and stillbirths, and they may pass the infection on to their newborn babies (Setel 1995). To cope with this problem, the affected women are counselled to use contraception and are discouraged from producing more children for fear of putting their lives and those of their newborns at risk.

Change in cultural practices which put people at risk of HIV infection has been effected through health education. For example, among the Baganda, the use of one piece of cloth (*enkumbi*) to clean the genitals of the couple after sexual intercourse has been discouraged. When a condom has been used to prevent possible transmission of HIV from one partner to another, the use of the same cloth could defeat the purpose of the condom. Inheritance of widows, sharing of wives, and sexual indulgence by the Baganda and Bagisu are decreasing (Mukiza-Gapere and Ntozi 1995).

Prevention of Sexually Transmitted Diseases (STDs) and early and complete treatment for treatable STDs is emphasized because of their role in facilitating HIV transmission (Washington 1993; WHO 1994; Lwihula and Over 1994). In Uganda, the STD/AIDS Control Programme in collaboration with the Ministry of Health has been launched to tackle this problem. There has been a decline in promiscuity reflected by lower levels of STDs among adolescents in Rakai. This is probably due to reduced sexual activity and successful campaigns against HIV infection and AIDS (Konde-Lule 1992).

### ***Marriage***

In Uganda, in former times, marriage was a respected institution and parents played a big role in the selection of their children's partners (Mukiza-Gapere and Ntozi 1995). Polygyny was popular in African societies: a man with numerous wives was highly respected by the community and was usually wealthy.

Several changes in marriage closely connected with the AIDS epidemic have taken place. Some of the coping mechanisms that have been reported in marriage in the AIDS era include delayed marriages, stability and fidelity in marriage, separation and divorce when one of the spouses is unfaithful and separation of beds if one of the spouses is promiscuous (Mukiza-Gapere and Ntozi 1995; Blanc *et al.* 1996). Polygyny as a marriage practice may decline in the long run among Muslims (Mukiza-Gapere and Ntozi 1995), as it is well known that polygyny compounds the AIDS problem (Kirkpatrick 1993).

Some people are opting for HIV testing before they commit themselves to any sexual relationship. These people usually have a commitment to marriage or stable sexual relationships.

### **Methodology and data sources**

The data used in this paper are from a multi-phase study entitled 'The evolution of household composition and family structure under conditions of high mortality in Uganda', carried out between 1991 and 1996. The survey was conducted in six districts of Uganda: Mbale and Iganga in the east, Masaka in the south, Mbarara and Kabale in the southwest and Hoima in the west. One of the objectives of the research was to study how the population was coping with the AIDS epidemic.

The study was done in four phases: phase 1 which consisted of the collection of ethnographic material, focus group discussions and elders' survey; phase 2, the baseline survey; phase 3, the follow-up survey; and phase 4 which covered the complete enumeration

of households and registration of vital events.

The elders' survey covered 143 households; phase 2 covered 1797 households. In phase 3, households previously considered in phase 2 were revisited, including those households which had lost someone during the inter-survey period. Phases 2 and 3 used the same questionnaire, which was a modification of the elders' survey questionnaire. Only data from the first three phases are used here. Topics considered are related to patient care, orphan care, marriage, behaviour patterns of widowed persons, attitudes towards death, and sexual behaviour.

## **Results**

### *Patient care*

Patient care was analysed for the three phases of the survey and the results are presented in Table 1. Results from the elders' survey in Table 1 show that parents and other relatives were the only carers for AIDS patients. Whereas 66.7 per cent of care for the male AIDS patients was provided by their parents, the percentage was 57.1 for the female AIDS patients. However, the care provided by other relatives benefited more the female AIDS patients than the male AIDS patients. Table 1 further shows the results from the 1992/93 survey. As in the elders' survey, the results show that a majority of AIDS patients were cared for by their parents (44.9%) followed by their siblings (16.7%). Other relatives made up 14.1 per cent of the carers; spouses accounted for 9.0 per cent. Neighbours or friends (2.6%) and children (3.8%) gave less care to AIDS patients. Variations between male and female patients being cared for are shown in the table. The male AIDS patients were being looked after by parents (44.1%) followed by brothers and sisters (20.6%), spouses (17.6%) and other relatives (11.8%) as principal carers. For the female AIDS patients, parents were the principal carers (45.5%) followed by other relatives (15.9%). Brothers and sisters accounted for 13.6 per cent and care by children, neighbours and friends was negligible.

The 1995 survey data show parents (31.8%) and other relatives (27.3%) as the principal carers for AIDS patients. Spouses accounted for 13.6 per cent, brothers and sisters for 11.4 per cent, and a small proportion of the children (4.5%) cared for their parents. Variations between males and females being cared for show that other relatives (35.3%) were the leading carers for male patients followed by spouses (23.5%) and parents (23.5%). Brothers and sisters offered the least assistance in caring for the male AIDS patients and accounted for 11.8 per cent. Female patients were mainly cared for by their parents (37.0%), followed by other relatives (22.2%) and brothers and sisters (11.1%). Spouses and children offered equal but the least assistance in patient care (7.4%).

Briefly, the trend of patient care was similar to that in the early survey of elders; the burden was mostly on the parents of the AIDS patients assisted by other relatives. This was because AIDS was a new disease and many people feared to be in close contact with the patients, thinking the disease was contagious. So the parents were obliged to take care of their sick children despite the fear of contagion, since no one else would assume that responsibility.

