

Because page numbers in the original article do not correspond to the page breaks in the format presented below, italicized notations in brackets are inserted into the text to indicate where page breaks occur in the published text. As in the original Supplement 3, page numbers include the letter "S."

[page S275]

A review of current literature of the impact of HIV/AIDS on children in sub-Saharan Africa

Geoff Foster^a and John Williamson^b

AIDS 2000, 14 (suppl. 3):S275-S284

Keywords: HIV, orphans, children, coping, impact, AIDS

Introduction

Of the 49.7 million HIV infections that had occurred worldwide by late 1999, 72% were in sub-Saharan Africa; 84% of AIDS deaths, 91% of child HIV infections and 94% of child AIDS deaths worldwide have occurred in Africa [1]. Of children orphaned by AIDS throughout the world, 95% have occurred in Africa where numbers of orphans will continue to rise throughout the next decade reaching 40 million by 2010 (Figure 1). Long term solutions will need to be crafted for these children because the impact of HIV/AIDS will linger for decades after the epidemic begins to wane. Even if rates of new infections were to level off in the next few years, the long incubation period means mortality rates will not plateau until 2020. Thus, the proportion of orphans will remain unusually high at least through 2030 [2]. For a variety of reasons, little attention has been paid to the situation of children affected by HIV/AIDS [3]. Greater understanding of the impact of HIV/AIDS on children is important in the design and evaluation of programmes to support children living in difficult circumstances. This paper reviews epidemiological characteristics of children affected by HIV/AIDS, coping mechanisms and current knowledge of the impact of HIV on children. Areas where important gaps in knowledge exist are highlighted.

Epidemiology

Until recently, little attention was paid to numbers of orphaned children, either globally or nationally [4]. Orphan studies are likely to assume greater prominence when the number of children affected by HIV/AIDS is accurately and consistently quantified.

From ^aFamily AIDS Caring Trust, Mutare, Zimbabwe and ^bDisplaced Children and Orphans Fund, Washington, US.

Correspondence and requests for reprints to: Dr Geoff Foster, Family AIDS Caring Trust, Box 970, Mutare, Zimbabwe.

Varying definitions of orphans

The English word “orphan” is derived from Greek and Latin roots meaning “a child bereaved by the death of one or both parents” [5] [6]. Whilst some orphan estimates are specific to children orphaned by HIV/AIDS, others include orphans from all causes. The wider definition is more useful for programming purposes since it is inappropriate at community level to determine eligibility for assistance based on specific cause of parental death. Most estimates and models define an orphan as a child whose mother has died. Maternal demographic data is more easily obtained and in surveys, biological mothers are more easily related to their children than fathers. Though some censuses count paternal orphans, until recently, no national estimates of paternal orphans were available. Impact on orphans depends upon whether children have lost a father or a mother [7]. Only in modern times has the death of a mother, as primary nurturer, been given so much significance. Throughout much of western history, the loss of a father led to reduced prospects for orphans with inheritance implications. In developing countries, loss of a father may have greater socio-economic impact than loss of a mother [8] [9] [10].

In addition to parental status, the other factor affecting orphan estimates is the age range chosen. Most orphan estimates are for children under 15 years old. Data from child health surveys is normally based on children under 15 years. Data on children 15-17 years is usually presented together with adult data in the 15-49 year category. From a “rights” perspec-

[page S276 in original begins here] tive a child is defined as a person under 18 years [11]. From a practitioner perspective, community programmes target children in difficult circumstances which includes maternal and paternal orphans under 18 years. There are still no estimates for orphans under 18 years, nor for paternal orphans in most countries with substantial HIV/AIDS epidemics. Yet numbers are important, after the adage “If you can't count it, it doesn't matter”.

Definitions which exclude paternal orphans underestimate total orphan numbers by 45-70%; definitions which exclude 15-17 year old children underestimate this figure by 25-35%. Broader definitions of orphans draw attention to the scale of the impact of HIV/AIDS on children yet still underestimate the problem. Children are directly affected by HIV/AIDS when they are orphaned. In addition, many more children are affected indirectly when their close or extended family, their community and, more broadly, the structures and services which exist for their benefit are strained by the consequences of the HIV/AIDS pandemic [12]. Firstly, an unknown number of children live with parents with HIV/AIDS- related symptoms; many more live with asymptomatic HIV-infected parents. In some countries, up to 25% of children born to healthy women may have at least one parent infected by HIV by their fifth birthdays [13]. In Thailand, for every child maternally orphaned by AIDS, there were twelve children living with mothers with HIV/AIDS [14]. For every Brazilian maternal orphan from AIDS, there were three children with mothers living with AIDS and twelve with mothers living with HIV infection [15]. For most countries, no estimates exist for children living with HIV-infected parents. Drawing attention to children living with HIV-infected parents highlights the future dimensions of the orphan epidemic and social, developmental and health problems these children may face even prior to orphaning [8,9]. Secondly, many children in Africa are fostered by relatives and do not live with either biological parent. In Tanzania, 34% of children lived with one parent and 12% were not living with either parent, yet 8% of children were orphaned due to loss of father or mother and 1% had lost both parents [16]. The impact of the loss of a

relative on fostered children may be as great as the loss of their natal parent. Children living with HIV-infected parents and in foster families affected by HIV/AIDS go unreported in most enumerations and are not measured in mathematical models.

The definition of orphanhood is significant in relation to child development. Loss of a parent in early childhood, at school age and in early or late adolescence affects children differently, both psychologically and developmentally. Defining orphans as children under 15 years detracts attention from the needs of older adolescents including the sexual and economic exploitation of adolescent girls [12]. Research is needed to identify the implications of different age and parental-status definitions in terms of willingness to respond, resource allocation decisions, programmes selected and their implementation.

