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Informal care for illness in rural southwest Uganda: the central role that women play*

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Abstract

In rural Uganda care for those who are ill tends to be home based because of inadequate and expensive health care facilities, lack of medication and poor staffing levels in health units. Research findings suggest that women are responsible for the bulk of caring activities. This paper questions the assumption that female informal carers are in a position to cope with illness episodes in the home. Data were collected from 54 female informants in a rural population in southwest Uganda. Supplementary data from in-depth interviews with survey participants and counsellors were also collected. Findings suggest that women are the main providers of informal care within the home. Many women, particularly in female-headed households, did not own or have direct access to the necessary finances to meet the family's health care needs as expected of them. Although relatives and friends were seen as a valuable resource, because of poor household proximity and financial constraints they were not always in a position to offer or provide assistance. The women also identified themselves as responsible for a variety of home and agricultural tasks; such activities were frequently disrupted by illness episodes. As women take on the additional burden of care for those with HIV/AIDS an inevitable conclusion is that their resources, both social and economic, will not be adequate. These data indicate the need for additional research and stress the importance of appropriate support and relief programs for those responsible for informal care.

In Africa, as in many parts of the world, illness often contributes to economic and social disruption and accentuates poverty. Historically the African extended family is regarded as the main source of social, economic and practical support for individuals. McGrath et al. (1993:57) state that in 'Uganda, as in much of Africa, the family is responsible for much of the nursing and health care, both in and out of the hospital'. Caldwell et al. (1993:8) cite research in Uganda and Ghana, showing that 'most families anticipate little help from the state or their neighbours, and in most cases the sick turn immediately to their families'. As many patients cannot afford hospital fees, home based care is often the only viable option.

Research findings suggest that it is women within the family unit who are responsible for the bulk of caring activities:

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> In practically every country, whatever its level of economic and social development, the majority of health workers are women. If the non-formal sector is also taken into account, women's contribution to health care is overwhelmingly greater than that of men (Panos 1990:59).

De Bruyn (1992:255) acknowledges that the psychological and social burden of AIDS is greater for women than men as 'women are generally entrusted with the care of family members, especially regarding health care. This pattern holds for the care of AIDS patients'. Such findings have been widely documented (Beer, Rose and Tout 1988; Bor 1990; McCann 1990; Seeley et al. 1993; Ankrah 1993). The rural Ugandan woman's situation is essentially no different; the burden of child care, household chores, a disproportionate share of farm labour and caring activities are often their responsibility (UNICEF 1989). Care for sick household members tends to be home based because of Uganda's turbulent history in which the health and social service infrastructures were severely damaged. Even though the current Ugandan government is committed to health issues it is at present unable to provide adequate drugs, equipment, health facilities and properly paid health care personnel.

This situation is exacerbated by the increasing numbers of those suffering with HIV/AIDS. There is evidence that 30 per cent of medical admissions to Kitovu, Mulago and Rubaga hospitals in Uganda are AIDS patients (WHO/GPA/IDS/HCS 1991). Consequently in 1987 the government began to endorse and promote home-based care for HIV-infected and AIDS patients and their families.

In the light of the HIV/AIDS pandemic it is important to understand how women cope with illness episodes within the home. Using data from rural Uganda we aim to provide a descriptive analysis of women's coping strategies when caring for someone who is ill within the home; to establish whether common strategies and resources are used at the local level and how successful they are at mitigating the effects of sickness. In turn this may help us begin to ascertain the implications for informal carers of having to care for someone with AIDS.

Background

This paper describes research carried out in collaboration with the Medical Research Council/Overseas Development Administration (MRC/ODA) Research Programme on AIDS in Uganda. The primary aims of the program are to study the dynamics of HIV-1 transmission, the natural history of HIV-associated disease, and strategies for AIDS control in a rural population. The main study population is made up of the inhabitants of a cluster of 15 neighbouring villages with a total population of approximately 9,950, about half of whom are over 13 years of age; the overall prevalence of HIV-1 infection in the adult population (over 12 years) is 8.2 per cent.

The study area is a rural subcounty in Masaka district, two hours drive southwest of Kampala. The majority of the population are Baganda living in dispersed settlements and small trading centres; the inhabitants are largely subsistence farmers who produce small amounts of cash crops such as bananas and coffee. Among the Baganda descent is patrilineal with virilocal marriage, where the woman moves to the man's home: it is not uncommon for the women to move some distance from their natal home for the purpose of marriage, thus the extended family group is often dispersed over a number of villages or a wider area.

