

knowledge of the mode of disease transmission is widespread, but whether or not these young people will change their sexual behaviour remains to be seen. However, their essays seem to suggest that, they may be deflecting some of their fear and uncertainty into anger at those (mainly elite people) whom they perceive as having only themselves to blame, and who are threatening the welfare of the country by wasting their privileged education. There is a complex range of explanations and of actions. People give different weight to different parts of the particular chain or chains of causal explanation which they choose to help them to cope. In part their choice of explanatory vocabulary and of the weighting they attach to different types of explanation appears to be linked to their position in society. Men choose escape hatches, women worry about their children, adolescents blame others and make moral judgements while looking to the effects of wasted investment as they look towards a new and uncertain future. Also, almost everyone recognises that AIDS threatens all the major expectations of people's lives - from sexual fulfilment, to marriage and having children, to being cared for in one's old age by one's children, through to having a proper burial, and being remembered in the community's consciousness after death.

#### Individuals coping with AIDS.

The discussion now moves to the ways in which people cope with the direct effects of the disease, once it strikes. Individual members of AIDS afflicted and affected households spend a lot of time in prayer at home, church and at Catholic shrines. Some people, at great financial sacrifice, have gone in search of a miracle AIDS drug supposedly developed in Zaire by a Zairian and an Egyptian doctor. Others have joined the bus-loads of people who travelled 126 miles over rough terrain to obtain curative soil from a visionary called Nanyonga.

Household members who participate in these activities are either involved in nursing or they are visiting temporarily. While in devout Christian and Muslim households the comfort of prayer and the clergy are actively sought, in other households the advice of the diviners is preferred. In both types of households people feared the spirits of people who died in anger or with a grudge. People who have died angry are considered to be a threat to the health of surviving household members. However, households differed in the ways in which they coped with the emotions surrounding illness and death.

In devout households, if a patient was not already in hospital, there would be eleventh hour attempts to get them there. Panic was usually triggered by faint murmurs of the patient: "Don't leave me in the dark" or "Are you letting me die without medical care". If the patient was left to die there, the household might be haunted by misfortune. Thus, hospital care was sought despite the heavy expense involved in repatriating bodies from hospitals to villages.

In less devout households, after pleas similar to the above, an elderly member of the household would volunteer to visit a diviner, acting as an intermediary between close relatives and the dying person. There were no local diviners in the research area, but there were some in adjoining counties in the district. Sometimes, people preferred to go outside the district, believing that a distant diviner could give better advice than a local one.

Diviners were consulted to find out whether the patient was satisfied, had been slighted by, or was angry with a household member. In cases of real or potential tension between the patient and care givers, diviners gave advice on how it might be resolved. A hen, cock, goat or sheep of particular colours may be required, and the purchase of herbal remedies necessary. Some diviners were paid right away, others asked the client to come and offer thanks when the problem was solved. Thus the diviner plays an important role in the coping process, acting as a kind of family therapist and bereavement counsellor, perhaps facilitating a 'settlement' of the affairs of the household at the time of death.

Care givers do listen carefully to the patients and many are diligent in meeting most of their physical demands. Whereas people are sure about the emotional state of anger, when a patient says, "Get me medicine for the pain" or "You have not told me the truth about this illness", they find it difficult to cope with a desperate fear of death, and beseechings such as - "don't abandon me". People publicly admitted that because the AIDS illness takes so long to kill its victims, it exhausts both the patients and care givers, in addition to reducing the patient to bones. AIDS was therefore referred to as *mukenena/mukenenya* (the body shrinker). In this state the patient may be extremely demanding of the care givers who are also overwhelmed with other family matters. This might be a source of unspoken tension as the following case reveals.