Orphan enumeration

Census and enumeration data is available in many countries enabling estimates of orphans numbers, though it is difficult to collect accurate data on orphans. Knowledge gained from specific orphan enumeration leads to doubts about the accuracy of estimates obtained from census data and vice-versa. Responses may depend on the way in which questions are phrased; for example, all Zambian languages have a word for “orphan” but none would apply to children staying with adult relatives [17]. Wide variations occur in reported orphan prevalence even in enumerations performed in the same area around the same time [18] [19] [20] [21]. Methodological differences in enumerations account for many of these differences. Under-enumeration is common because of stigma or because many orphans are fostered away from their household of origin. Infants and young children are subject to disproportionate under-enumeration [22]. The orphan status of girls under the age of 18 who themselves become parents is unclear. Over-enumeration may occur because of hopes of secondary gain by respondents. Children in single mother households may be over-enumerated if they are counted as paternal orphans or under-enumerated if paternal status is unknown.

Enumeration studies measure prevalence rather than incidence. In Zambia, a high prevalence of households containing orphans was found in poorer local

[page S277 in original begins here]

ities with high rates of female-headed households; high prevalence of orphanhood may be due to migration rather than a high incidence of parental death [23] [24]. Urban-rural migration occurs as a result of the “going-home-to-die” phenomenon whilst rural-urban migration occurs as widows move to towns to seek work or remarriage. The prevalence of orphans may be significantly affected by migration, so that those areas with the highest prevalence of orphans may not be those areas which have the highest incidence. Little is known about the nature and extent of this morbidity and mortality-related migration and its impact on affected children. There is need for standardised enumeration methodologies, comparisons of random household with community-based enumerations and serial enumerations. Incidence studies of orphans within a longitudinal framework are required to understand changes taking place in household composition [25].

Mathematical models of the orphan epidemic

The HIV/AIDS pandemic is a continuously evolving, progressive disaster. The resultant consequences of the pandemic will change over time. Mathematical models draw attention to

demographic implications of the epidemic which help policy makers make decisions based on likely future trends [26]. Without models, these changes might not be anticipated. In severely affected countries, models predict reduced average age of orphans, altered age compositions of populations, a relative shortage of females and worsened dependency ratios [27]. Different models to estimate the number of children orphaned by the AIDS pandemic have been reviewed. Most estimates are calculated using a demographic model. The estimates differ substantially because of differences in parameters such as current HIV prevalence, the future severity of the epidemic, incubation and survival periods, infant and child mortality, perinatal transmission and fertility. Only one model includes estimates for numbers of paternal orphans [28]. Owing to lack of adequate data, few studies have compared the findings generated by model simulations with existing data on orphanhood in sub-Saharan Africa [29]. Such comparisons would allow mathematical-model-based simulations to be evaluated and help to validate such models. Enumeration data can feed into mathematical models which generate predictive estimates at local levels and enable better planning.

The extended family safety net and the role of the community in coping

In many AIDS-affected communities, the mechanism that keeps families and households from destitution is comprised of material relief, labour, and emotional support provided by community members [30]. At times of distress such as bereavement, all community members are obliged to participate and contribute towards funeral costs [31]. People living in communities overburdened by AIDS recognise this principle, with some volunteering their time and skills to care for orphaned children [32]. The extended family remains as the predominant caring unit for orphans in communities with severe HIV/AIDS epidemics [33] [34]. Extended families involve a large network of connections among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations.

Coping mechanisms regarding orphans are complex and vary according to social setting. In most African communities, the concept of “adoption” does not exist in the western sense. Children are fostered, a prevalent, culturally sanctioned procedure whereby natal parents allow their children to be reared by adults other than the biological parent [35] [36]. Child fostering is a reciprocal arrangement and contributes to mutually recognised benefits for both natal and fostering families [37]. In Tanzania, less than one quarter of children being fostered by relatives other than their biological parent were orphans [16] [38]. In societies where “purposive” fostering is prevalent, “crisis” fostering which occurs following the death of a parent is common. The same relatives who have a right to claim a child through purposive fostering have an obligation at times of crisis to accept the role of foster parent [39]. Fostering by non-relatives is uncommon [40]; the prevalence of, reasons for and hindrances to such fostering has received limited study [41].

The role of the extended family and community in coping with orphans are in a state of flux. Where traditional values are maintained such as in rural communities, the extended family safety net is better preserved. Where countries are more urbanised, extended family safety nets are weakened. As the traditional practice of orphan inheritance by uncles and aunts has lessened, it has been replaced by alternate safety nets with care provided by grandparents or other relatives [18] [42]. Children who slip through the safety net may end up in a variety of vulnerable situations such as street and working children and child-headed households. Monitoring the background of such

children can be a valuable source of information about families which have the greatest difficulty caring for children and where efforts to strengthen capacity should be targeted.

Too often, the realisation that extended families are under stress leads to an assumption that the principal

[page S278 in original begins here]

response should be to develop other alternatives such as institutions, children's villages and adoptive placements. Institutional responses are often unsustainable and may be viewed as inappropriate by community members who recognise their potential to undermine existing coping mechanisms [43]. Those planning interventions must understand existing norms and practices and seek to strengthen family and community capacities to protect and care for vulnerable children [32].