This paper reports the findings of a small study carried out at the beginning of 1993 to look at women's coping strategies when faced with illness in the home.

Method

From the 15 MRC study villages 12 were considered for inclusion in the survey; three were excluded because it was felt they had been overexposed to a similar study; of these 12 villages three were then randomly chosen. For each village a list of all households was obtained and 83 households were selected by systematic random sampling. In each selected household a female above the age of 16 years was chosen for inclusion in the survey. In male-headed households the eldest female was selected: this was usually the wife of the household head; in female-headed households the female head was selected. In one household where two co-wives were resident, one of these wives was randomly selected.

Content analysis of four women's focus-group discussions was used to determine the survey questions. The survey respondents were asked questions about illness episodes within the home; they were not asked directly about caring for HIV/AIDS-related illness. No pre-definition of illness episodes was offered by the researchers, in acknowledgement that this term was open to interpretation by the women interviewed. Survey data were collected by structured interviews conducted in Luganda, which were transcribed and translated at a later date.

The household is a social unit defined by the sharing of the same abode or cooking facilities, members may be temporarily resident elsewhere. For the purpose of this study 'carer' was defined as the person providing the physical care and emotional comfort for someone who is ill within the home.

In the findings, reference is made to supplementary data from further in-depth interviews with selected survey respondents. Descriptive narratives of 'closed' client cases (clients who have died or moved from the area) and their families' endeavours to cope with HIV/AIDS, provided by three MRC counsellors, are also referenced in the findings and discussion section.

Findings

Out of the 83 identified households 54 women participated in the survey. Thirteen of the identified women refused to participate and five women were not found at home on three separate occasions when the interviewer visited. Four of the identified informants had recently moved, three had died and two houses were empty or demolished. One woman was very deaf and unable to hear the questions and one woman had not experienced any illness episodes within the last year and therefore did not see the point in answering the questions. One of the three selected villages had a high refusal rate, with eight women refusing to participate; refusals in the other villages numbered three and two. The interviewers commented that people in the first village often refused to participate in research activities because the MRC had not provided them with food during a period of drought.

Thirty-four respondents described themselves as married, seven widowed, 12 separated or divorced and one classified herself as single. Thirty-seven per cent of households were female-headed and the average number of household members was 5.6: both figures are representative of the study population. The survey participants were also representative of the study population as a whole in terms of religion, tribe and land ownership.

Of the 54 respondents, 46 stated that household members participated in activities which earn money. The main source of household income was selling the produce of cultivation or engaging in casual labour; often household income was supplemented by the selling of surplus crops, mats and baskets, pancakes or beer. Eight respondents stated that no one within the home earned an income: of these, seven were female-headed households.

The majority (n=27) of the 34 married respondents stated that their husbands were responsible for financial affairs within the home; of the remaining married respondents five

were jointly responsible with their husbands. Only two married women were responsible for finances; one of them received minimal support from her husband, because of the existence of a co-wife; and the other woman felt financial control was hers because she was responsible for all household purchasing. The remaining respondents (n=20) were either divorced or separated, widowed or single and all controlled household finances.

All except three women had experienced ill-health of one or more household members; in total 100 illness episodes were identified by the 54 women within the last year. In the majority of illness instances (n=73) the respondent said that she was the principal carer, in a few cases (n=8) the respondents identified the husband as the primary carer; care was also provided jointly by the husband and wife (n=8). In the remaining illness episodes (n=11) care was provided in the majority of instances by female rather than male relatives.

For the majority of the 100 illness episodes assistance was not offered by co-resident family members (n=53), relatives (n=62) or friends (n=69), primarily because the illness was considered not to be serious enough to warrant asking for assistance. When asked if males in the home were specifically involved in caring activities the majority (n=37) of the 54 respondents said 'yes'; this can be divided into adult male (n=27) and child (n=10) participation. Nine respondents said that no co-resident males participated in caring activities; they felt that the men were involved with other ventures, did not have the time, were not interested or did not want to participate. Seven respondents were not able to answer this question because there were no males present in the household.

When assistance was provided there tended to be a marked sexual division in the activities undertaken by co-resident family members, relatives, friends and co-resident males. Male involvement centred around the purchasing of tablets and food supplies, provision of water, transport for the sick person to the clinic and paying for any medical expenses incurred. Only seven of the resident 27 adult males assisted with some form of direct nursing care; female assistance tended to be the provision of local herbs, money and food, help with cooking, child care and other household duties together with physical care.