**Table 1a**  
**Percentage of persons caring for the sick by sex and illness of the patient in the three surveys**

**Elders Survey 1992**

|                     | <b>Males</b> |              |       |      | <b>Females</b> |              |       |      | <b>Both sexes</b> |              |       |      |
|---------------------|--------------|--------------|-------|------|----------------|--------------|-------|------|-------------------|--------------|-------|------|
|                     | AIDS         | AIDS-related | Other | All  | AIDS           | AIDS-related | Other | All  | AIDS              | AIDS-related | Other | All  |
| Person caring       |              |              |       |      |                |              |       |      |                   |              |       |      |
| Spouse              | 0.0          | 6.7          | 17.6  | 13.5 | 0.0            | 9.1          | 22.4  | 18.4 | 0.0               | 7.7          | 20.7  | 16.4 |
| Children            | 0.0          | 6.7          | 17.6  | 3.8  | 0.0            | 0.0          | 24.1  | 18.4 | 0.0               | 3.8          | 16.3  | 12.5 |
| Parents             | 66.7         | 33.3         | 35.3  | 36.5 | 57.1           | 63.6         | 25.9  | 34.2 | 60.0              | 46.2         | 29.3  | 35.2 |
| Brother/sister      | 0.0          | 0.0          | 5.9   | 3.8  | 0.0            | 9.1          | 3.4   | 3.9  | 0.0               | 3.8          | 4.3   | 3.9  |
| Other relatives     | 33.3         | 33.3         | 14.7  | 21.2 | 42.9           | 0.0          | 12.1  | 13.2 | 40.0              | 19.2         | 13.0  | 16.4 |
| Neighbours/ friends | 0.0          | 0.0          | 2.9   | 1.9  | 0.0            | 0.0          | 3.4   | 2.6  | 0.0               | 0.0          | 3.3   | 2.3  |
| Others              | 0.0          | 20.0         | 20.6  | 19.2 | 0.0            | 18.2         | 8.6   | 9.2  | 0.0               | 19.2         | 13.0  | 13.3 |
| Number              | 3            | 15           | 34    | 52   | 7              | 11           | 58    | 76   | 10                | 26           | 92    | 128  |
| Chi-square          | p=0.871      |              |       |      | p=0.048        |              |       |      | p=0.087           |              |       |      |

**Table 1b**  
**Percentage of persons caring for the sick by sex and illness of the patient in the three surveys**

**1992/93 Baseline Survey (Adapted from Ntozi (1995a))**

|                    | <b>Males</b> |              |       |      | <b>Females</b> |              |       |      | <b>Both sexes</b> |              |       |      |
|--------------------|--------------|--------------|-------|------|----------------|--------------|-------|------|-------------------|--------------|-------|------|
|                    | AIDS         | AIDS-related | Other | All  | AIDS           | AIDS-related | Other | All  | AIDS              | AIDS-related | Other | All  |
| Person caring      |              |              |       |      |                |              |       |      |                   |              |       |      |
| Spouse             | 17.6         | 24.7         | 21.7  | 22.2 | 2.3            | 12.8         | 15.1  | 13.9 | 9.0               | 18.9         | 18.2  | 17.9 |
| Children           | 0.0          | 5.6          | 5.4   | 5.2  | 6.8            | 14.7         | 19.0  | 17.4 | 3.8               | 10.1         | 12.6  | 11.6 |
| Parents            | 44.1         | 45.1         | 43.4  | 43.9 | 45.5           | 39.7         | 31.9  | 34.4 | 44.9              | 42.5         | 37.3  | 38.9 |
| Brother/sister     | 20.6         | 7.4          | 6.9   | 7.7  | 13.6           | 7.1          | 5.5   | 6.3  | 16.7              | 7.2          | 6.2   | 7.0  |
| Other relatives    | 11.8         | 9.9          | 14.2  | 13.0 | 15.9           | 14.7         | 16.4  | 16.0 | 14.1              | 12.3         | 15.4  | 14.6 |
| Neighbours/friends | 0.0          | 2.5          | 1.3   | 1.5  | 4.5            | 0.6          | 0.9   | 1.1  | 2.6               | 1.6          | 1.1   | 1.3  |
| Others             | 5.9          | 4.9          | 7.1   | 6.5  | 11.4           | 10.3         | 11.1  | 10.9 | 9.0               | 7.5          | 9.2   | 8.8  |
| Number             | 34           | 162          | 479   | 675  | 44             | 156          | 542   | 742  | 78                | 318          | 1021  | 1417 |
| Chi-square         | p=0.246      |              |       |      | p=0.270        |              |       |      | p=0.007           |              |       |      |



**Table 1c**  
**Percentage of persons caring for the sick by sex and illness of the patient in the three surveys**

**1995 Follow-Up Survey**

|                    | Males   |              |       | All     | Females |              |         | All  | Both sexes |              |        |      |
|--------------------|---------|--------------|-------|---------|---------|--------------|---------|------|------------|--------------|--------|------|
|                    | AIDS    | AIDS-related | Other |         | AIDS    | AIDS-related | Other   |      | AIDS       | AIDS-related | Others | All  |
| Person caring      |         |              |       |         |         |              |         |      |            |              |        |      |
| Spouse             | 23.5    | 21.1         | 25.8  | 25.0    | 7.4     | 15.3         | 23.1    | 21.0 | 13.6       | 17.5         | 24.3   | 22.8 |
| Children           | 0.0     | 4.1          | 5.1   | 4.8     | 7.4     | 9.4          | 14.2    | 13.0 | 4.5        | 7.4          | 10.0   | 9.4  |
| Parents            | 23.5    | 55.3         | 46.3  | 47.3    | 37.0    | 46.3         | 31.7    | 34.9 | 31.8       | 49.7         | 38.4   | 40.4 |
| Brother/sister     | 11.8    | 3.3          | 2.9   | 3.1     | 11.1    | 7.4          | 3.8     | 4.8  | 11.4       | 5.8          | 3.4    | 4.1  |
| Other relatives    | 35.3    | 8.9          | 9.3   | 9.8     | 22.2    | 13.8         | 12.7    | 13.2 | 27.3       | 12.0         | 11.1   | 11.7 |
| Neighbours/friends | 0.0     | 0.8          | 1.0   | 0.9     | 0.0     | 0.5          | 0.5     | 0.5  | 0.0        | 0.6          | 0.7    | 0.7  |
| Others             | 5.9     | 6.5          | 9.6   | 9.0     | 14.8    | 7.4          | 14.1    | 12.7 | 11.4       | 7.1          | 12.0   | 11.1 |
| Number             | 17      | 123          | 624   | 764     | 27      | 203          | 733     | 963  | 44         | 326          | 1357   | 1727 |
| Chi-square         | p=0.028 |              |       | p=0.000 |         |              | p=0.000 |      |            |              |        |      |