Impact of HIV/AIDS on children and families

In severely affected communities, HIV/AIDS has an impact on children, families and communities which is incremental. The continuous attrition rate of deaths in young adults leads to social and economic impacts which increase with the severity and duration of the epidemic. The impact of HIV/AIDS on children and families is compounded by the fact that many families live in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services. Strategies for coping of extended families have negative impacts on children in households indirectly affected by HIV/AIDS, thus enlarging the overall impact and number of children affected. For example, children may experience reduction in their quality of life when their mother goes to provide home care for an HIV/AIDS-affected relative or because of transfers of money to a sick relative's household. Children may see their standard of living deteriorate when cousins come to live with them following the death of an aunt or uncle. Figure 2 suggests the progression and relationship of problems among children and families directly affected by HIV/AIDS.

Impact of parental illness on households

Children are affected by HIV/AIDS before they are orphaned. When a parent develops HIV-related symptoms, children often shoulder new responsibilities; these include domestic chores such as cooking, cleaning, carrying water and laundry, care giving activities such as feeding, bathing, toileting, giving medication and accompanying relatives for treatment, agricultural or income generating activities and childcare duties. When a parent is ill, children's school attendance drops because labour is needed to pay medical expenses or because families cannot afford to pay school fees [9]. Adults make decisions that children should drop out of school to provide care for sick relatives or young siblings; child carers are frequently girls caring for female relatives [44] [45]. Research is needed into the impacts, both negative and positive, that caring has on children, the needs of children as care givers and the ways in which disruptions to schooling can be minimised.

Pre-planning for death can ensure that orphans are appropriately cared and provided for after parental death. Only 2% of families in Zimbabwe wrote a will prior to death [46]. Most adults receiving home care in Zambia had not talked to their children about what would happen in the future; children who discussed parental illness with their parent were significantly more

worried than those who had not [47]. Succession planning is a problem in Africa because of taboos. A person who talks to another about their impending death lays themselves open to charges of witchcraft. Conversations often focus on searches for cure rather than on arrangements to be made after death.

Inheritance practices

In much of Africa, widows are inherited through remarriage to a brother of the deceased husband; property is inherited by paternal relatives. In Tanzania, most widows had a sexual relationship with in-laws despite this being against their wishes; 97% were denied the right to inherit the deceased husband's property [48]. In Zimbabwe where widow inheritance is declining, most women refuse traditional remarriage [49]. However, brothers-in-law main-

[page S279 in original begins here]

tained sexual access to widows without accepting responsibility to provide for the widow's family [50]. Property was reportedly inherited by children with only 15% of respondents reporting "property-grabbing" [46]. In other countries where traditional practices are maintained and widows' rights are overridden, asset stripping appears to be more common. Traditionally, the inheritance of orphans in patriarchal societies was to paternal relatives. In many societies, the marital status of the parents has a significant bearing on inheritance. In Rwanda and elsewhere, if the parents were traditionally married and a bride price was paid by the prospective groom, orphans are taken in by paternal relatives [51]. Paternal relatives refuse to take orphans in them in if bride price is not paid leaving orphans to slip through the extended family safety net. Few studies have quantified the extent and consequences of traditional inheritance practices.

Changes in caregiver

Families cope with relatives' deaths by ensuring that children affected by HIV/AIDS receive care from a substitute caregiver. The extended family support network functions through changes in household composition, with relatives moving in to households to care for survivors or orphans moving out into one or more relatives' households. Different patterns of coping mechanisms exist within families depending on whether the father or the mother is sick or dies. Household resilience to the economic and social impact of prime-age adult deaths is considerable [8, 40] [52]. As the number of orphans in a community increases and uncles and aunts, the traditional first choice as substitute caregiver become unavailable, grandparents are recruited into childcare [42] [53] [54]. Grandparents are often a last resort as caregiver and agree to take orphans because other relatives refuse [55]. In some cases, what is viewed as a situation in which the elderly provide childcare is actually more akin to a situation of mutual support with increasingly frail grandparents becoming the care recipients of grandchildren. Figure 3 compares the number of orphans cared for by aunts/uncles and grandparents from four African countries. The data suggests that grandparents are more frequently recruited as caregivers in areas where the AIDS epidemic is more severe or where the extended family is weakened [42].

Ways in which decisions are made concerning the choice of caregiver for orphans vary. Decisions may be made by the eldest male member of the paternal family, surviving parents or orphans themselves [50] [56] [57]. In Zambia, one third of caretakers stated they had agreed to care for orphans only because nobody else would [55]. Few studies have specifically

examined the social and economic factors underlying such decisions or the consequences of desertion of orphans by widows and widowers [58]. One important question is at what point of family burden, do extended kinship networks abandon responsibility for orphaned children? The decision to leave children living in child-headed households in Zimbabwe was often made by relatives who were reluctant to foster older children. Child-headed households were more frequently established if a teenage child experienced in childcare was living in the household or if a relative lived nearby who could provide supervision. Decisions were influenced by siblings' wishing to stay together in their homestead or a dying mother's wish to preserve her family intact [57].

Children who belong to families with little regular contact with relatives are at risk of being abandoned if they are orphaned. Households headed by migrants, in urban areas and on commercial farms or estates have limited access to extended family and community safety nets. Most Zimbabwean migrant farmworker families and one quarter of indigenous farmworker families had irregular or no contact with relatives [59].