#### CASE STUDY

A patient who developed full-blown AIDS symptoms after giving birth died after two months. She came to realise slowly that she had AIDS but her educated family was having her tested for over half a dozen other illnesses except AIDS. The day before she died she confronted her family about lying to her and to themselves. The physical and psychic drain necessitated consulting diviners at least for the survivors' peace of mind. The care givers also seemed to seek reassurances about their negative feelings towards the patients. Sometimes the care giver would express their frustration with the job but at other times

Further indications of the importance of diviners and traditional health practitioners are also available from the work of Graham Thompson. See his unpublished paper: "Lessons from an anthropological survey of traditional health practitioners and their role in the HIV transmission and its prevention", presented to the conference AIDS in Developing Countries: Appropriate Social Research Methods, Brunel University, England, 10-11 May, 1990.

neighbours and friends would articulate their precise feelings for them. For example, patients were said to be unfair if they "appeared finished and yet hanging on to life". People referred to "having the will to live" as unfair to the living particularly the care givers. But ultimately it is the incurable disease (*lukonvuba*) that is to blame.

#### CASE STUDY: THE BUTCHER

The local butcher woke up one morning with a rash on his neck and legs. Experience told him that this was a symptom of AIDS. He was so frightened that he became hysterical. He told all of his customers. Most of them stayed for a few moments to express sympathy. Some muttered "this disease will wipe us all out".

The butcher continued to work until he was too weak to carry on. People continued to patronise him as he was the only butcher. Some came expressly to give him moral support. He spoke openly about his condition. When he finally became bed ridden he insisted that his bed be put in the sitting room of his house so that he could receive visitors. Nine months after the first manifestation of his symptoms, he still moves around the village, although it is an effort for him to do so as he becomes weaker.

#### CASE STUDY: THE TRADER

An itinerant trader, on finding that he had contracted AIDS, became a recluse. Although he continued to work, he stopped socialising with others in the community. Previously he had been considered a good conversationalist.

People knew that for the last three years this man had been having a relationship with the widow of a man who had died of AIDS.

Next we turn to a discussion of the way others cope with the death of members of the family. To take how women cope with the death of their husbands first, widows may stay in their homes, migrate to urban areas, remarry or return to their parents' home. It seems that the majority of widows remain in their marital homes to support themselves and their children. These widows experience a decline in the standard of living because women in general have less entitlement than men to other people's labour. Brothers-in-law, even when they live nearby, offer minimal help. Furthermore, widows

of migrants who had never legally acquired occupation rights in land, and widows living on land acquired by their husbands under occupancy rights but where the ownership has changed, have even less security of tenure and are sometimes threatened with eviction. In such cases, the landlords claim that the 1927 Busulu and Envujjo law was a contract between the landlord and the husband, specifically **excluding** the wife and children <sup>6</sup>. Since the 1975 Land Decree during the Amin period, there has been considerable confusion and uncertainty on this matter <sup>7</sup>. In the community chosen for intensive study, to date two widows of migrant squatters together with their children have been evicted on these grounds.

Widows who do not wish to undertake the heavy agricultural work alone and to continue living in rural poverty, migrate to the urban areas to improve their material well being. These widows join other urban migrants in self-employment such as craft production and food or beer vending.

There has been speculation among elite women in Kampala that Rakai widows will be pushed by desperation into polygynous marriages and prostitution. This has not happened so far but may in the future as a result of fierce competition between widows and other single women for sources of income. Young widows aged between twenty and forty are able to remarry single and unmarried, divorced or widowed men.

In one community studied with a total number of about two hundred households, there were ten widow remarriages in the study community. Six cases involved widows who had migrated or returned to the area, and four cases were of local widows. Widows who are young and attractive are assumed by many to be AIDS free because many people in Uganda find it difficult to

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<sup>6</sup> A. M. Mukwaya, *The Bussulu Envujjo Law*, East African Institute for Social Research, Makerere, 1954.

<sup>7</sup> Government of Uganda, *Decree on Land*, Uganda Government Printers, Entebbe, 1975.

