

## AIDS morbidity and the role of the family in patient care in Uganda \*



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### Abstract

Extended families and clans in African societies have extensive systems of treatment and patient management which can be used with AIDS sufferers. This paper used data from a baseline survey of six districts to study patient care in Uganda. The levels of AIDS illness are high, and highest in the sexually active age groups of 20-49 years. Of the nuclear family, parents, siblings, spouses and children are the dominant AIDS patients' primary carers in that order. Other relatives in the extended family also contribute much primary care. The contribution of neighbours and friends to primary caring and of other relatives as secondary carers is small. This is perhaps because of the financial burden of caring for the patients. However, there are indications that households and families are coping with the effects of the disease.

There is no longer any doubt in the minds of most Africans that AIDS is a killer disease, has no cure, and is an epidemic in sub-Saharan Africa in general and Uganda in particular. Awareness of AIDS has been found to be very high in many parts of the region. Lwihula et al. (1993) reported that almost 100 per cent of their sample of ten villages in Bukoba and Muleba districts of Tanzania knew of AIDS. Both in Uganda and Zambia, the level of awareness has been found to be 99 per cent (Gaisie, Cross and Nsemukila 1993; Tumwine 1995). Records of sentinel surveillance in Uganda indicated that over 42,000 people had developed AIDS by the end of 1994 (ACP 1995). Age-specific mortality rates from a one-year follow up HIV-1 baseline serostatus survey of 7,765 subjects in a rural area of Masaka were found to have increased dramatically from 11.4 to 17.2, 1.9 to 7.3, 1.6 to 14.6 and 0 to 7.9 per 1000 persons for ages 0-4, 13-24, 25-34 and 35-44 respectively (Mulder et al. 1994). This implied high seroprevalence rates among both men (18.1%) and women (13.3%) in the 25-34 age group. The situation in urban centres of Uganda is worse with seroprevalence rates of at least 20 per cent in Kampala (Goodgame 1990). Other countries in central and eastern Africa are experiencing equally high levels of seroprevalence. For example, Bukoba town in North Tanzania has recorded levels of 28 per cent for females (Killewo, Dahlgren and Sandstrom 1994).

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These high rates of seroprevalence tend to indicate high levels of morbidity. General morbidity rates of 67 per cent in men aged below 25 and of 96 per cent in women aged 65 years and over have been reported in a Ugandan rural area in the four weeks preceding a survey (Wagner et al. 1993). However, because of the rapid progression to death in symptomatic HIV-1 positives, the proportion of HIV-1 positive persons who were sick at the time of the study was found to be small in Masaka (3.3%) (Wagner et al. 1993). Nevertheless, the number of AIDS patients in Uganda continues to grow daily; so there is a need for a large study of patient care representing a bigger population in Uganda to give an indication of the proportion of sick persons that are AIDS patients and how they are being assisted.

### **AIDS patient care in sub-Saharan Africa**

The care of AIDS patients extends from the time the sufferers know their results until death. Various accounts of what happens to people with AIDS after being told their seropositive results have been documented. The practice in several African countries is that counselling precedes giving out results (Kaleeba 1990). Peltzer et al. (1989) reported denial, anger, fear, bargaining, depression, acceptance and resignation as stages of reaction to seropositivity among 127 Zambian AIDS patients. A similar reaction of shock, fear, anger and sadness at the news was recently confirmed in a Ghanaian study of 141 sufferers by Awusabo-Asare (1995). This is because the AIDS patients' seropositive results are a death warrant. They immediately think of being blamed, stigmatized, isolated and abandoned by their partners, relatives, friends and neighbours. This negative feeling was accentuated by the direct methods of telling patients their diagnosis by some traditional healers in Zambia who claimed to cure the disease, but the feeling can also be reduced by the indirect approach of revealing the disease in a tactful way to allow a period of emotional ventilation (Peltzer et al. 1989).

The negative reaction by sufferers is also due to what has happened to other patients in some places. Anarfi (1995) reported high levels of 31 per cent of the spouses, 20 per cent of the mothers, and 15 per cent of the fathers in Ghana being outraged by seropositive results of their partners and children. In Kagera region of Tanzania, Lwihula et al. (1993) claimed the public blamed AIDS patients for looking for trouble and getting it. Seeley et al. (1993) found cases of neglect and abandonment in Masaka which is a reflection of lack of sympathy from the relatives, despite the claims of Kalibala and Kaleeba (1989) that the African extended family is traditionally caring.

Consequently, the people with HIV/AIDS initially keep the seropositive news to themselves. Among 18 male patients in Agyeman's (1993) Ghana study, 16 did not inform their parents for fear of condemnation and ostracization, and none told their children or neighbours. In the same study, out of 32 females, only three let their fathers know their conditions, nine told their mothers, seven their brothers or sisters, two their friends and none confided in their children. In spite of this fear of blame and stigmatization by the patients, when relatives in another Ghanaian sample were interviewed, it was found that 89 per cent of the mothers and 50 per cent of the spouses were eventually sympathetic to the patients (Anarfi 1995).

In Uganda McGrath et al. (1993) found that AIDS patients in Kampala were reluctant to inform their mothers because they did not want to worry them, their fathers because they would not understand, and their employers for fear of losing their jobs. However, when the relatives were questioned, their worries were found to be different, namely those of facing the death of their loved ones and caring for their orphans, which was far from rejection.

Nevertheless, there are some incidents of rejection, especially by the neighbours, community and public. McGrath et al. (1993) reported cases of isolation in buses or taxis by fellow passengers and the neighbours refusing to use the same water source as patients. It is therefore no surprise that in Ghana, Tanzania and Uganda surveys no neighbour at all was

informed of the seropositive news (Lwihula et al. 1993; McGrath et al. 1993; Anarfi 1995). The neighbours are left to guess the cause of the changing conditions of AIDS patients.

There is also the need for post-result counselling and support. In most Ugandan societies, the traditional form of advice generally comes from the older members of the family to the younger generation (Seeley et al. 1991). However, AIDS being a new disease to the African societies which they do not understand, this tradition has not been very relevant. For instance, while the predominantly Catholic populations of Masaka and Rakai districts of Uganda initially considered AIDS as a punishment from God to His people for wrongdoing (Seeley et al. 1991), other segments of the population associated the disease with witchcraft (Kaleeba 1990), leading to even more stigmatization of the patients instead of helping them.

Counselling was therefore started in urban centres of Uganda by The AIDS Support Organisation (TASO) and missionary hospitals such as the one in Kitovu in Masaka town. TASO has emphasized the community-based approach of counselling involving families and peer groups, days for exchange of skills between sufferers for income generation, and community informal systems of health care (Kalibala and Kaleeba 1989). The main objective of the initial post-diagnosis counselling is to get the persons with HIV/AIDS to accept their results and try to live positively until death. This counselling is important given that some people, especially the poor who cannot afford the expensive modern and traditional treatments, have thought of suicide immediately after the seropositive news has been broken to them (Lwihula et al. 1993; Awusabo-Asare 1995).

### **Role of the extended family**

As the disease progresses, the patient becomes weaker and needs more attention in the form of emotional, psychological, physical, economic and medical support. Apart from medical assistance, the other types of support are expected primarily from the patients' family and network of friends. This combined support is referred to as social support, which is defined as 'information leading an individual to believe that he/she is cared for and loved, esteemed and valued and belongs to a network of mutual obligations' (Turner 1981:359).

Cobb (1976) argued that social support can protect people in crises from a wide variety of pathological states and reduce the amount of medication required, accelerate recovery and facilitate compliance with prescribed medical regimes. Bloom (1990) associates lack of social support with the isolation and loneliness of patients and quick death. Emotional support means less distress in life crises.

In the case of African societies, the families have developed an extensive repertoire of treatment and patient management approaches (Ankrah 1993). Defining the African extended family as consisting of a number of joint families and covering several generations, Ankrah (1993) believes that, despite a series of changes, the family has continued to perform significant roles in the crises of individual members. Knowing that the African family is traditionally caring, TASO has developed its patient-care approach on the basis of the family. In most Ugandan societies, a patient-care system exists as part of the larger extended-family mutual obligations. Failure of family members to care for the sick is believed to invoke the deceased person's spirit against the culprits (Ankrah 1993).