In order to obtain money for medical expenses the respondents often used money derived from their main source of income or if necessary would ask friends and relatives for assistance. However, it was evident that financial constraints and household proximity influenced relatives' ability and willingness to care for a sick person. For example, one informant, and subsequent in-depth interview participant, Florence, stressed that she was responsible for all child care, household duties and medical expenses. Although she is married, her husband, who lives with his second wife, would not offer her financial help. If money was required for medical expenses, Florence would ask for assistance from her adult children, but her requests were not always answered because of the distance involved.

Another married informant, Rose, commented that she was responsible for all household duties, payment of school fees and medical expenses because her husband was seldom in the home, as he worked in Kampala, but he paid for medical expenses when he was there. In such cases women were often left to their own devices to get funds, through sale of reserved crops, handicrafts or brewing beer.

Of the 54 respondents, 32 stated that they were in a position to plan for eventualities such as illness; by saving money, storing crops to sell, keeping animals such as chickens and goats, which can be sold when needed; and by setting aside cups, plates etc. for the patient. The remaining households (n=22) were not able to plan for such eventualities primarily because they were already struggling to provide essentials for day-to-day living.

Female-headed or single-adult households were particularly vulnerable in times of crisis. Not only were they more likely to be unable to generate an income, frequently they were not even in a position to plan for eventualities such as illness. Only half of the 20 female-headed households were in a position to plan, whereas 22 of the 34 married women could do so.

Evidence from the in-depth interviews further illustrates the difficulties encountered by female-headed households compared to homes with resident adult males:

Grace was 27, separated, and lived with her ten-year-old brother and her three children. She owned a small piece of land on which she was only able to produce subsistence crops. Grace worked locally as a casual labourer to pay for clothing, food, medical expenses and school fees. Many of her relatives were dead and her mother who lived nearby was ill. She looked after her mother, her children and her brother. No financial assistance was offered by the children's fathers. Grace commented that if she were to be unwell and unable to work, or if there was no work available, there would be no other source of household income.

However, as Florence's and Rose's situations illustrate, members of polygamous families or households where the main income earner works away from the family home may be just as vulnerable in times of sickness. Financial assistance is not always to hand, limited resources may be distributed between numerous sub-households or, as in Florence's case, the husband favours another of his households.

In addition to their caring activities the women were also responsible for a myriad household and cultivation based activities; food collection and preparation, digging the *kibanja* (plot of land), crop tending and picking, child care, animal husbandry, washing clothes, collection of firewood and water, mat and basket making and cleaning the compound area.

The majority of informants felt that household and cultivation activities were frequently disrupted by illness episodes. Eighteen of the 54 respondents felt that all household duties were affected and 29 respondents agreed that only activities such as digging, crop harvesting, animal husbandry (if applicable: not all the woman owned animals), and mat or basket weaving, if undertaken, were affected. Activities such as firewood and water collection, cooking and cleaning were essential and often assistance would have to be given by friends or relatives.

Only seven respondents felt that none of their household duties or responsibilities would be affected by an illness episode within the home. One woman worked as a school headmistress, another as a tailor, one ran a small shop within the home, another made pancakes to sell and others worked as casual labourers. However, these women all commented that their work activities were greatly affected when someone was ill: invariably illness episodes entailed a loss of income.

Discussion

Our findings reiterate those of other studies which suggest that African women are principally responsible for the bulk of care provision for ill health within the home (Panos 1990; McGrath et al. 1993; Caldwell et al. 1993). Furthermore, while medical care generally has to be purchased in the developing world, most of the women interviewed did not necessarily have direct access to finances to cope with the expenses incurred. This is corroborated by Welbourn's (1990) research in Uganda which found that while health issues are the prime responsibility of women and men are rarely involved, health care is becoming largely an issue of money, to which most women do not have immediate access.

Respondents tended to focus on the physical and financial rather than the emotional ramifications of ill health despite being provided with a ‘carer’ definition (p.3) which encompassed both the physical and emotional aspects of care provision. This does not necesssarily mean that the women did not provide or experience emotional support, rather, this may have been an expression of their primary experiences and concerns.