In the later surveys of 1992/93 and 1995, the burden of patient care is generally distributed differently but with the parents still the major care-givers. It seems probable that with time, people became aware that AIDS was not contagious and hence agreed to help in caring for AIDS patients as was required of them traditionally. For male AIDS patients, the burden of care on parents has decreased with time and in 1995 it moved to other relatives. It is likely that some of the parents had died. Also, some of these male AIDS patients may have been single in 1992/93 but later married. That is perhaps why the table shows that a relatively high number was being cared for by spouses in 1995. In African culture, when a married man falls sick it is the obligation of his wife to take care of him. The results related to care for female patients also show that although the parents' burden was large, it decreased across the three time periods. This may also be attributed to the death of parents. However, spouses and children generally gave the least assistance in patient care for the females, probably because when women, married or single, fall sick they go back to their parents' home to be cared for. The spouses and children are always left behind in the women's matrimonial homes. It should also be noted that men usually are not good at caring for the sick, whether or not the sickness is AIDS. Some of these female patients need not have gone home. Even at their spouses' homes, it is their own relatives who care for them.

### ***Orphan care***

Focus group discussion notes on the orphans and orphan care were reviewed. These discussions revealed that the number of AIDS orphans was increasing. Participants from focus group discussions stated that in the past it was the obligation of relatives to take care of orphans, because there were very few of them and it was therefore easy for the immediate relatives to look after them. The government also used to offer some assistance to orphans. The carer for motherless children was usually the deceased mother's sister, who would marry her sister's widower. It was also stated that on the death of her husband, sometimes the widow took care of the fatherless children.

The burden of orphan care was found to fall on the oldest members of the family, usually the grandparents, as AIDS mostly kills young adults. The siblings who were too young to care for others were nonetheless doing so because adult relatives had died.

Orphanages such as the Nalongo Orphanage in Kabale district cater for some of the AIDS orphans. Religious missions, for example, the Church of Uganda in Kabale district, gave AIDS orphans free education. Assistance from NGOs in the study districts was mentioned by participants. In Iganga district, some of the orphans are assisted by the Uganda Women's Efforts to Save Orphans (UWESO) while in Mbale district, NGOs such as the Salem Brotherhood, Child Care Project, OutReach and a few religious sects help orphans. In Hoima district, World Vision has helped the AIDS orphans by building two primary schools and contributing one-third of school fees. The government also cares for AIDS orphans of soldiers. In Kasonga village, Hoima district, there is a care centre for orphans. Reverend Kakongolo of Buswekera Parish is also caring for orphans at school. In Masaka, the orphans are assisted by World Vision, Catholic nuns at Makondo and individuals who are not relatives of the orphans. The community in Masaka district has also helped by building houses for orphans and giving moral support.

Table 2 shows the percentage distribution of elders' responses on orphans and orphan care in the community. The major problem mentioned in the community by elders was that the orphans lacked funds and parental care. This problem accounted for 56.7 per cent of the elders' responses. The next problem mentioned was the increasing number of orphans in the

community. This was reported by 26.7 per cent of the respondents. Orphans received some help from NGOs (8.7%) and some care from their close relatives (8%).

Table 2 also shows the percentage distribution of elders' responses on orphan care in the past 10-20 years. The most frequent response (44%) from the elders indicated that some of the orphans were mainly cared for by their relatives. This was followed by 22.5 per cent of the responses indicating that the heir was responsible for the care of some orphans; 7.1 per cent reported that the government, widows and widowers took care of some orphans; 9.9 per cent noted that aunts and uncles assisted and 3.3 per cent that care came from friends and NGOs.

**Table 2**  
**Orphan care : percentage distribution as perceived by elders, 1992 elders survey**

|   | Number | Per cent |        |
|---|--------|----------|--------|
| <b>Situation regarding orphans in the community</b>   |        |          |        |
| Lack of funds and parental care                       | 85     | 56.7     |        |
| Help from NGOs  | 13     | 8.7      |        |
| Close relative's care                                 | 12     | 8.0      |        |
| Number of orphans                                     | 40     | 26.7     |        |
| Total   | 150    | 100.0    |        |
| <b>Who cared for orphans in the past 10-20 years?</b> |        |          |        |
| Father's heir   | 41     | 22.5     |        |
| Grandparents  | 11     | 6.0      |        |
| Relatives   | 80     | 44.0     |        |
| Government  | 13     | 7.1      |        |
| Uncles and aunts                                      | 18     | 9.9      |        |
| Friends and NGOs                                      | 6      | 3.3      |        |
| Widowed parent  | 13     | 7.1      |        |
| Total   | 182    | 100.0    |        |
| <b>Who cares for orphans now?</b>                     |        |          |        |
| Relatives   | 104    | 48.4     |        |
| Grandparents  | 19     | 8.8      |        |
| NGOs and friends                                      | 50     | 23.3     |        |
| Themselves  | 39     | 18.1     |        |
| Father's heir   | 3      | 1.4      |        |
| Total   | 215    | 100.0    |        |
| <b>People caring for orphans doing a good job</b>     |        |          |        |
|   | Number | Yes (%)  | No (%) |
| Feeding them  | 142    | 44.4     | 55.6   |
| Clothing them   | 142    | 29.6     | 70.4   |
| Educating them  | 140    | 28.6     | 71.4   |
| Socializing them                                      | 140    | 58.6     | 41.4   |
| Providing bedding                                     | 134    | 21.6     | 78.4   |