An example of the traditional patient care system is that of the Banyankore of Mbarara, Ntungamo and Bushenyi districts in southwest Uganda. Among the Banyankore, the principal carers for the sick are the women. The women who care for the sick young ones of both sexes are relatives such as mothers, grandmothers, sisters, sisters-in-law, aunts and cousins. In ordinary ailments, women look after their husbands, fathers-in-law, mothers-in-law, brothers-in-law, fathers, brothers, and male cousins.

However, in cases of serious sickness, women are excused from caring for adult males except their husbands because the women are not allowed to handle the private parts of other

male relatives which is embarrassing to both parties; so the men are looked after by close male relatives such as adult sons, brothers, cousins and nephews, as well as fathers and uncles.

It is also worth noting that, although sick mothers are looked after by daughters, the care is not given at the home of the sons-in-law, but the home of the husband or sons. This is because married and unmarried sons tend to settle close to their fathers' homes where the mothers expect to be buried. Apart from reasons of privacy, sick women would not like to be cared for at the home of sons-in-law lest they die there and create problems for the in-laws in repatriating the remains. Likewise the sick man likes being looked after at his home or the home of one of his sons. After all, it is the responsibility of his sons to care for him during sickness or old age. This practice is almost the same as that of the Bakiga in Kabale district who share most of the culture and speak the same language as the Banyankore.

Although there are some differences in approach and emphasis, the other four ethnic groups in the study have a similar system of patient care to those of the Banyankore and Bakiga, perhaps because all six are Bantu groups. The major difference is that, unlike the situation among the Banyankore and Bakiga, it is taboo among the Baganda for individuals to be physically close to their parents-in-law. Perhaps that is why there is a neolocal marriage system of residence where the young couple form a new household far from the parents' homes (Southwold 1965). This means that individuals cannot physically care for their parents-in-law in sickness. However, the daughter-in-law and son-in-law make material contributions through their spouses: this support includes providing resources and preparing food for the parent-in-law. To a great extent, the Baganda system applies to the Basoga of Iganga and Banyoro of Hoima.

Another difference between the Banyankore-Bakiga culture and the Baganda system is the involvement of clan members in patient care. The Baganda still have a stronger clan system than obtains in other parts of Uganda. The clan members in Buganda are expected to assist each other in emergencies including patient care and funeral rites (Jaessen et al. 1984). In contrast, clan members in other parts of Uganda have dispersed over time through heavy out-migration and hence have largely lost contact with one another, perhaps because of the lack of uniting institutions as strong as the kingdom in Buganda.

Despite these differences, the family is still strong and useful in all the six districts, hence the preference for family or home patient care to hospitalization. A recent study of family-based care in Tanzania by the World Bank claimed that home-based AIDS care was 25 per cent less expensive for adults and 21 per cent less for children (Danziger 1994). Danziger (1994) reported WHO/GPA studies in Uganda and Zambia which found that home-based care improved the quality of the patient's life, reduced pressure on hospitals, and involved local communities in developing effective educational strategies. However, the same study noted the heavy investment that is required to start and sustain the home based care program. The investment is in the form of training and salaries of staff, equipment, transport costs, buildings and office space, medication and medical supplies and teaching materials.

### **The role of health units**

Another major type of patient care is at the medical unit, especially in hospitals. Keogh et al. (1994) found that over three-quarters of AIDS patients in Rwanda considered it worthwhile going to hospital for assistance in comparison to 17 per cent consulting the traditional healers. In Ghana, some patients seek expert advice when they are already too sick, perhaps because AIDS patients' care is expensive. Anarfi (1995) estimated the cost of AIDS medication to be equivalent to US\$100 per month which is about three months average income for ordinary Ghanaians. In contrast, all the patients in the study of McGrath et al. (1993) in Uganda were receiving free medical care from Nsambya hospital. Although in Kinshasa the average direct

cost of AIDS patients is lower at US\$170 per annum, it was higher than the per capita income of US\$160 in Zaire (Hassig et al. 1990).

In Tanzania, Lwihula et al. (1993) found that rich patients' initial reaction to seropositive results was to go shopping for medical advice, although he noted problems in the Kagera regional hospital in Bukoba. The hospital isolated AIDS patients and put them into separate wards which the public got to know. Patients resisted such isolation which would reveal their condition. It is claimed that the patients who knew about this isolation refused to be admitted to the hospital and those who found out later abandoned the AIDS wards and returned home. Another development reported by Lwihula et al. (1993) is that hospitals were tired of AIDS patients. A nurse in Bukoba was quoted as referring to the AIDS patients as a nuisance, unmanageable and violent.

Traditional healers form another type of medical care for patients in Uganda. Two types of traditional healers have been identified: first the herbalists who deal with the day-to-day treatment of patients; second the diviners who handle the supposed underlying causes of illness, especially the supernatural causes of sicknesses such as AIDS which has defeated the herbalists. Many AIDS patients are taken to traditional healers mostly because the families now know that modern medicines do not cure the disease while the diviners claim to cure it (Peltzer et al. 1989; Lwihula et al. 1993).

In addition to the traditional healers, there are the healing churches which claim to use the power of Jesus to cure AIDS. It is accepted by Peltzer et al. (1989) that through attention and constant prayers, the traditional diviners and healing churches are psychologically and emotionally useful to patients in the advanced stages of the disease.

The studies reported above consist of review work, ethnographic and anthropological research, laboratory studies and survey data in various parts of sub-Saharan Africa. However, in Uganda, as elsewhere in the region, field studies have been limited to small areas mostly within a district. Such studies are most useful for medical tests and anthropological purposes. Recently researchers have embarked on collecting data covering large areas representing bigger populations, so as to use the results as national indicators. This paper reports such a study.

### **Data sources and methods**

A multiphase study entitled 'Evolution of Household Composition and Family Structure under the Conditions of High Mortality in Uganda' has been conducted in six districts of Uganda since 1992. The districts covered were Iganga and Mbale in the east, Masaka in the south, Mbarara and Kabale in the southwest, and Hoima in the west of Uganda. For security reasons, the districts in northern Uganda were not included in the sample. However, these districts are believed to be least affected by AIDS.

In 1992 ethnographic materials were collected on the six major ethnic groups of the six districts. Secondly, focus-group discussions were held with elders and youth in the study areas. This was followed by an interview of selected elders using a structured questionnaire. Later in 1992, a major survey was conducted in all the sample districts except Hoima for logistic reasons; Hoima district was surveyed in mid-1993. In this quantitative study households that had experienced deaths in the last ten years were selected and their heads or competent adults interviewed. The questionnaire was in eight parts: household schedule for background characteristics of the household members; contribution of each member to the household welfare; past mortality since the formation of the household; current orphanhood and care-giving arrangements; migration and behavioural patterns of widows and widowers; care of recent patients in the household; attitude towards illness and death in the community; and reproduction in the household.

For each member of the household who was ill or had been sick in the four weeks before the survey, questions on name, sex, age, type of illness and duration of sickness were asked. Also asked were where the sick person was at the time of the survey, who cared for him or her, whether the main carers received any assistance and the effect of the illness on the rest of the household. Most of the data for this paper are from this section of the questionnaire.

Subsequent to the 1992 survey, a follow-up study was done in July and August 1995 in the same households to monitor the changes in the households in the three years. In addition, new households which experienced death in the inter-survey period were included to study characteristics of the new deaths. The 1992 survey questionnaire with minor modifications was used in the 1995 survey.

Also in 1995, an exercise of periodic recording of vital events in the study areas was started. This activity was expected to last one year and its objective was to supplement the follow-up survey in monitoring changes in fertility, mortality, marriage and migration.

### **Background information on the sample**

According to the 1991 Population and Housing Census of Uganda, the total population of the six sampled districts was four million (see Table 1), representing 24 per cent of the Uganda total population. However, the six ethnic groups represented in the sample, the Baganda, Banyankore, Basoga, Bakiga, Bagisu and Banyoro, form well over 50 per cent of the country's population (Republic of Uganda 1994).