The proportion of orphan households headed by elderly caregivers, the number of child-headed households and sibling dispersal or migration may serve as indicators of saturation of the extended family safety net [42]. The prevalence of child-headed households was 30/1000 households in the Rakai district of Uganda, 4/1000 households in Zimbabwe and 0.3/1000 in Tanzania [16] [57] [60]. Other indicators of a weakened extended family safety net include households with orphans from two or more families, increased numbers of working children, children removed from schooling to provide care and orphaned street children. There is need to understand the reasons why children slip through the extended family safety net and the quality of care provided to such children in order to strengthen

[page S280 in original begins here]

family and community capacities to protect and care for vulnerable children

Economic impact

The HIV/AIDS epidemic is taking its heaviest toll at household and community level [61]. Economic factors are crucial in determining the responses of the extended family to provide care for orphans. The care of children affected by HIV/AIDS in developing countries is falling on poorer people within communities, especially women. In Kenya, most families that agreed to take in foster children were living below the poverty line, whereas wealthier relatives tended to maintain minimal links with orphans [7]. In Uganda, orphan household *per capita* income was 15% less than non-orphan household income [62]. Death of a father within a household often has deleterious economic consequences for children because of high treatment and funeral costs, loss of the father's income and property grabbing [8]. In Zimbabwe, 89% of families relied on women as the breadwinner and only 3% of orphan households had a member who was a breadwinner in employment [63]. The situation of children living in child-headed households was particularly dire with average monthly incomes of \$8 compared to \$21 in non-orphan neighbours [64]. Private transfers of assets within families and communities are traditional mechanisms for alleviating distress [65]. In Tanzania, less than a quarter of orphans received support from the one parent who was still surviving and under 10% received support from other relatives or elsewhere [16]. In desperate circumstances when there are no other sources of income, poor households may sell off assets such as oxen which provide draught

power to provide desperately needed revenue at the cost of long-term development [66].

One way to gauge the strength of community coping mechanisms in the face of the impact of AIDS is to measure the strength of community responses. Seeking relief from family, friends and neighbours is a common response to economic crises which result from disasters [30]. In Tanzania, assistance from government or non-governmental organisation sources was considerably less than transfers from community members [8]. This community safety-net is being weakened as a result of the steadily growing impact of the AIDS epidemic. Better-off families find their economic reserves depleted because of continual demand from relatives affected by AIDS. They become less able to contribute in cash, kind or the provision of work to destitute families in need. As the number of families falling from poverty into destitution increases as a result of AIDS, the amount of relief that can be provided per destitute family decreases. There is a growing recognition that mobilising and strengthening community-based initiatives such as caring for the sick and orphans are as urgent as preventing the further spread of HIV [28] [67] [68]. Often, the groups best placed to strengthen family and community capacity are small grass-roots organisations, supported by non-governmental organisations [51] [69]. Community-based child support initiatives have a demonstrable ability to target small amounts of material support to large numbers of destitute orphan households [32, 53].

One of the less obvious economic impacts of the epidemic is an increase in the amount of work performed by children, sometimes as young as five years old [66]. The workload of children affected by HIV/AIDS starts when parents become sick and increases when children become orphaned; workload of orphans may be greater than non-orphans living in the same household [70]. Increased domestic workload is often disproportionately greater on girls than boys [71]. In order to generate an income, adolescents may leave orphan households to seek work in towns, as agricultural labourers for more prosperous farmers and as domestic labourers; some girls become involved in commercial sex or enter into marriage as girl brides in order to provide for the needs of younger children in their household.

Migration

Changes in the composition of households through migration of family members is an important mechanism by which extended families cope with the economic and child care need consequences of HIV/AIDS [8]. Urban-rural relocation may occur with the onset of serious illness in the “going-home-to-die syndrome” [72]. Rural-urban migration of adults occurs when widows migrate to towns in search of work or partners; more than one half of young widows and one quarter of young widowers under 35 years in Uganda moved from the household of their late spouse to earn money or for remarriage [58]. Mobility is especially common in adolescents affected by HIV/AIDS [57]. Non-resident young relatives may become carers in urban households in preference to resident urban children forfeiting their education [45]. Children affected by HIV/AIDS are particularly likely to be relocated before or following parental death [18]. Children from child-headed households were more likely to have moved in the preceding two years compared to children of non-orphan neighbours (12/37 vs 0/42) [64]. Intra-rural or intra-urban migration of orphans may occur leading to clustering of orphan households in poor areas [23]. Economic and social factors are crucial determinants in decisions made concerning migration. There is need to better understand migration practices in order to mitigate their deleterious effects upon children.

Separation of siblings following parental death is a strategy of families to share the burden of

care between

[page S281 in original begins here]

several relatives which has been little documented. Children, especially those under five, may be fostered leaving siblings living by themselves [57]. Adolescent girls may be “pawnd”, sent to a relative or neighbour to work in return for money paid to the fostering family [7]. Few households in Zambia found the idea of separating orphaned siblings from one another acceptable [55]; dispersion of siblings was a significant independent variable for the prediction of emotional distress in urban orphans [73].

The HIV/AIDS epidemic is leading to increasing numbers of street children in Africa. In both Zambia and Zimbabwe, there was an increased probability that street children were orphaned [74] [75], (Foster G *et al*, unpublished manuscript, 2000). Children of HIV-infected commercial sex-workers are particularly likely to end up on the streets or working for other people; in Kenya, a non-governmental organisation encouraged 11 sex-workers to establish linkages with relatives who might care for their children after their demise; at the time of maternal death, 8/39 (21%) children had become street-children, 3/39 (8%) were commercial sex workers, 2/39 (5%) were casual labourers and one was married as a girl child (3%) with other orphans being cared for by family members [76].