believe that somebody can be a carrier of the disease while remaining perfectly healthy. This can give rise to anxiety when marriage is being considered. For example, in five instances during fieldwork, prospective husbands were warned by concerned friends about the dangers posed to them by an AIDS widow. It appears that some of the men knew the risk and were willing to take it. Such men answered those whom they perceived to be interfering: "What benefit do people get if they die late of old age?"; "Bodies are all buried the same way; Will they sew me into timber? (*ndibajjibwamu mbawo?*)"; "Will I grow into mushrooms (and be edible)? (*ndimera butiiko?*)"; "Who is never going to die? (*ani ataliffa?*).". These somewhat gnomic utterances appear to indicate a certain fatalism in the face of a disease which people recognise to be fatal. However, it is not only fatalism which is indicated. It also has to be recognised that they may indicate efforts to continue a 'normal' existence in circumstances which are rapidly becoming increasingly 'abnormal'. Such attitudes may appear perverse, but they must be seen for what they are, one way of coping with the presence of death in close association with sexuality. In unsolicited statements, professional men regarded celibacy as a temporary solution until a cure for AIDS was found. By and large marriage was seen as a buffer against AIDS. Religious messages in sermons and posters promoted 'love faithfully' as a precaution against AIDS. Both men and women enter into sexual relationships with, and even marry someone who looks healthy on the basis that they must be AIDS-free. On the basis of the ACP-Rakai project (in which blood was taken from a large and well-designed sample), sero-positivity rates amongst men and women between 19-35 years make marriage a very hazardous choice, as the earlier section has explained in more detail. However, the dangers are becoming more apparent to the people themselves. In the community which was studied, there have been three cases in which women, after six months or a year of marriage, woke up to find their husbands covered with the distinctive

blotches of *Kaposi's Sarcoma*, or the rash of *Herpes Zosta*. The women in shock claimed that they had been duped. In all three cases the reaction of the women was to leave the home, the husbands having to depend upon other people for support and care.

Young widows with two or three young children tended to return to their natal home. Fear of the exclusive burden of farm work, insufficient money to hire labourers and the desire to receive unconditional help with the children were given as reasons for this move.

Other widows have opted for celibacy. They feel that it is not good to "tempt fate" since they had been lucky enough to escape AIDS with their deceased partner. In this predominantly Catholic community, most people affected by AIDS either as patients or as survivors of an AIDS-infected spouse have turned to religion for comfort. Widows perceive the nuns as their model of piety, celibacy and work. However, this is not solely a response to the disease, as celibacy has always been one of the strategies which Ganda widows have used to avoid involvement and problems arising from men who might be after their property.

Turning now to the way in which men cope with the illness and death of their wives, in our own fieldwork as well as in the study of orphans (Hunter 1989), it seems that many more men have died than women, and that widowers are much rarer than widows. Men, whose wives are ill and eventually die, cope in similar ways, although access to economic support in terms of labour to work the farm and cash to enable the sufferer to receive treatment from diviners, healers and hospital is usually very much easier than for women. It is probably true to say that they spend less time attending to the needs of their wives while ill (cooking special meals and staying with them in times of particular need). The caring for children can sometimes be arranged through the husband's sister and other of his female relatives. Refuge in the

company of other men in bars is another way of sharing the burden.

Coping with the greatly increased number of orphans is a major concern. It has been estimated that there are 24,524 orphans in the District of Rakai (SCF, 1989, results published by Hunter, 1990). The way in which established practice of caring for children who have been orphaned, or whose parents for one reason or another are absent from home for a long period, has been stretched to breaking point has been reported elsewhere by these authors (Barnett and Blaikie, 1990a and b<sup>8</sup>).

#### Access to resources

So far in this paper we have discussed the perceptions and explanations of AIDS in Buganda, and how these differ depending upon the experience of the levels of morbidity and mortality in any one area. Within each area, men and women have had substantially different experience of the impact of the disease, and their expectations of life in the future have been affected differently. Here, the substance of what people think about AIDS is linked to broader processes in economy and society. Every society experiences social and economic change, and a disaster such as AIDS impacts upon these ongoing processes. A heuristic model is presented in Figure 1 which formalises the impact of AIDS on the changing patterns of access to resources involved in earning a living. It shows how individuals (usually as part of households and more extended familial networks) gain access to physical resources (e.g. land, labour, agricultural implements, shelter etc) in order to combine them to

<sup>8</sup> Barnett, A S, Blaikie, P M (with Obbo C), 1990 Community Coping Mechanisms In the Face of Exceptional Demographic Change. Report to the Overseas Development Administration. Mimeo, 117 pps.

support themselves. It can be viewed as a more general model of that developed by Sen (1981),<sup>9</sup> which uses the concept of entitlements in an explanation of famines. This model of access was originally developed for a computer simulation of the Nepalese economy (Blaikie, Cameron and Seddon, 1979),<sup>10</sup> and has since been adapted to the analysis of land degradation and its impact upon households in different rural economies (Blaikie, 1985)<sup>11</sup>. Also, Cannon at this conference has used the same explanatory framework in the explanation of famine (Cannon, 1991).