Table 1 also shows the number of households interviewed as 1,797 with each district contributing approximately 300 households. In these households, there were 24,079 members in the recent past, of whom 13,258 were currently living in the households, 1,793 were occasional members, 336 children were in boarding schools, 4,261 had permanently left the household, 4,106 had died and 325 were in other categories.

Of the dead, 41.8 per cent had died of AIDS or related disease. The corresponding percentages for the males and females were 38.9 and 45.4 per cent respectively, confirming previous reports of higher female than male mortality (see Berkley et al. 1990). The levels of the AIDS-associated mortality in the six districts are also given in Table 1.

Masaka had the highest rates of AIDS-associated mortality (67.3%) followed by Kabale (40.4%), Mbale (36.3%), Iganga (35.0%), Mbarara (26.2%) and Hoima (21.5%). The high rates in Masaka were expected given that the AIDS epidemic has been associated with the district for a longer period than other districts; the rates are within the range of 23-89 per cent that Mulder et al. (1994) found in one of the rural parts of the district. The surprising result is that Kabale district reported a higher rate than Mbarara, Mbale and Iganga contrary to other reports (ACP 1995). But this high rate in Kabale corresponds to the highest proportion (23.3%) of reported household members who had died in the recent past in each district of the study.

**Table 1**  
**Some characteristics of the 1992 sample**

District	1991 population (thousands) a	No. of households	Total No. of household members since the formation of households			Persons who had died since household formation		Percentage of deaths constituted by AIDS and related deaths		
			Males	Females	Total	N	%	Males	Female s	Both Sexes
Hoima	197.9	311	1938	2020	3958	539	13.6	19.8	23.9	21.5
Iganga	945.8	316	1979	2235	4214	613	15.0	33.5	37.5	35.0

Kabale	417.2	286	1457	1635	3092	716	23.3	38.1	43.7	40.4
Masaka	838.7	287	2715	2726	5441	1056	19.9	64.3	70.6	67.3
Mbale	711.0	321	2006	2095	4101	727	17.8	31.4	42.1	36.3
Mbarara	930.8	276	1558	1715	3273	455	14.1	26.9	25.5	26.2
All	4,041.4	1,797	11,653	12,426	24,079	4106	17.3	38.9	45.4	41.8

<sup>a</sup> Source: Republic of Uganda 1995: Table A2.3

### *Patients with AIDS and related diseases by age and sex*

During the survey the interviewers found a total of 1315 persons who had been sick in the last four weeks. Out of these 1292 informed the interviewers of their ages and cause of illness. The causes of sickness were then categorized as AIDS, AIDS-related illness and other diseases. The percentage distribution by cause of sickness and sex of patients is shown in Table 2.

Out of 1292 patients 64 stated they were suffering from AIDS, 290 described their illness as AIDS-related and 938 named other diseases. Nearly all the AIDS patients were aged between 20 and 54 years for males and 20 and 45 years for females with low rates at 1-4 years. This is consistent with findings of earlier studies that AIDS patients are mostly in young adult life and the sexually active age groups. It is significant that no AIDS patients were found in ages 5-19 and 55 years and above. This is perhaps because the disease is not yet symptomatic in most HIV infected adolescents (Adeokun et al. 1995) and AIDS patients who contracted it when they were sexually active would have died by age 55. Furthermore, the ratio of female to male AIDS patients is 1.29, comparable to 1.4 reported by Berkley et al. (1990) for deaths and higher than reported for other causes.

The age pattern of the patients with AIDS-related illness is also interesting. The levels are high at infancy but decrease with age up to 24 years. The rates then increase with age for males up to 39 years and remain high but unstable thereafter. Similarly, the levels for females are high after the age of 25 but oscillating. The high percentage in infancy and early childhood is not surprising since most of the diseases in these age groups are malaria, diarrhoea and vomiting (Kaijuka et al. 1989), which can easily be related to AIDS. Furthermore high rates of sickness in the 20-49 age groups attributed to AIDS-related diseases are closer to the findings of high prevalence of AIDS in these ages (Mulder et al. 1994).

About 27.4 per cent of current patients are sick with AIDS and related diseases. This rate is lower than the percentage of deaths associated with AIDS and related causes (41.8% in Table 1) and proportions reported by previous studies: for example Mulder et al. (1994) reported 42 per cent in Masaka. The reason for the differences may be that some of the illness was still in early stages (asymptomatic) of AIDS and could not be identified as related to the disease but would be known by the time of death. Another reason may be that patients and their carers hid some information. Additionally, the rate is for six districts with widely varying levels of seroprevalence in comparison with the area of study by Mulder et al. (1994), Masaka, which is considered to have one of the highest seroprevalence levels in Uganda. Lastly it is possible that the lower levels may reflect a recent decline of seroprevalence in the country following massive educational campaigns.

**Table 2**  
**Per cent contribution of causes of illness by age and sex of patients.**

Age	Causes of illness									Female/Male Ratio		
	AIDS			AIDS related			Others					
	Males	Females	Both	Males	Females	Both	Males	Females	Both	AIDS	AIDS	All

Groups												& causes related disease	
0	0	0	0	45.5	42.1	43.3	54.5	57.9	56.7	0	1.60	1.73	
1-4	3.8	2.5	3.2	33.3	36.3	34.6	62.9	61.3	62.2	0.5	0.79	0.76	
5-9	0	0	0	19.5	24.2	21.6	80.5	75.8	78.4	0	0.94	0.76	
10-14	0	0	0	16.4	14.0	15.2	83.6	86.0	84.8	0	0.89	1.04	
15-19	0	0	0	15.6	13.3	14.4	84.4	87.7	85.6	0	0.86	1.00	
20-24	7.5	13.3	10.6	15.0	13.3	14.1	77.5	73.3	75.3	2.0	1.33	1.12	
25-29	9.8	15.3	13.0	24.4	23.7	24.0	65.9	61.0	63.0	2.25	1.64	1.44	
30-34	25.0	23.8	24.4	25.0	16.7	20.9	50.0	59.5	54.7	0.91	0.77	0.95	
35-39	7.7	19.4	14.5	26.9	19.4	22.6	65.4	61.1	62.9	3.50	1.56	1.38	
40-44	9.1	5.9	7.1	18.2	20.6	19.6	72.7	73.5	73.2	1.00	1.50	1.55	
45-49	6.3	0	2.0	25.0	15.2	18.4	68.8	84.8	79.6	-	1.00	2.06	
50-54	5.9	0	1.9	17.6	10.8	13.0	76.5	89.2	85.2	-	1.00	2.18	
55-60	0	0	0	35.3	18.5	25.0	64.7	81.5	75.0	0	1.25	1.59	
60+	0	0	0	20.2	26.5	23.7	79.8	73.5	76.3	0	1.58	1.21	
All	4.6	5.3	5.0	23.1	21.8	22.4	72.3	72.9	72.6	1.29	1.09	1.12	
Number	28	36	64	141	149	290	441	497	938	-	-	-	

#### *Patients with AIDS and related diseases by districts.*

The data on patients of AIDS and related diseases are disaggregated into districts as shown in Table 3. Because of the small numbers of AIDS patients in each district it was decided to combine the patients with AIDS and those with diseases associated with AIDS. The data were further regrouped into four broad age groups of 0-4, 15-19, 20-39 and 40+ which are known to have distinct levels of AIDS prevalence in Uganda (Seeley et al. 1993).

Table 3 shows a distinct pattern which is quite unexpected. Iganga and Mbale districts show generally the highest levels of AIDS-associated sickness followed by Kabale district. Surprisingly, Masaka district, considered to have experienced one of the highest seroprevalence rates in Uganda (ACP 1995), is fourth in AIDS-related illness. It is possible that the Masaka epidemic has reached its peak and is declining unlike the ones of Mbale, Iganga and Kabale which may be on the rise.

Secondly, Hoima district has in the past been considered to have low seroprevalence, much lower than Mbarara, but the former is reported to have higher rates than the latter in the case of males and about the same for females. This may have to do with the reporting of AIDS cases in previous sentinel surveys in the two districts. According to ACP (1994), Mbarara has levels of seroprevalence in the same category as Mbale, Kabale and Iganga which are reported by this study to have much higher levels.