Education

Early evidence for the impact on children’s school attendance as a result of orphanhood came from Uganda; the financial strain led to households with orphans failing to raise funds to send their own children to school [77]. Education is often disrupted when parents become sick, especially older girl children who are required to take over household and caregiving chores. In Uganda, amongst children 15-19 years whose parents had died, only 29% continued their schooling uninterrupted; 25% lost school time and 45% dropped out of school; school-age children with the greatest chance of continuing their education were those who lived with a surviving parent; those fostered by grandparents had the least chance (7%) [9].

Studies from several countries confirm significantly less enrolment rates in orphans than non-orphans and identified risk factors such as girl orphans, children orphaned by AIDS, rural or poor households and orphans living in households headed by men [8][37][62] [78]. In seven African countries, primary enrolment rates of orphans, especially double orphans, were generally lower than in non-orphans, especially in countries with low overall enrolment rates and in households with least assets [8]. Other studies from Uganda and Tanzania found little difference in school attendance between orphans and non-orphans[16, 25]. A Kenyan study found that school performance was significantly poorer among children orphaned by AIDS [79]. More research is needed to determine whether maintaining or re-establishing orphans’ education has social, economic or psychological benefits to children and their households.

Health and Nutrition

A close correlation was reported between child morbidity and the quality of parenting [80]. Fostered children in West Africa experienced higher mortality than other children because of poorer care, malnutrition and reduced access to modern medicine [81] [82]. It might be expected that the health of orphans, especially those in the care of elderly and adolescent caregivers would be worse than other children; substitute caregivers may be uninformed about

good nutrition, oral rehydration treatment for diarrhoea and the recognition of serious illness [83]. In Zaire, no differences were reported in morbidity between children orphaned by AIDS and controls in a two-year follow-up from birth in children without HIV infection [84]. A two-year follow-up of orphans in Tanzania found no significant difference in mortality compared to other children [16]. A four-year follow-up of orphans in Uganda found a higher though non-significant mortality in under-fives compared to non-orphans without HIV infection [25]. Younger orphans in rural Zambia were more likely to have frequent illnesses than non-orphans [73]. Failure to find evidence of increased morbidity and mortality in orphans may be because orphan prevalence is not high and extended families still have sufficient capacity to cope with orphans.

Reduced household agricultural production was noted in one quarter of households in an AIDS-afflicted area of Uganda [85]. Orphans in Tanzania and Zambia were more likely to be stunted but no more likely to be wasted than non-orphans [10, 47]. In an urban slum in Nairobi, Kenya, orphans were significantly more malnourished than non-orphans [86]. Neither study excluded possible bias because of increased likelihood of HIV infection in orphans. In Zaire, there was no significant difference between orphans and non-orphans regarding frequency of eating breakfast [84]. In Tanzania, stunting was increased in orphans, regardless of the level of household assets, possibly because parental illness and household death interferes with child rearing [8].

Psycho-social impact

In developing countries, the social and economic impact of HIV/AIDS on children has overshadowed concern about the psychological impact of HIV/AIDS on children. Where basic needs are not met, it is difficult for agencies to concentrate on addressing less immediate or obvious psychological need. In some contexts, a blanket and food may be more appropriate than counselling [87]. Yet the impact of HIV/AIDS

[page S282 in original begins here]

on children in developing countries is essentially no different from developed countries, with most children showing psychological reactions to parental illness and death. Stigmatisation, dropping out of school, changed friends, increased workload, discrimination and social isolation of orphans all increase the stress and trauma of parental death. In a Ugandan study, most children felt hopeless or angry when their parents became sick and scared their parents would die. Most orphans were depressed, with lower expectations about the future: fewer orphans expected to get a job, wanted to get married or wanted children than non-orphans. Depression was more likely in 10-14 years old than 15-19 years and such children were more likely to be living with a widowed father than with a widowed mother, suggesting that the loss of a mother is more distressing than the loss of a father [9].

Stigmatisation may be associated with adverse mental health. In orphans in Zimbabwe, stigmatisation was common and was based on orphan status or poverty rather than being associated with HIV/AIDS [70]. This was probably due to reluctance to state publicly that an individual died of AIDS; the same observation was made in Uganda [88]. In Zambia, 82% of those caring for children noted changes in behaviour during illness of a parent. Parents noted that children became worried, sad, tried to help in the home and stopped playing to stay nearby. Children were more likely to become solitary, appear miserable or distressed and be

fearful of new situations, compared to control children. There were no differences in externalised behaviour changes [47]. Changes were noted in self-esteem but not in sociability. Orphans exhibit internalised behaviour changes such as depression, anxiety and low self-esteem, rather than acting out and sociopathic behaviour such as stealing, truancy, aggression and running away [89] [90]. Internalised behaviour change is less likely to be noticed than externalised reactions and can easily be overlooked. In view of the possible link between childhood bereavement and later adult depressive illness, it is important to set up long-term studies and observe the mental health of children especially those experiencing multiple bereavements [91].