Although all the respondents mentioned some way of obtaining money for medical expenses it is important to consider that households may not always be able to generate the

required finances. Crops are seasonal and in periods of drought this resource base may be diminished. Cultivation and other work activities are frequently affected when it is necessary to care for a sick household member; thus a means of supplementing income in times of illness can be affected by merely having to divert time to caring. Even though most respondents felt that financial assistance would not be refused by family and friends it is important to consider that inter-household and intra-household loans, which may be part of a community-wide or kinship-insurance mechanism, may come under threat in times of severe and prolonged illness. While animals or land could be sold, the disposal of valuable productive assets may diminish the households' long-term income-generating activities and thus their ability to cope in the future, for many assets can only be sold once.

It is not possible to gauge accurately how successful the women were at mitigating the effects of illness, or to produce a list of strategies commonly used by all the women. Households are not homogeneous units, and the composition may vary over time given the transient nature of some household members. Resource allocations are complex issues: not all women have access to relatives and friends who could offer assistance, nor do all the women have equal access or equitable inter-household or intra-household resource allocation. Ultimately such variability will influence the coping strategies used in caring for someone who is ill within the home, and their success criteria. We are, however, able to suggest a rudimentary framework of resource management which is similar to that identified by Corbet (1988).

Primary policies. Short-term coping mechanisms: sale of crops; reduction of current consumption levels; use of inter-household loans; increased petty commodity production, e.g. beer; casual labour; changes in cropping and planting practices; and sale of non-productive possessions.

Secondary policies. Disposal of productive assets: sale of livestock, agricultural tools; sale or mortgaging of land.

Tertiary policies. Distress migration; either the patient returns to the family home or relatives move in to the patient's home to provide care.

Household composition, the proximity or existence of friends and relatives and the severity of the illness episodes determined the action taken and the resources used. Female-headed or single-adult households appeared to be particularly vulnerable when someone was ill within the home. Often they were not in a position to plan for eventualities such as illness episodes, and had limited income and access to a family resource base: in most instances a married couple will have access to both their families in times of need whereas a single parent may only have access to her or his own family for support.

For short-term illness episodes the women were likely to engage in primary policies; for the more prolonged or serious episodes secondary and tertiary policies would be undertaken. An in-depth interview and a 'closed' client case history provided by the MRC counsellor exemplify the sequence of coping strategies employed by women for both short-term and more prolonged illness episodes:

Eva was a divorced woman of 27 years who lived with her 12-year-old sister and two children. Eva owned a plot of land and was able to produce enough crops for subsistence and to save some for unexpected events. To supplement her income she fried pancakes and made table-cloths and mats. When someone was ill in the home, Eva would attempt to sell her reserved crops or handicrafts. If needed she would ask friends and relatives for financial assistance.

Agnes was married with four children. Agnes, her husband and their two younger children were HIV-positive. Initially Agnes was able to care for her husband and children and provide money for medical expenses by selling crops and beer. Following her husband's death her own health began to deteriorate so that she was no longer able to earn a regular

income. Eventually her mother arrived and provided care and financial support until Agnes's death.

Interviews with the MRC counsellors further illustrate the resource management undertaken by adult patients and their extended families in order to cope with the effects of HIV/AIDS. As the disease progresses patients may return to their family home to be cared for by their relatives and the coping cycle will commence again:

Jennifer, a middle-aged woman, was HIV-positive; when she became ill she had no local friends or relatives to provide assistance. A counsellor managed to contact her relatives in a neighbouring district; a female relative arrived to provide nursing care. This relative gradually had to sell various household items and then land to pay medical expenses. When the finances and resources finally ran out Jennifer was taken to her carer's home.

Paul was 28 and HIV-positive; he used to earn his income from trading work in Kampala but as his health declined he separated from his wife and moved back to his parents' village with his three children. For a while Paul earned money by selling crops he produced on a small piece of land he owned. As his health deteriorated further and Paul was unable to work on his land he sold his radio. Once this money had run out he was dependent on his mother and father for his financial support and care.

It is evident that relatives and friends are valuable resources in times of need. Research has, however, questioned the notion that the extended family is a resource to be relied upon at all times and has suggested that families may not be able to deal with AIDS as they have with other health problems (Eberstein, Serow and Ahmad 1988; Panos 1990; Hunter 1990; Seeley et al. 1993; Ankrah 1993).

As Armstrong (1993:5-6) emphasizes,

> Today, the continent's [Africa's] age-old social security system is buckling under the unprecedented strain of AIDS... Many families are brought to their knees even before the death of the breadwinner by the long, costly months of nursing them through AIDS.