Furthermore, a sex pattern emerges from Table 3. Although there is no distinct sex pattern of levels of AIDS-associated patients for all the districts together, there are some interesting sex differentials on a district basis. In infancy and early childhood, males have higher levels in Hoima and Masaka while females have higher levels in Iganga, Kabale, Mbale and Mbarara. Secondly, Iganga displays consistently higher levels of AIDS-associated sickness of males than females after age 5 while Mbarara does the reverse below age 40. The Iganga result is surprising because a high proportion of males in the district are circumcised since they are Moslems and are expected to have low exposure to HIV infection. However, Iganga is situated along the African highway from Mombasa to central Africa which exposes the area to long-haul truck drivers known to be highly HIV-positive, although this would affect women more than men.



**Table 3**  
**Percentage of patients with AIDS and related diseases by age, sex and district.**

Districts	Sex	Age Group				All ages %	Number
		0-4 %	5-19 %	20-39 %	40+ %		
Hoima	Male	47.4	16.1	16.0	14.6	20.7	116
	Female	16.7	13.3	19.0	27.3	20.4	113
Iganga	Male	18.2	37.5	67.9	36.0	45.8	72
	Female	33.3	8.3	46.4	28.6	32.4	74
Kabale	Male	33.3	27.3	41.7	21.7	30.7	75
	Female	63.6	26.1	33.3	15.9	28.2	117
Masaka	Male	40.0	6.7	37.5	15.2	21.3	155
	Female	31.6	16.7	38.5	17.8	24.2	157
Mbale	Male	47.1	30.1	46.7	58.8	40.5	111
	Female	51.5	29.2	46.2	27.6	39.3	112
Mbarara	Male	18.8	11.1	7.4	17.6	12.6	87
	Female	33.3	12.0	31.0	16.3	21.1	109
All Districts	Male	37.9	17.6	35.8	24.4	27.4	616
	Female	39.4	17.9	36.3	21.5	27.1	682
	Both						
	Sexes	38.6	17.7	36.0	22.6	27.3	1298

#### *Persons caring for the patients*

Respondents were asked to tell the interviewers what relation the primary carer was to the patient. The responses are given in Table 4. Because some respondents reported more than one primary carer, the counts are more than the number of patients. While the age groups in the table refer to those of patients, the percentages in the cells are for the care providers.

It is evident from Table 4 that the majority of the primary care providers of patients with all sicknesses who are close relatives are parents (37.8%), followed by spouses (18.0%) notably wives (10.3%), children (11.4%) and siblings (6.7%). Other relatives also contribute substantially (24.4%) and neighbours and friends are last (1.6%). This pattern of general patient care is expected of African families (Agyeman 1992; Ankrah 1993).

Table 4 shows distinct age patterns of patient care. First, the parents care for the young, their children from infancy upwards with a decreasing trend. In contrast, other household members' pattern of care increases with age; they tend to take over where the parents stop. Thirdly, brothers' and sisters' care is concentrated on patients in their teens and twenties, because most of the siblings would be in these ages. Fourthly, the other relatives of patients tend to help the parents caring for the young and less for the older patients.

**Table 4**  
**Percentage of persons caring for the sick by age of patients and relationship of carer**

Age group of patients	Wife	Husband	Mother	Father	Un-specified parent	Son	Daughter	Brother /sister	Other relatives	Neighbour / friend	Total
0-4	0.0	0.0	42.6	9.9	21.1	0.0	0.0	0.9	25.1	0.4	16.0

5-9	0.0	0.0	39.5	7.4	15.4	1.2	0.0	2.5	33.9	0.0	11.6
10-14	0.0	0.0	40.0	12.2	7.0	0.9	0.9	8.7	30.1	0.0	8.2
15-19	0.0	4.2	33.3	12.5	13.5	0.0	1.0	11.5	21.9	2.1	6.9
20-24	5.4	7.6	27.2	5.4	16.3	2.2	0.0	14.1	21.7	0.0	6.6
25-29	9.1	14.5	20.0	6.4	7.3	0.9	0.0	11.8	27.3	2.7	7.9
30-34	22.1	11.6	10.5	8.4	9.5	1.1	2.1	10.5	21.1	3.2	6.8
35-39	16.7	12.1	10.6	7.6	4.5	6.1	6.1	9.1	22.7	4.5	4.7
40-44	23.7	27.1	3.4	1.7	5.1	11.9	10.2	6.8	8.5	1.7	4.2
45-49	16.9	20.3	1.7	1.7	1.7	8.5	18.6	5.1	25.4	0.0	4.2
50-54	14.0	17.5	3.5	0.0	0.0	8.8	15.8	8.8	26.3	5.3	4.1
55-59	18.8	12.5	0.0	0.0	0.0	18.8	16.7	8.3	22.9	2.1	3.4
60+	23.6	6.1	0.5	0.0	0.9	20.3	17.5	4.2	24.1	2.8	15.2
All	10.3	7.7	22.0	6.2	9.6	5.7	5.7	6.7	24.4	1.6	100.0
Total											
Number	143	107	307	87	134	80	79	94	340	23	1394

$X^2$  test  $p=0.000$

When this information is broken down by sex and disease of the patients, the picture becomes clearer. As can be seen in Table 5, the parents make the highest contribution to the patients' care of all the three categories of diseases: AIDS (43.5%), AIDS related sickness (41.2%) and other illness (36.2%). Most of this support came from the mothers. It is noteworthy that, of the three categories of illness, parents' care dominated AIDS cases.

Of the close relatives the second leading care providers to AIDS patients are brothers and sisters (16.7%) followed by wives (9.0%) and daughters (3.8%). There was no contribution from the husband or son. Other relatives' caring is sizeable (23.1%) but the support from the neighbours and friends is small (3.8%). The neighbours and friends are not part of the family and so would be informed of the condition of the patients last and only if their assistance was sought.

**Table 5**  
**Percentage of persons caring for the sick by sex and illness of the patients and relationship of carer**

Person caring	Males				Females				Both sexes			
	AIDS related	AIDS	Others	All	AIDS related	AIDS	Others	All	AIDS related	AIDS	Others	All
Wife	17.6	24.1	19.4	20.4	2.3 a	0.6 a	1.1 a	1.1 a	9.0	12.6	9.7	10.3
Husband	0.0	0.6 b	2.3 b	1.8	0.0	12.2	14.0	12.8	0.0	6.3	8.5	7.6
Mother	14.7	22.2	25.9	24.4	20.5	21.8	19.2	19.8	17.9	22.0	22.3	22.0
Father	11.8	9.9	6.5	7.6	4.5	5.8	4.8	5.0	7.7	7.9	5.6	6.2
Parent - unspecified	14.7	11.1	10.2	10.7	20.5	11.5	6.6	8.5	17.9	11.3	8.3	9.5
Son	0.0	2.5	3.8	3.3	0.0	8.3	8.7	8.1	0.0	5.3	6.4	5.8
Daughters	0.0	3.1	1.7	1.9	6.8	6.4	10.3	9.3	3.8	4.7	6.3	5.8
Brother/	20.6	7.4	6.7	7.6	13.6	6.4	5.2	5.9	16.7	6.9	5.9	6.7

sister												
Other relatives	20.6	16.7	22.1	20.7	25.0	25.6	28.8	27.9	23.1	21.1	25.7	24.5
Neighbour/friend	0.0	2.5	1.5	1.6	6.8	1.3	1.3	1.6	3.8	1.9	1.4	1.6
Total %	100.0	100.1	100.1	100.0	100.0	99.9	100.0	100.0	99.9	100.0	100.1	100.0
Total numbers <sup>c</sup>	34	162	479	675	44	156	542	742	78	318	1021	1417
x <sup>2</sup> test p =			0.1450				0.0032				0.0003	

<sup>a</sup> May care for co-wives or sisters-in-law who can be called husbands metaphorically in some cultures.

<sup>b</sup> May care for brothers-in-law who can be called wives metaphorically in some cultures.

<sup>c</sup> Total numbers are higher than in previous tables because of multiple carers and missing data in Table 4 through respondents not reporting their ages.