Note: the difference in totals is due to multiple responses and missing cases

**Table 3**  
**Per cent distribution of orphan care, 1992/93 and 1995 Surveys.**

|  | 1992/93<br>All orphans | Baseline survey<br>AIDS orphans | 1995<br>All orphans | Follow-up survey<br>AIDS orphans |
|--|------------------------|---------------------------------|---------------------|----------------------------------|
| <b>Effect of death on the children</b>                       |                        |                                 |                     |                                  |
| No parental care   | 32.1                   | 34.8                            | 32.1                | 31.3                             |
| No effect  | 8.9                    | 8.3                             | 10.1                | 13.4                             |
| No funds   | 57.6                   | 54.6                            | 56.1                | 53.3                             |
| Household split  | 1.7                    | 1.5                             | 0.7                 | 1.0                              |
| Care by themselves   | 0.3                    | 0.6                             | 0.1                 | 0.3                              |
| Died   | 0.2                    | 0.1                             | 0.8                 | 0.8                              |
| <b>Person who made the decision for care of the children</b> |                        |                                 |                     |                                  |
| Grandparents   | 6.1                    | 10.8                            | 2.5                 | 2.0                              |
| Grandfather  | 7.4                    | 10.4                            | 5.1                 | 5.1                              |
| Grandmother  | 2.0                    | 2.6                             | 1.5                 | 0.7                              |
| Father   | 7.7                    | 10.2                            | 5.7                 | 4.2                              |
| Mother   | 14.6                   | 14.8                            | 9.2                 | 4.4                              |
| Stepmother   | 0.3                    | 0.2                             | -                   | -                                |
| Uncle  | 3.8                    | 5.3                             | 4.7                 | 7.5                              |
| Aunt   | 1.1                    | 1.6                             | 0.1                 | -                                |
| Brother  | 0.6                    | 1.0                             | -                   | -                                |
| Sister   | 0.1                    | 0.3                             | 0.2                 | 0.5                              |
| Brothers/sisters   | 0.5                    | 0.5                             | -                   | -                                |
| Family members   | 9.1                    | 6.9                             | 21.2                | 20.8                             |
| Clan members   | 17.3                   | 14.4                            | 21.3                | 25.9                             |
| Friends  | 0.2                    | 0.2                             | 0.3                 | 0.7                              |
| Customary  | 5.7                    | 3.2                             | 7.4                 | 3.5                              |
| Deceased's will  | 3.0                    | 3.6                             | 4.8                 | 6.0                              |
| C or P leaders   | 0.3                    | 0.7                             | 0.8                 | 0.4                              |
| Themselves   | 20.1                   | 13.4                            | 15.1                | 18.2                             |
| <b>Person who takes care of the children</b>                 |                        |                                 |                     |                                  |
| Grandfather  | 6.3                    | 6.6                             | 7.5                 | 7.4                              |
| Grandmother  | 8.4                    | 9.4                             | 13.2                | 13.6                             |
| Grandparent  | 10.6                   | 18.0                            | 12.9                | 13.1                             |
| Surviving father   | 9.7                    | 8.7                             | 10.2                | 8.1                              |
| Surviving mother   | 31.0                   | 24.4                            | 29.1                | 20.9                             |
| Unspecified parent   | 0.3                    | -                               | 0.6                 | -                                |
| Brother  | 4.6                    | 3.3                             | 3.4                 | 5.1                              |
| Sister   | 2.0                    | 1.5                             | 0.9                 | 1.4                              |
| Uncle  | 10.0                   | 10.1                            | 9.6                 | 15.2                             |
| Aunt   | 5.7                    | 8.8                             | 6.0                 | 6.5                              |
| Stepmother   | 2.6                    | 2.3                             | 1.6                 | 1.2                              |
| Other relatives  | 1.3                    | 0.8                             | 2.4                 | 3.9                              |
| Friends  | 0.4                    | 0.3                             | 0.3                 | 0.7                              |
| Themselves   | 6.5                    | 4.3                             | 1.8                 | 1.9                              |

|                    |     |     |     |     |
|--------------------|-----|-----|-----|-----|
| NGOs               | 0.4 | 0.8 | 0.7 | 0.7 |
| Stepbrother/sister | 0.3 | 0.6 | -   | -   |

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As regards the type of orphan care at the time of the survey, Table 2 shows that some of the orphans were mainly being cared for by their relatives (48.4%). Twenty-three per cent of the responses indicated that NGOs and friends were offering care while 18.1 per cent reported that some orphans were caring for themselves. That result is supported by other studies conducted in Uganda (UNICEF 1994; Konde-Lule *et al.* 1995) which found that some children took care of their younger siblings. Further evidence from 8.8 per cent of the responses showed that orphans received care from grandparents and this was also mentioned in focus group discussions. The fewest responses (1.4%) indicated that the heir was also responsible for the care of some of the orphans.

Results from the elders' responses on people caring for orphans with food, clothing, education, socializing and provision of proper bedding are shown in Table 3. The majority of the respondents claimed that the carers were not doing a good job except in the area of socialization.

Table 3 further shows that the major effects of parents' deaths on the children mentioned by most elders were shortage of funds and lack of parental care. As a result, people in this community devised ways of providing substitute care for the orphans and looking after their welfare.

The results from the 1992/93 survey on orphans in general show that respondents mentioned the orphans themselves (20.1%), clan members (17.3%) and mothers (14.6%) as mainly the decision makers in matters related to orphan care. For the AIDS orphans, the same survey showed that most respondents mentioned the mother (14.8%), clan members (14.4%) and the orphans themselves (13.4%) as the decision makers. In the 1995 survey the respondents reported clan members (21.3%), family members (21.2%) and orphans themselves (15.1%) as the leading decision makers in the care of the orphans in general as well as for the AIDS orphans. There was an increase of participation in the decision making by the family and clan members between 1992/93 and 1995, perhaps because both parents died before the 1995 survey. This is supported by the results which show a decrease in decision making by fathers and mothers from 1992/93 to 1995.

In addition, Table 3 presents the responses about the carers of orphans. The 1992/93 survey shows that the most mentioned carers for orphans in general were the surviving mothers (31%), followed by grandparents (10.6%) and uncles (10%). Similar results were obtained for the AIDS orphans. For the 1995 survey, the most reported carers for orphans in general were the surviving mothers (29.1%), grandmothers (13.2%) and unspecified grandparents (12.9%). As for AIDS orphans, the most mentioned carers were the surviving mothers (20.9%), uncles (15.2%), grandmothers (13.6%) and grandparents (13.1%).