Each household has an array of resources which is broadly defined as economic, financial and social assets, which when combined, allow for the production and reproduction of the household, and the satisfaction of culturally defined needs. Box 4 in Figure 1 represents an array of households, each with different resources. Note that some of these households are polygynous, and that others are female-headed representing a point in time between partnerships (serial polygyny) when there is no current husband, who is providing any substantial resources to that household. Each household is conceived of as viewing an array of possible economic activities listed in Box 5, which in combination provide a livelihood. Typically in Buganda, most of these income opportunities are different crops, but there are important non-agricultural opportunities, such as trading, agricultural labouring on the farms of others, selling beer, fishing, and employment in the government sector. Each of these income opportunities has an access qualification. For example, the cultivation of banana (matoke) requires access to a previously planted banana

<sup>9</sup> Sen, A. K., 1981: Poverty and Famines. Oxford, Clarendon Press

<sup>10</sup> Blaikie, P M, Cameron J, and Seddon J D, 1977 Centre, Periphery and Access in West-Central Nepal: Approaches to social and spatial relations of inequality, monographs in Development Studies No 4, University of East Anglia. pps 159

<sup>11</sup> Blaikie P M, 1985 The Political Economy of Soil Erosion in Developing Countries. Longman Development Series No 1, Longman, London, pps 188.



grove, and the necessary labour to prune the plants, mulch the ground underneath and weed it, if necessary. Annual crops will also have a typical seasonal profile of labour demand, and will require seed, land and labour. It can be appreciated that, when any event which reduces the availability of labour such as an epidemic, one of the most important access qualifications is the ability to mobilise sufficient labour at times of peak labour demand. Other income opportunities have lesser access qualifications, and usually are oversubscribed and therefore are less well remunerated (agricultural labouring, being the commonest example in this region). Trading activities will have a variety of necessary qualifications, depending on the scale and nature of the trading. Some types will demand that the trader is male, others may require considerable capital or the ownership of a lorry (or at a less ambitious scale, a bicycle). Employment in government service will require a particular level of schooling, and so on. Each of these income opportunities has a pay-off, and contributes to the household budget (stylised in Box 7). Gender is often an important access qualification to many income-earning opportunities. Indeed, so many income opportunities are denied to women with the result that the economic insecurity of women is a major determinant of the way in which AIDS impacts on Buganda society (as it patterns the way in which they are forced into prostitution or other liaisons to secure a bread winner). Marriage or the securing of a male partner can be viewed partly as a "bread-ticket" for some women in a situation where other more conventionally economic activities are denied to them.

Pay-offs for each income opportunity are determined by a number of factors. Yields of the crops grown, the price the producer is able to secure for produce in the market, and margins in trade are the most common. However there are other important non-technical and non-economic factors too, which decide the level of pay-off, especially where the pay-off is subject to

prevailing structures of power. For example, a woman may be constrained by her husband in the extent she may enter the market to sell goods, which she has produced. A woman was conventionally given a matoke grove to cultivate, but she may have to sell the bananas through her husband, and retain for herself part of the proceeds. The degree to which elderly relatives may receive remittances, labouring help on the farm, or other assistance is subject to expectations and norms, which lie outside the market. These factors collectively have been labelled 'power and the allocation of resources', and are represented in Box 6. They operate at a number of different levels. Within the household, they depend principally on gender, seniority, and relationship with those with access to income opportunities. Within family and kin, but outside the household, they typically involve obligations of material assistance on a regular basis and at life ceremonies, the temporary looking after of children of a relative, and in the settlement of property issues at times of death, divorce or other change in family structure. Also some important processes involved in the allocation of resources involve the state. The level of maintenance of law and order is one example. The social upheavals in the mid-1970's involving the collapse of the existing distributive and trading network, resulted in a massive upsurge of smuggling, rapid inflation, and violence. The way in which land law is interpreted and upheld, particularly in disputes between widows and the deceased husband's relatives, or between cultivators and landlords, all have profound effects upon both access qualifications and pay-offs.