Furthermore, Table 5 shows some differences in the care of AIDS patients of different sexes. The contribution of parents to caring for females is higher than to caring for males and the reverse pattern is true for siblings. This is probably because the mothers, who are mostly the parents providing care, find it difficult to care for the older men perhaps for privacy reasons and because of the extra physical energy the latter's care requires. Hence, the siblings' care for male AIDS patients is more than for females. Also care from spouses is higher with males than females, because most of them are wives caring for husbands. In contrast the children's care is more for the mothers than fathers perhaps because the fathers are looked after by their wives while the mothers need their children's care. For the same reason, the contribution from other relatives and persons is less for males than for females. In the case of neighbours and friends, there was no contribution to the caring for male AIDS patients. The bivariate chi square test between the contribution from different sources shows a high level of significance for females and both sexes but not for males, implying substantial differential caring of different sexes.

For the purpose of analysing the district differentials, Table 6 is presented. Because of the very small numbers of AIDS patients, this table is on responses of patients with AIDS or related diseases (most of whom are believed to be HIV-positive without symptomatic AIDS). In almost all cases, the parents, especially mothers, are the close family members that contribute most care to the patients. The exception to this pattern is Iganga males for whom most care providers are wives who are second in other districts.

**Table 6**  
Percentage of persons caring for AIDS and AIDS related patients by districts and relationship of carer

Person caring	Hoima		Iganga		Kabale		Masaka		Mbale		Mbarara	
	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females
Wife	26.2	1.6 a	35.6	1.1 a	10.5	0.0	13.6	2.4 a	18.3	0.8 a	22.5	0.0
Husband	0.8	7.3	0.0	14.8	1.2 b	8.1	0.6 b	9.4	4.3 b	17.5	4.5 b	22.2
Mother	27.0	28.2	21.1	14.8	19.8	21.1	24.9	17.1	28.7	20.0	22.5	17.1
Father	7.9	4.0	6.7	8.0	2.3	2.4	7.1	2.9	7.8	5.8	13.5	8.5
Parent (unspecified)	4.0	5.6	5.6	4.5	12.8	5.7	11.2	7.1	13.9	17.5	18.0	10.3
Son	5.6	5.6	3.3	11.4	5.8	8.9	2.4	7.6	2.6	7.5	0.0	8.5

Daughters	4.8	14.5	3.3	8.0	0.0	5.7	1.2	10.0	0.9	8.3	1.1	8.5
Brother/ sister	4.0	4.8	10.0	13.6	10.5	6.5	11.2	7.1	7.0	4.2	1.1	0.9
Other relatives	18.3	25.8	13.3	23.9	31.4	36.6	27.8	35.9	14.8	16.7	15.7	23.9
Neighbour /friend	1.6	2.4	1.1	0.0	5.8	4.9	0.0	0.6	1.7		1.1	0.0
Total %	100.2	99.8	100.0	100.1	100.1	100.0	100.0	100.1	100.0	100.0	100.0	99.9
Total numbers <sup>c</sup>	126	124	90	88	86	123	169	170	115	120	89	117

x2 test p= 0.0000 0.0000 0.0011 0.0000 0.0000 0.0000

<sup>a</sup> May care for co-wives or sisters-in-law who can metaphorically be called husbands.

<sup>b</sup> May care for brothers-in-law who can metaphorically be called wives.

<sup>c</sup> See Table 5.

Children were also reported to be doing well as carers in all districts while brothers and sisters were substantial care providers in Iganga, Kabale and Masaka. Husbands' care for wives was also not small in most districts and high in Mbarara and Iganga. Further, the table shows that other relatives contributed a lot to the care of patients, both males and females. However, the contribution by the neighbours and friends was negligible in all districts.

#### *Assistance to primary carer*

For the African extended family and clan system to work effectively, mutual assistance in emergencies is essential to the network. Members of the family and clan are expected to assist other members during emergencies by giving an extra hand in caring for patients, bringing provisions such as food to the patient's home and helping during funerals. A question was asked of the primary providers or the patients about additional assistance given and the person who gave it. The responses to this question are tabulated in Table 7 showing percentages of contribution of additional assistance and the source.

Table 7 shows that additional support was minimal irrespective of the disease of the patient. Although relatives and friends led the way, this contribution was very low (5.1%), followed by health units (3.0%) and TASO (0.6%). However, assistance for the AIDS patients was higher at 20.7 per cent for males and only 12.8 per cent for females. Nevertheless almost half of this assistance came from TASO, perhaps in the form of counselling, rather than from the expected source, relatives and friends. Also the level of support from health units of 3.6 per cent is low. This perhaps explains why AIDS patients do not want to go to the health units. As Lwihula et al. (1993) found in the Bukoba hospital, the hospital staff are not sufficiently trained and equipped to care for AIDS patients. In fact, even for other diseases patients do not rush to the health unit for assistance because of the two decades' decay of Uganda hospitals which has left them with no medicine and medical staff with low morale.

**Table 7**

**Per cent distribution of assistance to primary carer by sex and source of assistance**

Source of help	Males				Females				Both sexes			
	AIDS related	AIDS	Others	All	AIDS related	AIDS	Others	All	AIDS related	AIDS	Others	All
Health units	3.4	3.7	3.2	3.4	3.7	3.3	2.4	2.7	3.6	3.5	2.8	3.0
TASO	10.3	0.5	0.4	0.9	5.5	0.4	0.1	0.4	7.7	0.5	0.2	0.6

Relatives/ friends	6.9	4.2	4.8	4.8	3.7	4.4	5.9	5.4	5.1	4.3	5.4	5.1
No help	79.3	91.7	91.6	91.0	87.2	91.8	91.7	91.5	83.7	91.7	91.6	91.3
Total %	99.9	100.1	100.0	100.1	100.1	99.9	100.1	100.0	100.1	100.0	100.0	100.0
Total No	87	432	1331	1850	109	452	1521	2082	196	884	2852	3932
$\chi^2$ test p =	0.000			0.000				0.000				

Table 8 presents data on additional assistance to AIDS patients on a district basis. With the exception of Hoima, where the figures were based on small numbers, there was little additional assistance in the five districts. The proportion of patients who did not receive assistance ranged from 50 per cent in Hoima to 87.5 per cent in Mbale. What is revealing about the table is that the interviewed patients in Kabale and Mbale had not received assistance from health units, and those in Kabale and Mbarara had not been to TASO for assistance, while principal carers in Hoima and Mbale had not received assistance from relatives or friends.

#### ***Impact of AIDS illness on the household***

One of the reasons that people avoid helping the AIDS patients is the negative effect the disease has on the households and families. It is therefore appropriate to present the results on this aspect of patient care. Respondents were asked to evaluate the effect of the patients' disease on the household.

**Table 8**  
**Per cent distribution of assistance to AIDS patients' primary carers by source of help and district**

Source of help	Districts						
	Hoima	Iganga	Kabale	Masaka	Mbale	Mbarara	All
Health Units	37.5	5.1	0	1.3	0	8.3	3.6
TASO	12.5	5.1	0	11.7	12.5	0	7.7
Relatives/ friends	0	7.7	13.9	1.3	0	8.3	5.1
No help	50.0	82.1	86.1	85.7	87.5	83.3	83.7
Total %	100.0	100.0	100.0	100.0	100.0	99.9	100.1
Total no.	8	39	36	77	24	12	196

The effects of AIDS on the household were given in four categories. First, the illness had created financial problems including spending household savings on the treatment of the patient, failure to pay school fees for children, and failure to purchase food for the family. Secondly, as a result of the illness, regular work had been suspended by the patients and often the carers; this had financial implications as well. Thirdly, members of the household are depressed, socially isolated and stigmatized. The fourth category is 'no effect'. The responses are summarized according to those four categories in Tables 9 and 10.

According to Table 9, financial problems formed the biggest effect of illness of all types for the males and females, followed by regular work being at a standstill, with no effect and social depression being last.

Regarding AIDS illness, the effect of financial problems (75%) on the household is felt more than in other sickness (65% for AIDS associated and 57.5% for other diseases). It is

interesting to note that suspension of work is not as high with AIDS as with other diseases, perhaps implying that carers continued doing regular work since they knew the patient would die soon and not recover to compensate for the lost work. For other diseases, the providers may abandon their regular activities to care for the patients with the hope that when the patient recovers, some of the lost work will be made up.