It is evident from the surveys that the surviving mothers shouldered the greatest responsibility of caring for their fatherless children. Perhaps this is because the mothers do not want to part with their children upon the death of the fathers for fear that relatives may neglect and abuse the children. Kirkpatrick (1993) found that at times, through fear of AIDS, AIDS orphans are evicted from their homes and have to go elsewhere to be cared for by their mothers. Grandmothers and unspecified grandparents were also mentioned as potential carers of orphans. These older relatives bear a big responsibility in caring for orphans when the younger adults die of AIDS.

However, the proportion of the surviving mothers as carers decreases with time. For instance, while the 1992/93 survey showed higher percentages of 31 per cent for all orphans and 24.4 per cent for AIDS orphans being cared for by their mothers, the percentages dropped to 29.1 and 20.9 respectively. Probably this is because some of the mothers had died. In contrast, the percentages for grandmothers (13.2% for all orphans, 13.6% for AIDS orphans) and unspecified grandparents (12.9% for all orphans, 13.1% for AIDS orphans) in the 1995

survey were higher than those of 1992/93, but not for AIDS orphans. The general picture is that the burden of orphan care was increasingly on the grandmothers, probably upon the death of the surviving mothers. Uncles were also found to care for AIDS orphans in 1995 more than in 1992/93. This may be due to the death of both parents in the inter-survey period.

Table 4 shows the percentage distribution of carers of orphans according to which parent had died. The 1992/93 survey shows that a majority of responses (42.8%) indicate that fatherless children in general were mainly cared for by their surviving mothers; this also applied for the AIDS orphans (36.9%). Uncles also provided orphan care; they accounted for 10.9 per cent of the responses for all orphans and 10.7 per cent for the AIDS orphans. Unspecified grandparents (14.7%) were also mentioned as principal carers for the AIDS orphans. All motherless children were mainly cared for by their surviving fathers and unspecified grandparents.

The 1995 survey results show that most respondents mentioned the surviving mothers, uncles and unspecified grandparents as the main carers for all fatherless children as well as those whose fathers had died of AIDS. For motherless children, the responses indicate the surviving fathers, grandmothers and unspecified grandparents were the principal carers. The results for AIDS orphans, however, show the grandmothers as the most mentioned (21.5%) carers, followed by the surviving father (19.3%), grandparents (17.5%) and uncles (11.7%).

The findings from both surveys are expected because upon the death of one parent, the surviving parent is obliged to take care of his or her children unless incapacitated. The responses on AIDS orphans from the 1995 survey for surviving mothers and fathers as carers are smaller than those for the 1992/93 survey. This may be due to more deaths of the mothers and fathers which occurred between the two surveys. This is partly confirmed by the responses which indicate an increase among uncles and grandmothers as carers of orphans between 1992/93 and 1995.

### ***Widowhood***

The focus group discussions indicated that the inheritance of widows resulting in men having many wives has been affected by fear of AIDS. In Iganga, it was reported that widows were helped economically by relatives rather than by marriage.

### ***Remarriage as a coping mechanism for the widowed***

The questionnaire asked whether the widowed person had remarried or acquired a new sexual partner. The responses are shown in Table 5 which shows that more of the widowed had remarried in 1992/93 than in 1995. Both surveys show that higher proportions of widowers (56.1% in 1992/93 and 42.9% in 1995) had remarried than widows (27.3% in 1992/93 and 20.8% in 1995). In Ugandan societies, it is easier for men to remarry than for women. For instance, while all the widowers aged 15-19 had remarried in both surveys, none of the widows in that age group had remarried in the 1995 survey. This implies that widow inheritance may be declining since widows were in the past expected to remarry into their late spouses' extended family or elsewhere (Standing and Kisekka 1989; Kirumira 1992).

**Table 4**  
**Per cent distribution of caretaker of orphans by identity of deceased parent, 1992/93 and 1995 surveys**

| Caretaker          | 1992/93 Baseline Survey |              |             |              | 1995 Follow-Up Survey |              |             |              |
|--------------------|-------------------------|--------------|-------------|--------------|-----------------------|--------------|-------------|--------------|
|                    | Father dead             |              | Mother dead |              | Father dead           |              | Mother dead |              |
|                    | All orphans             | AIDS orphans | All orphans | AIDS orphans | All orphans           | AIDS orphans | All orphans | AIDS orphans |
| Grandfather        | 6.0                     | 5.9          | 6.8         | 7.9          | 6.8                   | 4.9          | 8.1         | 9.9          |
| Grandmother        | 7.5                     | 9.7          | 10.4        | 8.8          | 6.8                   | 8.8          | 21.3        | 21.5         |
| Grandparent        | 8.3                     | 14.7         | 15.9        | 24.1         | 10.6                  | 10.1         | 15.8        | 17.5         |
| Surviving father   | -                       | -            | 27.8        | 22.5         | -                     | -            | 26.8        | 19.3         |
| Surviving mother   | 42.8                    | 36.9         | -           | -            | 47.9                  | 34.5         | -           | -            |
| Unspecified parent | 0.3                     | -            | 0.4         | -            | 0.3                   | -            | 0.0         | -            |
| Brother            | 4.9                     | 3.0          | 3.9         | 3.9          | 5.3                   | 7.0          | 1.3         | 2.7          |
| Sister             | 1.8                     | 1.5          | 2.4         | 1.7          | 0.5                   | 0.9          | 2.2         | 2.2          |
| Uncle              | 12.7                    | 11.9         | 7.7         | 8.9          | 11.2                  | 18.6         | 9.2         | 11.7         |
| Aunt               | 4.8                     | 8.2          | 11.8        | 11.5         | 3.8                   | 4.6          | 9.7         | 9.4          |
| Stepmother         | 2.3                     | 2.7          | 3.4         | 1.5          | 1.5                   | 1.8          | 1.3         | 0.4          |
| Other relatives    | 1.0                     | 0.9          | 2.1         | 0.6          | 2.9                   | 6.4          | 0.9         | 0.4          |
| Friends            | 0.5                     | 0.2          | 0.3         | 0.5          | 0.0                   | 0.0          | 0.9         | 1.8          |
| Themselves         | 6.4                     | 2.6          | 6.7         | 7.3          | 1.5                   | 1.5          | 2.2         | 2.7          |
| NGOs               | 0.4                     | 1.6          | 0.4         | 1.0          | 0.8                   | 0.9          | 0.2         | 0.4          |
|                    | p=0.000                 |              |             |              | p=0.000               |              |             |              |