Vulnerability

There is need to understand the circumstances in which children affected by HIV/AIDS are vulnerable to HIV infection so that targeted interventions can be established. Failure to prevent HIV infection in this increasingly large group has implications for future generations. Children who end up on the streets have a particularly high risk of HIV infection [92]. Most street children in Accra, Ghana were sexually active and had their first sexual experience on the streets and with prostitutes; most had misconceptions about HIV/AIDS and were doing little to protect themselves from contracting HIV [93]. Though a considerable literature exists on the vulnerability of street children to HIV/AIDS and other sexually transmitted infections, there is a striking lack of research on the prevalence and circumstances surrounding vulnerability of orphans. Social, economic and psychological impacts of HIV/AIDS on orphans increase their vulnerability to HIV infection through early onset of sexual activity, commercial sex and sexual abuse. In Uganda, sexual debut occurred earlier in orphans than non-orphans; by age 12, 30% of orphan girls were sexually active rising to 85% by age 18. The reasons for becoming sexually active included economic need, peer pressure, discovery, lack of parental supervision and rape by strangers, relatives and teachers [94]. Although most orphans were aware of the existence of HIV/AIDS, few knew how to protect themselves [95]. When orphaned adolescents or adults become ill, they will have no mothers they can turn to for home care during terminal illness; after orphaned parents have died, there are no grandmothers available to look after their children, so-called "grand-orphans". Programmes which support and supervise orphans may be effective in reducing vulnerability and in protecting them from HIV infection. Perhaps nowhere is the imperative to link the provision of care and support activities to HIV prevention seen more clearly than with orphaned children [96].

Research partnerships

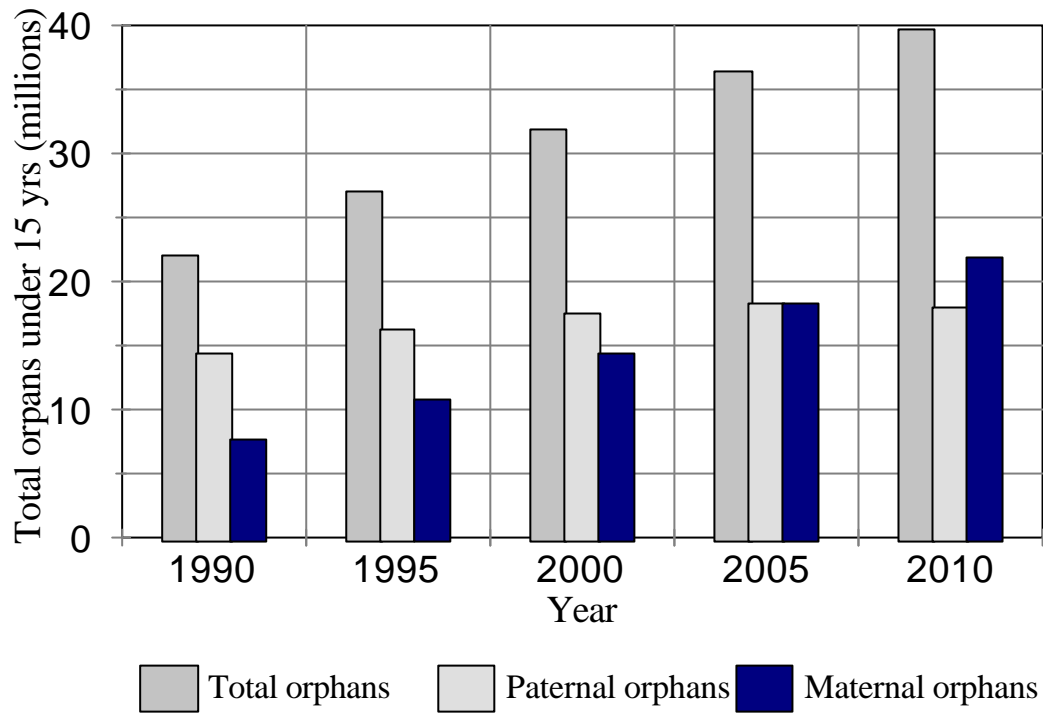
A cause for concern is that in spite of the considerable amount of activity being carried out by community groups throughout Africa to support children affected by HIV/AIDS, there is lack of data and limited study of many key issues. Research agendas have been developed to guide practitioners and policy makers responding to the plight of children affected by HIV/AIDS [2]. Agencies involved in research frequently fail to conduct studies in partnership with children, affected communities and implementing agencies such as community-based and non-governmental organisations. More such partnerships are needed. These are mutually beneficial, helping community-based programmes to answer questions of concern to their communities while enabling agencies to gain a better understanding of community coping mechanisms.

Acknowledgement

We wish to thank Tim Brown for his useful comments on earlier drafts of this paper.

[Appeared on page S276 in the original.]