**Table 9**  
**Per cent distribution of effect of patients' illness on household by type of illness and sex**

Effects	Males				Females				Both sexes			
	AIDS	AIDS related	Others	All	AIDS	AIDS related	Others	All	AIDS	AIDS related	Others	All
Financial problems	82.8	71.1	62.3	65.4	69.2	58.7	53.5	55.4	75.0	65.0	57.5	60.1
Work at standstill	13.8	14.5	23.1	20.5	20.5	28.4	34.1	32.1	17.7	21.3	29.0	26.7
Social depression	3.4	8.8	4.4	5.5	5.1	4.5	4.3	4.4	4.4	6.7	4.4	4.9
No effect	0	5.7	10.2	8.6	5.1	8.4	8.1	8.0	2.9	7.0	9.1	8.3
Total %	100.0	100.1	100.0	100.0	99.9	100.0	100.0	99.9	100.0	100.0	100.0	100.0
Total no.	29	159	451	639	39	155	531	725	68	314	982	136

$\chi^2$  test

0.008

0.488

The comparison between sexes shows that the financial effect of females' sickness is less than that of males, and vice versa for loss of work. This may be reflecting the less direct financial contribution females make to households and the higher contribution they make in regular work. Another sex differential is that no respondent reported that males' illness had no effect, unlike the reports on females' sickness (5.1%), reflecting the importance of males, irrespective of age, to households in comparison to females such as daughters who may grow up and leave the home.

The results of the survey are shown for AIDS and related diseases on the basis of districts in Table 10. Kabale district seems to be hardest hit financially by AIDS illness, followed by Mbale, Masaka, Iganga, Mbarara and Hoima. The districts that mentioned financial problems are those with high levels of AIDS and perhaps have suffered the disease for a longer time than those with lower levels. The districts in the latter category, Hoima, Mbarara and Iganga, also stressed the problem of work being at a standstill. Although with AIDS patients only, in five out of six districts (the exception being Masaka) there were no reports of 'no effect' (not shown in table), responses about the AIDS-related disease patients included 'no effect' for all districts except Iganga. 'No effect' was especially applicable to young children.

**Table 10**  
**Per cent distribution of effect of AIDS and AIDS-related illness on household by district**

Effects	Districts						
	Hoima	Iganga	Kabale	Masaka	Mbale	Mbarara	All
Financial problems	38.5	63.1	79.7	75.3	75.6	51.4	66.8
Work at standstill	32.7	29.2	11.9	19.8	10.0	31.4	20.7
Social depression	9.6	7.7	3.4	1.2	11.1	2.9	6.3

No effect	19.2	0	5.1	3.7	3.3	14.3	6.3
Total %	100.0	100.0	100.1	100.0	100.0	100.0	100.0
Total no.	52	65	59	81	90	35	382

## Discussion

The data presented above have limitations. First, since some tables were presented by age groups, like other data collected in sub-Saharan Africa this set is affected by age-misstatement errors. Although interviewers were trained to probe for ages of patients correctly, most of the age errors are made by the respondents, who have no reason to know their exact ages. However, as it is assumed that most of the age misreports are due to digital preferences, errors can be ironed out by adopting the conventional five-year age groups. In some of the tables, these errors are further minimized by using the broad age groups of 0-4, 5-19, 20-39 and 40+.

The second limitation of the data set is that there was no HIV/AIDS testing to establish whether respondents were HIV-positive or negative. The study relied on the verbal reports of the respondents who were either the patients, the care providers, or the heads of the household in the absence of the first two or in case of their inability to be interviewed. One of the three persons answered all the questions on patient care except the one on effect of illness on the household which excluded the patients. Since we were not able to test the serostatus of the household members, we could not calculate the morbidity rates of the HIV-positive and negative persons. If we had done that, we would have been able to directly compare our results to those of Wagner et al. (1993) in Masaka. Nevertheless, the proportions of sick persons reported to suffer from AIDS and related diseases are useful to health policy makers and planners of health care in Uganda.

The third limitation of the data is the exclusion of northern Uganda districts. The Uganda AIDS surveillance system has consistently showed Gulu district in the north to have high seroprevalence rates, although it is suspected that most of the reported AIDS cases are from Laco hospital which attracts many AIDS patients from outside the district and perhaps mostly from outside northern Uganda. Hence while the inclusion of the north would have ensured a more national representative sample, other reports from the north indicate low seroprevalence rates, such as 12.8 per cent among pregnant women in Moyo (US Bureau of Census 1993), which therefore could be excluded in a study of patients without much effect on the results.

Perhaps a more serious problem of the data that limited analysis is the small number of reported AIDS patients. In one district, Mbarara, there was no male patient reported to suffer from AIDS. It was therefore necessary to combine patients with AIDS and related sickness in order to get enough figures for analysis. Even then, it was difficult to raise the number of cases necessary for multivariate analysis on a district basis. This problem seems to be common in many of the studies of HIV and AIDS, perhaps because of underreporting of HIV/AIDS patients in order to avoid stigmatization by the society.

Despite the above limitations, the data set has the advantage of covering a larger area than most previous studies have done and representing over half of the Ugandan population. In addition, bivariate analysis of the data is the most relevant for most variables under study, since the primary objective of the study is to give indicators rather than explaining relationships between variables. The associations between the variables are mostly explained by the use of ethnographic materials.

From the information in Table 2, the proportion of AIDS sufferers among the sick is low (5.0%) and that of persons with AIDS-related diseases is sizable (22.3%). This is probably because respondents found it easier to report symptoms of their disease rather than the disease itself, because they were not sure they had the disease and in most cases not capable of

diagnosing it. However, as expected, illness due to AIDS is concentrated in the sexually active age groups 20-39 with a peak of 30-34 years for both sexes.

The district pattern of proportions of patients suffering from AIDS and related diseases in Table 3 shows Iganga and Mbale with the highest levels followed by Kabale and Masaka. This suggests that the sickness associated with AIDS and related disease may have started declining in Masaka district which has suffered the AIDS epidemic for a long time. Reports from other Masaka studies seem to confirm this. For instance, Wagner et al. (1993) estimated 1.2 per cent as the crude HIV-1 attributable diseases burden for the current disease compared to 4.3 per cent in the past for rural Masaka. The highest rates in Mbale, Iganga and Kabale may be due to earlier stages of the epidemic.

Furthermore, Mbarara and Hoima districts reported the lowest proportions of patients having AIDS and related diseases. The relatively low rates of Mbarara are surprising given that it is on the African highway and borders Rakai and Masaka. The only explanation is that the areas of Mbarara bordering Masaka and Rakai are either cattle ranches or sparsely populated and so the contacts between villages are few. In contrast, Hoima district would be expected to have low levels of sickness due to AIDS and related diseases because it is far from the epidemic of HIV/AIDS found along the African highway to Central Africa.

Regarding the person caring for AIDS patients, it is clear that parents, mostly mothers, are the primary providers of patient care; because the mothers are at home while fathers are out working. In the case of AIDS and related diseases, the role of a parent as a carer is more prominent than for patients with other diseases because they are more sympathetic to their children than anybody else. As studies elsewhere have shown, mothers and even fathers are more sympathetic to their children when they learn that the latter have HIV/AIDS (Agyeman 1992; Anarfi 1995; Awusabo-Asare 1995 in Ghana; McGrath et al. 1993 in Uganda). They are also the most likely to be told the seropositive news first.

The second principal group of primary carers for AIDS patients who are close family members are the brothers and sisters. Not surprisingly, siblings are second to parents in closeness to family members and hence would also receive news of seropositive results (Anarfi 1995) which would challenge them to assist. Despite natural rivalries between siblings, they tend to be close and fight together against an outside force. As shown by Table 5, the closeness tends to be truer between brothers who are close geographically than sisters who may be married and living far from each other.

The third group of persons caring for AIDS patients comprises the spouses and children. It is important to note the low contribution (9.0%) by wives to the husbands who were AIDS patients. Similar cases of abandonment by wives after learning that the husband had AIDS were reported in Uganda (Seeley et al. 1993) and Ghana (Agyeman 1993). To make matters worse for men, the daughters' contribution to their fathers' care was nil in comparison to their care for mothers, reflecting the difficulties women have in caring for their fathers who have AIDS. However, it is possible that the wives were also bedridden or had died of AIDS and so could not help (Seeley et al. 1993).