**Table 5**  
**Percentage of widows/widowers who had remarried by age**

| Age Group | 1992/93             |                   | 1995                |                   |
|-----------|---------------------|-------------------|---------------------|-------------------|
|           | Widowers<br>(N=296) | Widows<br>(N=781) | Widowers<br>(N=133) | Widows<br>(N=283) |
| 15-19     | 100.0               | 35.7              | 100.0               | 0.0               |
| 20-24     | 50.0                | 40.9              | 33.3                | 21.2              |
| 25-29     | 60.0                | 30.2              | 50.6                | 34.0              |
| 30-34     | 57.6                | 30.9              | 46.2                | 19.6              |
| 35-39     | 56.9                | 32.1              | 33.3                | 23.7              |
| 40-44     | 68.4                | 27.9              | 36.8                | 22.7              |
| 45-49     | 62.5                | 19.0              | 63.6                | 11.8              |
| 50-54     | 57.1                | 21.2              | 66.7                | 21.1              |
| 55-59     | 66.7                | 20.0              | 37.5                | 0.0               |
| 60+       | 37.7                | 6.0               | 29.4                | 10.8              |
| Total     | 56.1                | 27.3              | 42.9                | 20.8              |

p=0.000

p=0.496

Source: Ntozi (1996)

One explanation for none of the widows aged 15-19 years having remarried by the 1995 survey is that people started fearing AIDS which they suspected was the cause of death of the husbands of the young widows. The second explanation is that perhaps by the time the 1995 survey was conducted, these widows had not formalized their relationships with those who had married them. In all ages, higher percentages of widowers than widows were shown to have remarried in both surveys with a significant difference in the 1992/93 survey ( $p=0.000$ ) but not in the 1995 survey ( $p=0.496$ ). Most probably, a young AIDS widow is no different from an old AIDS widow since both of them probably have the disease.

#### ***Migration as a coping mechanism for the widowed***

Table 6 shows the percentages of the widowed who moved out of their late spouses' households. The proportions of widowers and widows who migrated in the 1992/93 survey were 17.3 per cent and 37.0 per cent respectively; in the 1995 survey, the percentages went up to 23.1 per cent among widowers and 38 per cent among widows. The widows moved out of their late spouses' homes more than the widowers because in most Ugandan societies, the widows usually have to move to their new spouses' homes and leave their deceased husbands' homes as they are not allowed to invite new partners into their deceased husbands' homes. It is considered by the in-laws and the fatherless children as morally unacceptable, a taboo and disgrace to do so. In contrast, it is easier and more acceptable to the society for the widowers to get new spouses and stay in their matrimonial homes. This is perhaps because it is an ancestral home to the man, not the wife.

**Table 6**  
**Percentage of widows/widowers who moved from households of the late spouses by age**

| Age Group | 1992/93             |                   | 1995                |                   |
|-----------|---------------------|-------------------|---------------------|-------------------|
|           | Widowers<br>(N=294) | Widows<br>(N=809) | Widowers<br>(N=134) | Widows<br>(N=297) |
| 15-19     | 0.0                 | 73.3              | 0.0                 | 66.7              |
| 20-24     | 44.4                | 63.0              | 25.0                | 77.1              |
| 25-29     | 25.0                | 52.9              | 28.6                | 55.6              |
| 30-34     | 25.8                | 46.5              | 30.4                | 39.1              |
| 35-39     | 18.4                | 39.5              | 16.7                | 30.8              |
| 40-44     | 17.1                | 19.4              | 23.8                | 27.3              |
| 45-49     | 17.6                | 18.6              | 23.1                | 22.2              |
| 50-54     | 8.6                 | 13.5              | 12.5                | 15.8              |
| 55-59     | 11.1                | 10.3              | 12.5                | 0.0               |
| 60+       | 5.7                 | 0.6               | 27.8                | 5.7               |
| Total     | 17.3                | 37.0              | 23.1                | 38.0              |
|           | p=0.011             |                   | p=0.001             |                   |

Source: Ntozi (1996)

The pattern of proportion of widowers who moved out of the late wives' households in the 1992/93 survey shows a decline as the age of widowers increased. The 20-24 age group had the highest percentage (44.4%) of those who moved out of the late wife's household while those aged 60 and above had the lowest percentage (5.7%). This is an expected demographic pattern as it is commonly known that younger adults are more likely to migrate than older ones. Besides, the younger widowers are still sexually active and have to seek new sexual partners away from their former place of residence for fear of stigmatization. On the other hand, the 1995 survey shows an irregular pattern of widowers who moved out of the households of their late wives. The 30-34 age group shows the highest proportion (30.4%) and age groups 50-54 and 55-59 both have the lowest proportion (12.5%).

Both surveys show a regular pattern of widows who moved out of their late husbands' households. The proportion of widows decreased with increased age in both surveys. This migration pattern is similar to the one observed above among the widowers in the 1992/93 survey. Both surveys showed a significant association based on the chi-square test between ages of widows who moved out of the late husbands' home. Similarly the chi-square test of the difference between widows and widowers shows a significant difference in both surveys (1992/93  $p=0.011$  and 1995  $p=0.001$ ). From the  $p$  values, the association is greater in 1995 compared to the 1992/93 survey indicating wider differences over time.

### **Death**

Data were collected on the perception of death by elders and the results are shown in Table 7. The table shows the responses on coping when a household head died. A majority of responses (35.8%) indicated the provision of orphan care by relatives. Mourning for a long time, widow inheritance and performing of rituals were also mentioned. The fewest respondents (6.8%) said that orphan care was also provided by the widows.