The sum of these pay-offs together constitute a livelihood, and flow into the household budget, as shown in Box 7. Thus the household budget consists of inflows in the form of crops and materials for use and sale, with or without further processing. Typical examples of the latter are beer-making, the weaving of mats and containers, and bark processing to produce a fabric used

for clothing and funeral shrouds. Cash may also enter the household from sale of crops (here this is predominantly coffee, matoke and sometimes, Irish potatoes). Outflows consist of consumption of foodstuffs, payment of wages to labourers, fees to the Parent Teachers Association (which can be particularly onerous), and the money spent on other purchased household items.

The stock and flow situation of the household budget can be monitored at certain time intervals (most usefully at the beginning of each agricultural season, when stocks are typically at their lowest). If the net situation is in surplus, then the household may accumulate wealth, either temporarily, or maybe invest in further income-earning opportunities. In Buganda at the present time, trade is the most common, since investment in coffee production gives little return. The state has a legal monopoly of purchase of all coffee, the price paid to farmers most unattractive, and payment often delayed for many months. Other productive opportunities have mostly declined during the past twenty years of unrest. If the net situation is negative, the household must reduce consumption, and/or borrow or somehow secure enough of their basic needs to survive.

In this way households are formed, grow, split up, and disappear. New members are added through marriage and birth, and others lost through marriage, divorce, death and out-migration. Their economic fortunes may improve or decline through time. The model is iterative, illustrating the way in which some households accumulate and others disinvest. Into these ongoing processes of earning a living and of longer term agrarian change, AIDS is introduced. In the following paragraphs, a summary of the socio-economic impacts of AIDS is given and provides a conceptual overview of the detail which has already been provided in earlier papers (Barnett and Blaikie, 1990)<sup>12</sup>.

<sup>12</sup> Barnett A S and Blaikie P M op.cit.

The disease directly affects the numbers in the household upon the death of one or more members, see Box 2.. Household structures may change with desertion of a sick partner, and the sending of children to relatives, as mentioned at the end of the last section (Box 3). Upon the onset of the more debilitating symptoms of the disease, the sufferer can no longer work productively, and the access qualifications of some crops may become too high. Remittances from non-agricultural income opportunities may cease upon the death of a son in government employment or in trade, for example. The household budget will suffer a sharp decline in cash and possibly food crop inflows. Children may have to be taken out of school, and other purchased household items will simply become too expensive..Finally, in the longer term the disease itself may begin to have an impact on the the way in which existing resources are allocated, and on the way power is distributed and used in the community and wider society.

The socio-economic impact of AIDS is not the major focus of this paper and has been reported in other papers by the present authors. These downstream effects involve a reduction in the availability of household labour for productive activities. Labour power becomes sick and eventually dies. Also others (particularly women) have to care for the sick and their productive labour time is thus diverted from the farm to domestic work and caring. Income opportunities dry up, not only from the farm but from non agricultural livelihoods, with a cessation of cash remittances. Typical responses are to remove children from school thereby reducing cash requirements to the Parent Teachers Association and releasing labour for the farm. Reducing consumption levels, finding waged employment outside the household and readjusting seasonal labour demands to grow less demanding crops are some other typical responses.