The more disturbing result about this group of carers is that neither the husbands nor the sons cared for the AIDS sufferers implying a heartless attitude of males towards AIDS patients. A similar finding was obtained in a Ghanaian study where Anarfi (1995) observed that fathers refused to check on their children's condition in hospital when they learnt that they had AIDS. However, the result emphasizes the leading role women play as patient care providers in many African societies. In African traditional families, husbands and sons are secondary care providers, primarily providing money for the treatment of their close relatives.

When the numbers of persons caring for patients with AIDS and related illness are put together and district per cent distributions are calculated, the parents again show the highest percentages in most districts. Further, the role of other household members is prominent in all



districts and highest in Iganga district which emphasizes the leading role the spouses and children play in caring for their partners and parents respectively. Where the percentages of wives are low, such as in Masaka (13.6% for males), it may mean that the spouses are also too sick to assist. This is not surprising for Masaka where the proportion of the population currently sick of any disease was found by Wagner et al. (1993) to be 52.9 per cent for the males and 61.9 per cent for females.

A remarkable finding is the role of other relatives including nieces, uncles, aunts, grandparents and in-laws in caring for the patients. As a group, other relatives were reported to contribute a lot to the care of the family members; in Kabale and Masaka districts their contribution was more than that of parents. This result emphasizes the strong bond between members of the extended family in these rural populations and contradicts the claim by Seeley et al. (1993) that an extended family in Uganda was a safety net with holes in the face of the AIDS epidemic.

Perhaps Table 6 shows that the even distribution of contribution across all relations in Kabale is an example of the influence of the extended family and clan system on patient care. Of the six districts, Kabale is unique in that it has a high population density (246 persons per km<sup>2</sup>) living in homesteads of extended families and sometimes clans. Also, the in-migration effect in Kabale is low (a rate of 0.43% per annum). This perhaps means that extended family sentiments are strongest, and most neighbours are family members or clanmates and other relatives also tend to live nearby. However, it is not understood why a similar pattern of patient care from relatives should not obtain in Mbale where the population density is even higher (284 per km<sup>2</sup>) and in-migration rate is low (1.88% per annum). The difference between the patterns of Kabale and Mbale with similar geographical conditions may have to do with the different character of the family and clan systems.

The findings on the additional assistance given to the patient carer are interesting. It is evident from Table 7 that most of the principal carers did not receive adequate assistance from other sources to help them look after the patients better. Perhaps an exception was Hoima where half the carers received assistance from health units and TASO if this was not a product of the small sample (8 respondents). This table implies that AIDS patients did not want to go to the health units or that the health units had sent them home to die. Both actions are probable given what Lwihula et al. (1993) found in Bukoba hospital where the AIDS patients were stigmatized, isolated and misunderstood by the medical personnel so that the patients reacted by keeping away from the hospital. However, in a recent study of 55 HIV-positive Rwanda women in Kigali, more than three-quarters considered it worthwhile going to hospital for assistance (Keogh et al. 1994), and all 24 AIDS patients in Kampala were receiving treatment in Nsambya hospital and preferred this to going back to the rural areas where health facilities were not as good (McGrath et al. 1993).

Furthermore, TASO and other non-government organizations that assist AIDS patients in Uganda were reported to have given minimal support especially in Iganga, Kabale and Mbarara. It appears from the results that most of the patients were not aware, did not understand the use of counselling or were too weak to travel to the NGOs' offices which were operating in all major towns of the country at the time of the survey. This shows that a small proportion of patients are helped by these NGOs. However, in Hoima, Masaka and Mbale, the presence of TASO and other NGOs in the business of AIDS care is noticeable.

A more disappointing finding is the low level of assistance rendered to principal care providers by relatives and friends in all districts. This slight help supports the observation made by Seeley et al. (1993) that the extended family in Masaka is a safety net with holes. The reasons found by these authors to justify lack of assistance from extended family were: lack of food and money to help with, having other responsibilities to attend to, caring for other sick relatives, believing it was witchcraft requiring a diviner, blaming the patients for their

condition, the lack of available adult assistance among the relatives, poverty or sickness among relatives, and family disputes.

Given the above discussion, it is necessary to briefly evaluate the effect of AIDS on the household and family and how they have coped with the epidemic. As Tables 9 and 10 show AIDS is different from other diseases in that it makes the patients bedridden for a long time, often between six months and two years, which calls for the care providers to be around all this time. Consequently, neither the patients nor the carers are able to go out and earn a living for themselves and their households. Secondly, the previous investment and savings of the household are spent on the expensive treatment of the patient. Since the carer or patient cannot work to replace this expenditure, the household or family ends up with financial problems as was reported by all the districts as the most important effect.

Another effect of AIDS is on the regular economic activities of the household. Both the patient and carer find it increasingly difficult to attend to their gardens, shops and professional occupations as the sickness becomes advanced. The gardens become bush, shops close and professional development is retarded. By the time the patient dies, the carer has lost most of his or her investment and may have to start again. This effect of AIDS on the household activities is reported to be 20.7 per cent on average, implying a substantial reduction in income, which is important.

The third effect of AIDS on households is social depression. Pakenham, Dadds and Terry (1995) found that the most common element of AIDS carers' burden in Queensland was distressing emotions, relationship difficulties, somatic symptoms and grief, which were positively related to the patient's emotional, existential and instrumental concerns as well as their deteriorating health status.

In Uganda, it was found that the family members were depressed by the prospect of facing the death of a loved one and the burden of looking after the patient's children after the death (McGrath et al. 1993). Our study found that this effect on family members and carers exists but was not ranked as high as the financial and work-related problems. This implies that after the long experience of the epidemic the household and families have learnt to cope with it psychologically and socially.

Although questions about coping with AIDS were not asked in this study, the likely response can be inferred from Tables 7 and 8 on additional assistance from relatives as well as from the survey questions on coping with orphans and deaths. It has been claimed that despite the large numbers of orphans, families are looking after most of them through the extended family arrangements (Ntozi and Mukiza-Gapere 1995) and that deaths are no longer mourned by the whole village through absence from work for several days (Mukiza-Gapere and Ntozi 1994). Further it can be seen in Tables 7 and 8 that other members of the family give little assistance to the principal carer; perhaps they have stopped over-worrying about AIDS patients and continued with their normal business. Hence the responses of no effect on households in five out of six districts and the indication of less social depression in Table 10 are a reflection of the families managing to cope with AIDS. It is also possible to interpret the relatively low levels of work or standstill in the districts of Mbale, Kabale and Masaka as a result of family members continuing with their regular economic activities in the midst of AIDS in the family.

In the long run, the relationship of mutual obligations and concerns between family members is being changed by the disease. Agyeman noted:

The harsh reality is that individuals, families and neighbours have all been caught up in the web of modernisation and urbanisation as a way of life, namely the survival of the fittest (Agyeman 1993:11).

Some of the useful elements of the extended family care of patients are being overridden by the need to continue with life after the death of a patient. Hence, although the extended family is not yet a safety net with holes, as Seeley et al. (1994) suggest, it has been weakened by the epidemic and will probably not be the same in the post-epidemic era.

### **Recommendations**

The recommendation arising out of these findings is that a health care strategy to deal with a high level of AIDS in the society should be developed. The strategy should focus on reducing the heavy dependency of the patients on the family for care, training the family to care for AIDS patients without risks and developing income-generating projects for carers to enable them to further support patients financially. Secondly, the health units in the country should be made more attractive to the patients. Ill-treatment and stigmatization from the health personnel should be discouraged by the units training them to be sensitive to the needs of the patients through special programs. Government should subsidize the drugs of AIDS patients and require them to pay reasonable charges unlike the present situation where most of the drugs are in the open market where prohibitive prices are charged.