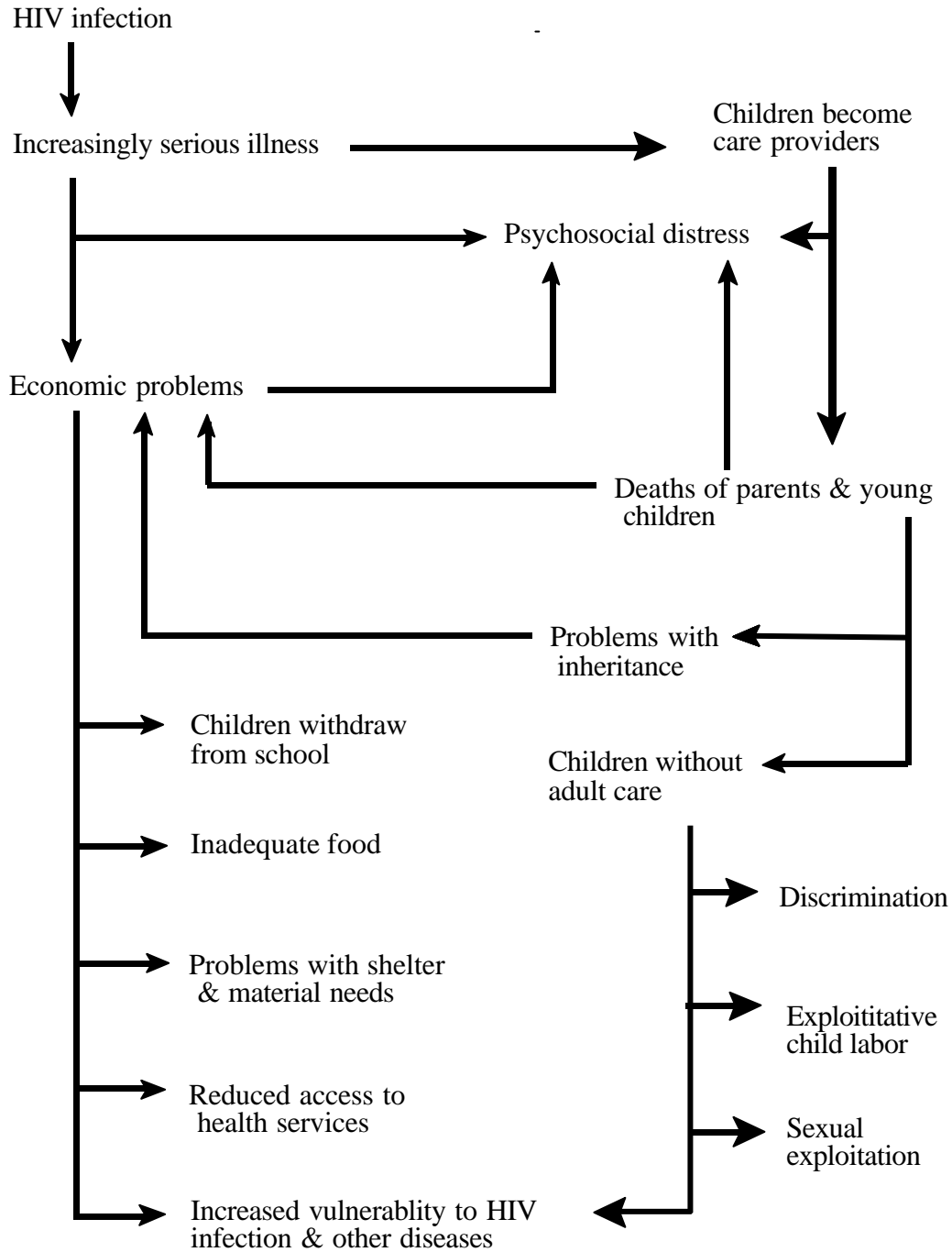
Fig. 1 Cumulative orphan estimates for 19 African countries, 1990-2010 (maternal orphans



includes children who have lost their mothers or both parents) [28].

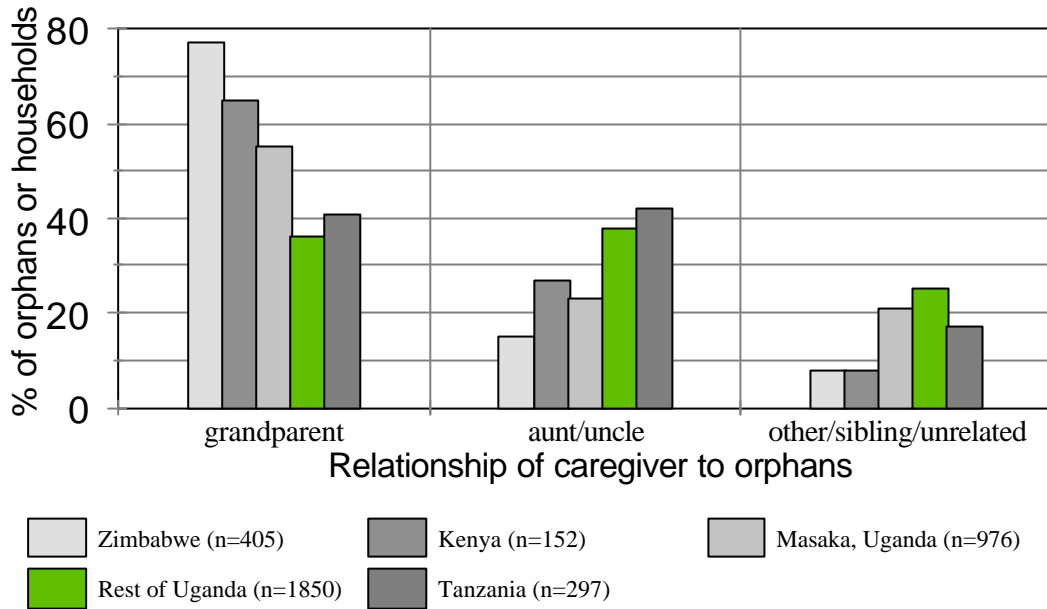
[Appeared on page S278 in the original.]

Fig.2: Problems among children and families affected by HIV/AIDS.



[Appeared on page S279 in the original.]

Fig 3. Relationship of caregiver to orphans in four countries [7, 16, 18, 38, 56].