In the face of the growing HIV/AIDS pandemic it is probable that disruption to general household duties and income earning activities will intensify. Demand for valuable resources will also increase as members of a kinship group or community are affected by the same event. In turn this may precipitate the breakdown of the traditional household and community reciprocal relations on which Africa has relied for so long. We must therefore question whether the traditional reliance on extended kin systems will address the needs of HIV/AIDS patients and their informal carers.

Conclusions

This research has shown that illness episodes are problematical for many households in the study population, in particular single-adult households. The findings suggest that women are the main providers of informal care, and that many of these women struggle to provide the necessary time, resources and finances to cope with the effects of illness episodes in the home. In particular, many women do not own or have direct access to the necessary finances to meet the health care needs of their families.

These findings are dispiriting when families affected by HIV/AIDS are considered. As women take on the additional burden of care for those with HIV and AIDS their resources, both social and economic, are likely to be severely constrained. An inevitable conclusion is that without adequate support and appropriate intervention women will be unable to manage the care of persons with HIV/AIDS.

It is hoped that this paper will stimulate complementary research and enhance our understanding of the many dilemmas encountered by those who provide care in the informal

setting. This and similar reports will inform and guide policy makers and development practitioners concerned with the plight of home, family and community care. In particular, it should alert policy-makers, development workers, non-governmental organizations, politicians and academics to the need to be gender-sensitive when planning intervention, support and relief programs for 'community care has fertile ground in which to grow if only the seeds of organisation and financial assistance can be sown' (Kaleeba and Kalibala 1989).

An extended version of this paper is available from the Medical Research Council, Uganda Virus Research Institute, PO Box 49, Entebbe, Uganda or Overseas Development Administration, 94 Victoria Street, London.

References

Ankrah, E.M. 1993. The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited. *AIDS Care* 5,1:5-22.

Armstrong, S. 1993. The lost generation. *World AIDS* (March).

Beer, C., A. Rose and K. Tout. 1988. AIDS—the grandmothers' burden. Pp. 171-174 in *The Global Impact of AIDS*, ed. A.F. Fleming. New York: Alan R. Liss Inc.

Bor, R. 1990. The family and HIV/AIDS. *AIDS Care* 2,4:409-412.

Caldwell, J.C., P. Caldwell, E.M. Ankrah, J.K. Anarfi, D.K. Agyeman, K. Awusabo-Asare and I.O. Orubuloye. 1993. African families and AIDS: context, reactions and potential interventions. Pp. 1-16 in *Sexual Networking and HIV/AIDS in West Africa*, ed. J.C. Caldwell et al. Supplement to *Health Transition Review* 3. Canberra: Australian National University.

Corbet, J. 1988. Famine and household coping strategies. *World Development* 16,9:1099-1112.

De Bruyn, M. 1992. Women and AIDS in developing countries. *Social Science and Medicine* 34,3:249-262.

Eberstein, I.W., W.J. Serow and O.B. Ahmad. 1988. AIDS: consequences for families and fertility. Pp.175-182 in *The Global Impact of AIDS*, ed. A.F. Fleming. New York: Alan R. Liss Inc.

Hunter, S.S.1990. Orphans as a window on the AIDS epidemic in sub-Saharan Africa: initial results and implications of a study in Uganda. *Social Science and Medicine* 31:681-690.

Kaleeba, N. and S. Kalibala. 1989. AIDS and community-based care in Uganda: the AIDS support organisation, TASO. *AIDS Care* 1,2:173-175.

McCann, K. 1990. Care in the community and by the community. *AIDS Care* 2,4:421-424.

McGrath, J.W., M.E. Ankrah, D.A. Schumann et al. 1993. AIDS and the urban family: its impact in Kampala, Uganda. *AIDS Care* 5,1:55-70.

Panos. 1990. *Triple Jeopardy: Women and AIDS.* London.

Seeley, J., E. Kajura, C. Bachengana et al. 1993. The extended family and support for people with AIDS in a rural population in south west Uganda: a safety net with holes? *AIDS Care* 5,1:117-122.

UNICEF. 1989. *Children and Women in Uganda.* Kampala.

Welbourn, A. 1990. *Report on the Social and Economic Dimensions of Ill-Health among Ugandan Households*. Nairobi: Overseas Development Administration.

WHO/GPA/IDS/HCS 92.3. 1991. *Report of the World Health Organization Commonwealth Secretariat Regional Workshop on HIV/AIDS Community Based Care and Control.* Entebbe.