Thirdly, counselling of patients, carers and the community is important if family members, neighbours, friends and colleagues at work are to accept the AIDS patients, and the patients themselves are to accept the sad news and live a positive life until death. It is, therefore, necessary for TASO and other NGOs involved in the counselling of patients to spread to rural areas so that they are known and their services used. At present, most of the NGOs operate in urban centres, which are too far from the patients to be visited often. This counselling should target the family as well as the community in order to distribute the burden away from the primary carers.

Fourthly, social support and spiritual care is important for the AIDS patients. Relatives, friends and workmates should be encouraged to visit, give social support and boost the morale of the patients. Also, spiritual care focusing on the resurrection and forgiveness of sins would give hope to the patients and reduce their guilt.

Lastly, there is need for the researchers to develop an agenda that would emphasize national surveys of AIDS patient care in order to know what is happening to the whole country. In this regard, an extension of this study to the ethnic groups in north and north-eastern Uganda would make the results more representative. For example, the big groups of Luo, Ateso and Lugbara should be studied. Both longitudinal surveys and vital registration for several years would help in monitoring changes in AIDS morbidity and mortality in Uganda and provide trends that would assist in knowing the direction of HIV and AIDS in Uganda societies.

### **References**

- Adeokun, Lawrence, J. Twa-Twa, A. Ssekiboobo and R. Nalwadda. 1995. Social context of HIV infection in Uganda. Paper presented to the Continuing Demographic Transition: the John C. Caldwell Seminar, Canberra, 14-17 August.
- Agyeman, D.K. 1992. Care of AIDS patients in Ghana. Paper presented at Workshop on AIDS and Society, Makerere University, 14-16 December.
- Agyeman, D.K. 1993. Families, neighbours and the AIDS epidemic. Paper presented at Workshop on Social Dimensions of HIV/AIDS, University of Cape Coast, 18-20 October 1993.

- AIDS Control Programme (ACP). 1994. *AIDS Surveillance Report, December 1994*. Entebbe: Ministry of Health.
- AIDS Control Programme (ACP). 1995. *HIV/AIDS Surveillance Report, March 1995*. Entebbe: Ministry of Health.
- Anarfi, J.K. 1995. The condition and care of AIDS victims in Ghana: AIDS sufferers and their relations. Pp. 253-263 in Orubuloye et al. 1995.
- Ankrah, M.E. 1993. The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care* 5,1:5-22.
- Awusabo-Asare, K. 1995. Living with AIDS: perceptions, attitudes and post-diagnosis behaviour of HIV/AIDS patients in Ghana. Pp. 265-278 in Orubuloye et al. 1995.
- Berkley, S., W. Naamara, S. Okware, R. Downing, J. Konde-Lule, M. Wawer, N. Musagara and S. Musgrave. 1990. AIDS and HIV infection in Uganda: are more women infected than men? *AIDS* 4:1237-1242.
- Bloom, J.R. 1990. The relationships of social support and health. *Social Science and Medicine* 30,5:635-637.
- Cobb, S. 1976. Social support as a moderator of life stress. *Psychosomatic Medicine* 38,5:300-314.
- Danziger, R. 1994. The social impact of HIV/AIDS in developing countries. *Social Science and Medicine* 39,7:905-917.
- Gaisie, S.K., A.R. Cross and G. Nsemukila. 1993. *Zambia Demographic and Health Survey, 1992*. Columbia MD: Macro International Inc.
- Goodgame, R. 1990. AIDS in Uganda: clinical and social features. *New England Journal of Medicine* 323:383-389.
- Hassig, S.E., J. Pierriens, J.E. Baende, M. Kahotwa, K. Bishagara, N. Kinkela and B. Kapita. 1990. An analysis of the economic impact of HIV infection among patients at Mama Yemo hospital, Kinshasa, Zaire. *AIDS* 4:883-887.
- Jaessen, C., J. Harmsmith, T. Kabwegyere and P. Muzaale. 1984. The Uganda social and institutional profile. Paper prepared for USAID, Uganda, Kampala.
- Kaijuka, E.M., E.Z.A. Kaija, A.R. Cross and E. Loaiza. 1989. *Uganda Demographic and Health Survey, 1988/89*. Entebbe: Ministry of Health.
- Kaleeba, N. 1990. From Uganda casebook. *World Health* November-December.
- Kalibala, S. and N. Kaleeba. 1989. AIDS and community-based care in Uganda: the AIDS support organisation, TASO. *AIDS Care* 1,2:173-175.
- Keogh, P., S. Allen, C. Almendal and B. Tamahagili. 1994. The social impact of HIV infection on women in Kigali, Rwanda: a prospective study. *Social Science and Medicine* 38,8:1047-1053.
- Killewo, J., L. Dahlgren and A. Sandstrom. 1994. Socio-geographical patterns of HIV-1 transmission in Kagera region, Tanzania. *Social Science and Medicine* 38,1:129-134.
- Lwihula, G., L. Dahlgren, J. Killewo and A. Sandstrom. 1993. The AIDS epidemic in Kagera region, Tanzania: the experience of local people. *AIDS Care* 5,3:347-357.
- McGrath, J.W., E.M. Ankrah, D.A. Schumann, S. Nkumbi and M. Lubega. 1993. AIDS and the urban family: its impact in Kampala, Uganda. *AIDS Care* 5,1:55-70.
- Mukiza-Gapere, J. and J.P.M. Ntozi. 1994. Impact of AIDS on the family and mortality in Uganda. Paper presented at Workshop on Sexual Networking, STDs, AIDS and Interventions, Ondo State University, Ado-Ekiti, 22-25 August.
- Mulder, D.W., A.J. Nunn, A. Kamali, J. Nakiyingi, H.U. Wagner and J.F. Kengeya-Kayondo. 1994. Two-year HIV-1 associated mortality in a Ugandan rural population. *Lancet* 343:1021-1023.

- Ntozi J.P.M. and J. Mukiza-Gapere. 1995. Care for AIDS orphans in Uganda: findings from focus group discussions. Pp. 245-252 in Orubuloye et al. 1995.
- Orubuloye, I.O., John C. Caldwell, Pat Caldwell and Shail Jain (eds). 1995. *The Third World AIDS Epidemic*. Supplement to *Health Transition Review* 5. Canberra: Australian National University.
- Pakenham, H.I., M.R. Dadds and D.J. Terry. 1995. Carers' burden and adjustment to HIV. *AIDS Care* 7,2:189-203.
- Peltzer, K., S.K. Hira, D. Wadhawan, J. Kamanga, D.C.E. Ferguson and P.L. Perine. 1989. Psychological counselling of patients infected with HIV in Lusaka, Zambia. *Tropical Doctor* 19:164-168.
- Republic of Uganda. 1994. *The 1991 Population and Housing Census (National Summary) Uganda*. Entebbe: Ministry of Finance and Economic Planning.
- Republic of Uganda. 1995. *The 1991 Population and Housing Census. Analytical Report, Vol. 1. Demographic Characteristics*. Entebbe: Ministry of Finance and Economic Planning.
- Seeley, J., E. Kajura, C. Bachengana, M. Okongo, U. Wagner and D. Mulder. 1993. The extended family and support for people with AIDS in a rural population in southwest Uganda: a safety net with holes? *AIDS Care* 5,1:117-122.
- Seeley, J., U. Wagner, J. Mulemwa, J. Kengeya-Kayondo and D. Mulder. 1991. The development of a community-based HIV/AIDS counselling service in a rural area in Uganda. *AIDS Care* 3,2:207-217.
- Southwold, M. 1965. The Ganda of Uganda. Pp. 41-78 in *The People of Africa*, ed. J.L. Gibbs. New York: Holt, Rinehart and Winston.
- Tumwine, F.R. 1995. Marriage patterns and trends in Kitagwenda county, Kabarole district, 1960-1993. M.A. dissertation, Makerere University.
- Turner, R.J. 1981. Social support as a contingency in psychological well-being. *Journal of Health and Social Behaviour* 22:357-367.
- United States Bureau of Census. 1993. *HIV/AIDS Surveillance Data Base*. Washington DC: US Department of Commerce.
- Wagner, H.U., A. Kamali, A.J. Nunn, J.F. Kengeya-Kayondo and D.W. Mulder. 1993. General and HIV-1 associated morbidity in a rural Uganda community. *AIDS* 7:1461-1467.