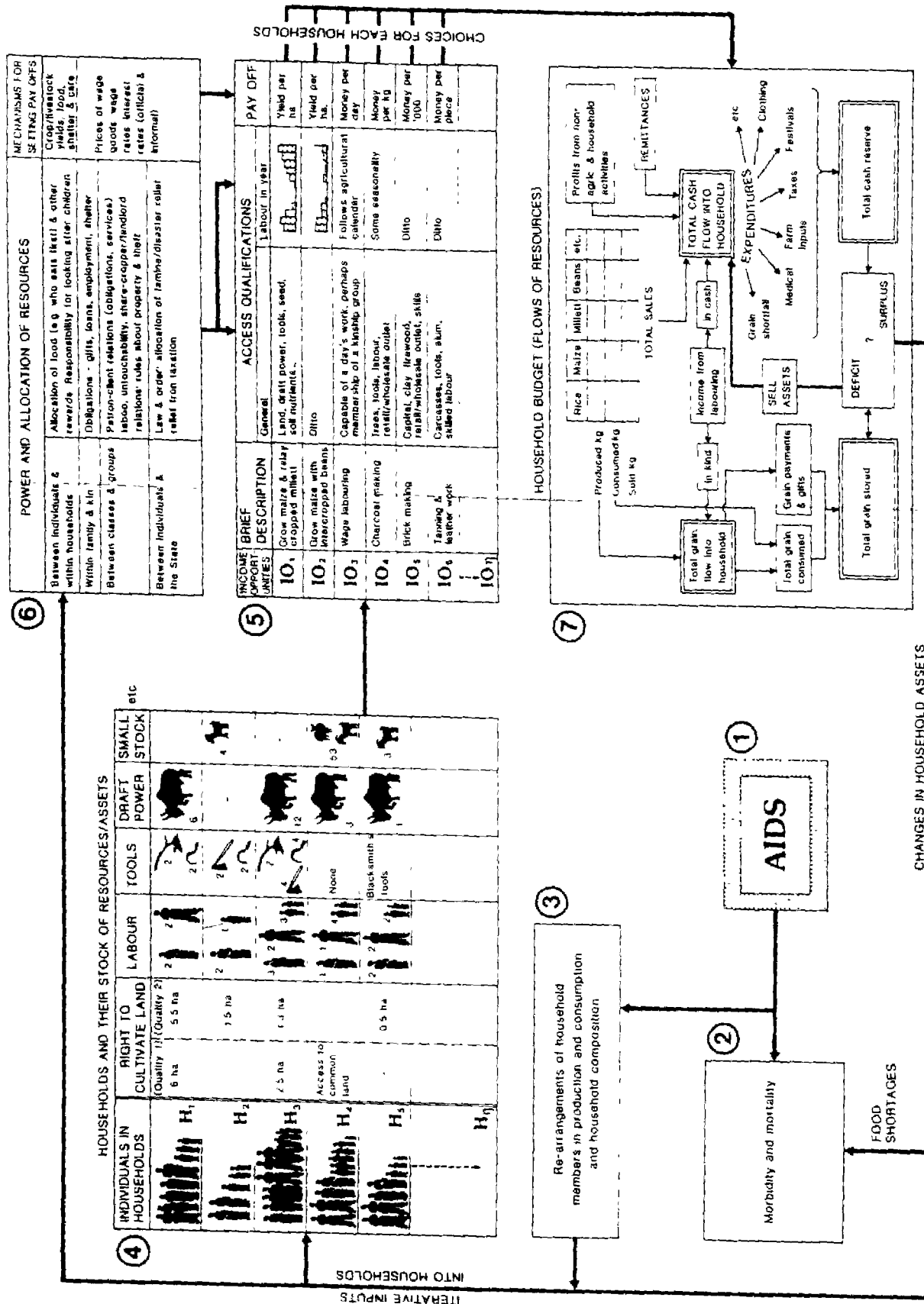


Figure 1 Schema for analysis of the impact of AIDS on households

The methodology for charting the growth and development of this long wave disaster consists of three dynamic elements.

First, the spatial and temporal dimensions of the diffusion of AIDS is a crucial driving force which determines the extent and sequencing of coping mechanisms across space and time.

Second, the spatial variation in patterns of household access to income opportunities can be cross classified with the spatial diffusion of the AIDS pandemic to provide patterns of coping which will vary between households. The explanatory models of AIDS given by the local population will also vary between different households and will be subject to the experience of morbidity and mortality as they increase in an area. Third, there are broad patterns of farming systems with their characteristic sets of labour demands and pay-offs. These are broad regional variations which the growing AIDS pandemic cross cuts, to provide a pattern of varying acuteness of labour shortages ( see Blaikie and Barnett, op.cit., Ch. 7).

## Conclusion

This paper has provided a framework in which a society can define a disaster and, if it is unprecedented, to attempt to use past experience of coping to structure future expectations. The Baganda confront just such a novel situation in which a major disaster is in the process of unfolding. They are experimenting with new forms of action and are adjusting their expectations of the fulfilments of life based on their experience of illness and death.