**Table 7**  
**Perception of elders about death, Elders Survey of 1992**

|  | Number | Per cent |
|--|--------|----------|
| <b>What used to happen when household head died</b>    |        |          |
| Men take over widows                                   | 28     | 18.9     |
| Mourn for long time                                    | 32     | 21.6     |
| Relatives take orphans                                 | 53     | 35.8     |
| Widows care for fatherless children                    | 10     | 6.8      |
| Perform rituals  | 25     | 16.9     |
| Total  | 148    | 100.0    |
| <b>Effect of AIDS on traditional norms</b>             |        |          |
| Widow not inherited                                    | 85     | 58.6     |
| No support for orphans                                 | 18     | 12.4     |
| Widow migrates   | 3      | 2.1      |
| Dissolution of households                              | 6      | 4.1      |
| Very short ceremony                                    | 19     | 13.1     |
| No change  | 5      | 3.5      |
| Relatives care   | 9      | 6.2      |
| Total  | 145    | 100.0    |
| <b>How people manage after death of household head</b> |        |          |
| Manage by themselves                                   | 50     | 36.0     |
| Relatives take over                                    | 55     | 39.6     |
| Orphan helpless  | 16     | 11.5     |
| Widow takes over                                       | 14     | 10.1     |
| Widow migrates   | 4      | 2.8      |
| Total  | 139    | 100.0    |
| <b>How people respond to death these days</b>          |        |          |
| Worried and scared                                     | 63     | 44.7     |
| Not bothered   | 23     | 16.3     |
| Death too common                                       | 23     | 16.3     |
| Death no longer feared                                 | 32     | 22.7     |
| Total  | 141    | 100.0    |

Note: the difference in totals is due to multiple responses and missing cases

The effects of AIDS on traditional norms regarding death in the community were examined in the elders' survey. The results in Table 7 show that the majority (58.6%) of elders reported that men in the community no longer inherited widows on the death of their husbands. Thirteen per cent said that people opted for very short burial ceremonies. This response was similar to the one given by the focus group discussions.

The largest portion of the elders (39.6%) reported that it was the duty of the relatives to take over the management of the households when the head of the household died; 36 per cent said that the household members took over the management of households, and 10.1 per cent said that widows took over the households when their husbands died. Only a few elders mentioned migration of widows.

Regarding the current response to death at the time of the elders' survey, a majority of the elders (44.7%) said that people were worried and afraid; 22.7 per cent said that people no

longer feared death. Other respondents (16.3%) reported that people no longer bothered and that death was too common.

Table 8 shows that lack of funds and conflicts in the households were the major problems the households faced in the 1992/93 survey. During the 1995 survey, conflicts and property wrangles were also mentioned. This implies that people are concerned about conflicts within the family after the death of heads of households. In the past, witchcraft as an alleged cause of death made the family afraid to fight for the deceased estates, but this is no longer the case.

**Table 8**  
**Percentage distribution of responses on attitudes towards death and behaviour change, 1992/93 and 1995 Surveys**

|   | 1992/93 Survey |          | 1995 Survey |          |
|---|----------------|----------|-------------|----------|
|   | Number         | Per cent | Number      | Per cent |
| <b>Changes death caused to household</b>          |                |          |             |          |
| High cost of treatment                            | 243            | 3.9      | 79          | 6.0      |
| No funds for family                               | 2035           | 32.8     | 624         | 47.5     |
| Depression  | 872            | 14.0     | 310         | 23.6     |
| Family rift                                       | 93             | 1.5      | 20          | 1.5      |
| Property wrangles                                 | 46             | 0.7      | 7           | 0.5      |
| No effect   | 898            | 14.5     | 263         | 20.0     |
| Conflict  | 2024           | 32.6     | 11          | 0.9      |
| Total   | 6211           | 100.0    | 1314        | 100.0    |
| <b>Felt about death</b>                           |                |          |             |          |
| Normal  | 215            | 12.1     | 307         | 13.4     |
| Sad-bad   | 926            | 52.3     | 513         | 22.4     |
| Too many people die                               | 631            | 35.6     | 1470        | 64.2     |
| Total   | 1772           | 100.0    | 2290        | 100.0    |
| <b>Is the way you felt about death different?</b> |                |          |             |          |
| Yes   | 1531           | 85.6     | 2040        | 87.3     |
| No  | 258            | 14.4     | 298         | 12.7     |
| Total   | 1789           | 100.0    | 2338        | 100.0    |
| <b>Reason for difference</b>                      |                |          |             |          |
| Too much  | 1467           | 82.8     | 1888        | 88.9     |
| Normal to die                                     | 266            | 15.0     | 186         | 8.8      |
| Worried   | 38             | 2.1      | 50          | 2.4      |
| Total   | 1771           | 99.9     | 2124        | 100.1    |
| <b>Changes in behaviour due to AIDS</b>           |                |          |             |          |
| Great change                                      | 851            | 50.7     | 721         | 32.6     |
| Some change                                       | 377            | 22.5     | 596         | 27.0     |
| No change   | 450            | 26.8     | 892         | 40.4     |
| Total   | 1678           | 100.0    | 2209        | 100.0    |

Note: the difference in totals is due to rounding, multiple responses and missing cases.

People's feelings about death have changed. Whereas in 1992/93 the majority of respondents agreed that death was sad (52.3 %), in 1995 most respondents said that deaths were too numerous (64.2%). Instead of respondents considering death as bad and sad, the majority looked at it in terms of numbers. There was a small rise among those who said that

death was normal from 12.1 per cent in 1992/93 to 13.4 per cent in 1995, possibly because in 1992/93, people thought that although AIDS was fatal, it would soon have a cure, but by 1995 people had started to be resigned to the fact that many would die of the disease since there was no cure in sight.

In both surveys, the respondents contended that the way they had felt about death a few years before the survey was different from how they felt about death during the time of the surveys. The reason given for the difference was that death had become too prevalent by the 1995 survey (88.9%), showing a higher percentage than in the 1992/93 survey (82.8%).

It is surprising that when respondents were asked whether the community had changed its behaviour because of AIDS, the 1992/93 survey gave higher percentages agreeing (50.7%) than the 1995 survey (32.6%). The possible explanation is that more people thought there were too many deaths in 1995 (88.9%) than in 1992/93 (82.8%). The respondents attributed more deaths in 1995 to less behaviour change than in 1992/93. Most of the respondents in this study were from rural areas where people have been less exposed to AIDS awareness and control campaigns than have those in the urban centres. It seems from the surveillance reports that HIV/AIDS is increasing in rural areas (*New Vision* 1 April 1997), which perhaps reflects high-risk behaviour.

### ***Marriage***

All the three phases of the study asked a question about marriage. It is important to analyse how people are coping with the marriage norms of the society.

During focus group discussions the first topic was marriage. A number of statements showed that AIDS had brought about significant changes in the society's marriage norms. Regardless of district, ethnicity, education or age, almost all groups stated that there had been an improvement in fidelity within marriage; marriages had become stable and young people were discouraged from entering marriage for fear of contracting HIV. However, in one focus group in Masaka, a participant gave a different opinion of early marriage:

These days, AIDS has forced the youth to marry early so that they get permanent wives. In Masaka men opt to marry very young girls on the assumption that they do not have HIV/AIDS.

A contrary statement was made in a focus group in Kabale:

Men get very old women whom they think do not have AIDS.

The rationale for the two statements is that the young girls are assumed to be virgins and the old women had passed the age when women are tempted to engage in risky sexual relations; hence both groups are free of AIDS.

Another conclusion from the focus group discussions was that if one of the spouses was unfaithful or suspected of being HIV-infected, the couple decided to sleep in separate beds or to dissolve the marriage. However, a recent study in Masaka and Lira (Blanc *et al.* 1996) reported that sleeping in separate beds resulted in serious problems and quarrels. Indeed, in Iganga, female participants of the focus groups found such a decision very difficult, particularly if it was the man who was unfaithful. Notwithstanding these views, sleeping separately was most popular among couples who had tested for HIV and found that one of them was positive. They were advised to take such action by the counselling agents of TASO.

Another marriage norm that has been much practised but was mentioned to be decreasing is polygyny. In Iganga where there were many Muslims who practised polygyny, extra strictness was observed within these families and co-wives co-operated to spy on their

husband's extramarital sexual behaviour.

Table 9 shows that 35.7 per cent of responses stated the average number of wives a mature man should have as two. Generally, over 70 per cent reported more than one wife. The data reflect a polygynous society and the major reason mentioned by the majority (59.7%) of the elders was that people regarded a man with several wives as rich and respectable. However, a sizeable proportion of respondents (23.4%) said that such a man was at risk of acquiring AIDS in modern times.

The study found that as a consequence of AIDS, the marriage institution has been affected. Forty-three per cent of the elders said that young people were coping by choosing to remain single; 26.3 per cent of the responses indicated that polygyny was becoming less common; 22 per cent stated that people intending to marry selected potential marriage partners carefully; others decided to marry early as indicated by 4.6 per cent of the responses.

**Table 9**  
**Percentage distribution of attitudes towards marriage norms as perceived by elders**

|  | Number | Per cent |
|--|--------|----------|
| <b>Average number of wives a mature man would have</b>     |        |          |
| 1  | 34     | 24.3     |
| 2  | 50     | 35.7     |
| 3  | 26     | 18.6     |
| 4  | 18     | 12.9     |
| 5  | 12     | 8.6      |
| Total  | 140    | 100.0    |
| <b>How people regard a man with several wives</b>          |        |          |
| Rich and respectable                                       | 92     | 59.7     |
| Normal for Muslims   | 6      | 4.0      |
| At risk of AIDS  | 36     | 23.4     |
| Having burden  | 13     | 8.4      |
| Not respected  | 7      | 4.5      |
| Total  | 154    | 100.0    |
| <b>Effect of AIDS on marriage</b>                          |        |          |
| Select partner carefully                                   | 33     | 21.7     |
| Early marriage   | 7      | 4.6      |
| Youth fear to marry  | 66     | 43.4     |
| Polygyny less common                                       | 40     | 26.3     |
| No widow inheritance                                       | 6      | 3.9      |
| Total  | 152    | 99.9     |
| <b>Number of people who got married</b>                    |        |          |
| None   | 19     | 13.5     |
| 1-5  | 70     | 49.6     |
| 6-10   | 9      | 6.4      |
| 7+   | 43     | 30.5     |
| Total  | 141    | 100.0    |
| <b>Number of people who tested for HIV before marriage</b> |        |          |
| None   | 89     | 90.8     |
| 1-2  | 7      | 7.2      |
| 3+   | 2      | 2.0      |
| Total  | 98     | 100.0    |
| <b>Marriage customs affected by AIDS</b>                   |        |          |
| Fewer sexual partners                                      | 16     | 12.6     |
| Widow inheritance decreasing                               | 55     | 43.3     |
| Less payment of bride price                                | 26     | 20.5     |
| No change  | 11     | 8.7      |
| More cohabiting  | 12     | 9.4      |
| Late marriages   | 7      | 5.5      |
| Total  | 127    | 100.0    |

According to the elders surveyed, marriage customs in Ugandan communities were affected by AIDS. People had dropped some of their marriage customs such as widow inheritance, reported by 43.3 per cent to be decreasing. There were changes in sexual behaviour in choosing fewer sexual partners (12.6%) and delaying marriage (5.5%).

## Conclusion

There are various ways of coping among households in the AIDS epidemic in Uganda. These coping mechanisms reflect the various attempts by individuals to survive in the AIDS era. They reflect the need to realize that AIDS is fatal and has had adverse effects on various communities in Uganda. There is little doubt that AIDS is the greatest social, economic and health problem in Uganda. Marriages are becoming monogamous; widow inheritance is disappearing; many widows and widowers migrate to other areas after the death of their spouses; the sick are nursed by relatives, particularly the parents, whose role is decreasing; and surviving parents are responsible for fatherless or motherless children. The burden of caring for orphans is transferred to aunts and uncles upon the death of the second parent.

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