- 1.UNAIDS. *AIDS epidemic update*. Geneva: UNAIDS; 1999.
- 2.Levine C, Foster G. *The White Oak Report: Building International Support for Children Affected by AIDS*. New York: The Orphan Project; 2000.
- 3.Foster G. **Orphans**. *AIDS Care* 1997, **9**:82-87.
- 4.Ainsworth M, Over M. *The Economic Impact of AIDS: Shocks, Responses and Outcomes*. Technical Working Paper No. 1. The World Bank Africa Technical Department, Population, Health and Nutrition Division; 1992.
- 5.Back, C, Michaels, D, Levine C. **A comparison of definitions of HIV/AIDS orphans and implications for policy development**. *XI International Conference on AIDS*. Vancouver, July 1996 (abstract Th.D.4889).
- 6.Michaels S, Back S, Levine C. **Projections of AIDS orphans**. In *AIDS in the World, Vol II*. Edited by Mann J, Tarantola D. Oxford: Oxford University Press: 1996.
- 7.Saoke P, Mutemi R, Blair C. **Another song begins: children orphaned by AIDS**. In *AIDS in Kenya: Socio-economic Impact and Policy Implications*. USAID AIDSCAP/Family Health International, 1996:45-64.
- 8.World Bank. *Confronting AIDS: Public Priorities in a Global Epidemic*. New York: Oxford University Press; 1997.
- 9.Sengendo J, Nambi J. **The psychological effect of orphanhood: a study of orphans in Rakai district**. *Health Trans Rev* 1997, **7** (Suppl):105-124.
- 10.Semali I, Ainsworth. M. **The impact of adult deaths on the nutritional status and growth of young children**. *IXth International Conference on AIDS and STD in Africa*. Kampala, December 1995 (abstract MoD066).
- 11.United Nations. **Convention on the Rights of the Child**. GA Res 44/25, UN GAOR, 44th Session, 41st plenary meeting, Annex, UN Doc A/44/25, 1989.
- 12.Tarantola D, Gruskin S. **Children confronting HIV/AIDS: Charting the confluence of rights and health**. *Health & Human Rights* 1998, **3**:61-86.
- 13.Palloni A, Lee YJ. **Some aspects of the social context of HIV and its effects on women, children and families**. *Population Bulletin of the United Nations* 1992, **33**:64-87.
- 14.Brown T, Sittitrai, W. *The Impact of HIV on Children in Thailand*. Bangkok: Program on AIDS, Thai Red Cross Society; 1995.
- 15.UNAIDS. **Global orphan project, Boston & Brasilia estimates**. In *Children living in a world with AIDS media briefing*. Geneva: UNAIDS; June 1997.
- 16.Urassa M, Boerma T, Ng'weshemi JZL *et al*. **Orphanhood, child fostering and the AIDS epidemic in rural Tanzania**. *Health Trans Rev* 1997, **7** (Suppl 2):141-153.
- 17.USAID / UNICEF / SIDA / Study Fund. *Situation Analysis of Orphans in Zambia 1999: Summary Report*, (Draft). Joint USAID / UNICEF / SIDA / Study Fund Project, 1999.
- 18.Foster G, Shakespeare R, Chinemana F *et al*. **Orphan prevalence and extended family care in a peri-urban community in Zimbabwe**, *AIDS Care* 1995, **7**:3-17.
- 19.Webb D. **Children in especially difficult circumstances in Zambia: a situation analysis**. *SafAIDS News* 1996, **4**:1 2-6.

20. Hunter S. **Orphans as a window on the AIDS epidemic in sub-Saharan Africa: initial results and implications of a study in Uganda.** *Soc Sci Med* 1990, **31**:681-690.
21. Dunn A, Hunter S, Nabongo C *et al.* *Enumeration and Needs Assessment of Orphans in Uganda: Survey Report.* Kampala: Save the Children Fund (UK) & Makerere University, 1991.
22. Ewbank D. *Age Misreporting and Age Selective Under-enumeration: Sources, Patterns and Consequences for Demographic Analysis: Report Nr 4.* Washington DC: National Academy Press; 1981.
23. McKerrow N. *Responses to Orphaned Children.* Lusaka: UNICEF; 1996.
24. Haworth A. *A Study of the Effects of AIDS upon Children in 116 Zambian Families.* Lusaka: University of Zambia; 1991.
25. Kamali A, Seeley JA, Nunn AJ *et al.* **The orphan problem: experience of a sub-Saharan Africa rural population in the AIDS epidemic.** *AIDS Care* 1996, **8**:509-515.
26. Gregson S, Zaba B, Garnett GP. **Low fertility in women with HIV and the impact of the epidemic on orphanhood and early childhood mortality in sub-Saharan Africa.** *AIDS* 1999, **13** (suppl A):S249-S257.
27. Gregson S, Garnett GP, Anderson, R. **Assessing the potential impact of the HIV-1 epidemic on orphanhood and the demographic structure of populations in sub-Saharan Africa.** *Population Studies* 1994, **48**:435-438.
28. Hunter S, Williamson J. *Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS.* Washington: USAID; 1998.
29. Gregson S, Garnett G, Shakespeare R, Foster G & Anderson R. **Determinants of the demographic impact of HIV-1 in sub-Saharan Africa: the effect of a shorter mean incubation period on trends in orphanhood.** *Health Trans Rev* 1994. **4** (Suppl):65-92.
30. Donahue J. *Community-based economic support for households affected by HIV/AIDS. Discussion papers on HIV/AIDS care and support No. 6.* Arlington, VA: Health Technical Services (HTS) Project for USAID, June 1998.
31. Tibaijuka AK. **AIDS and the economic welfare in peasant agriculture: Case studies from Kagabiro Village, Kagera Region, Tanzania.** *World Development* 1997, **25**(6).
32. Drew RS, Makufa C & Foster G. **Strategies for providing care and support to children orphaned by AIDS.** *AIDS Care* 1998, **10** (Suppl):S9-S15.
33. Ankrah EM. **The impact of HIV/AIDS on the family and other significant relationships: the African clan revisited.** *AIDS Care* 1993, **5**:5-22.
34. Ntozi JPM. **AIDS morbidity and the role of the family in patient care in Uganda.** *Health Trans Rev* 1997, **7** (Suppl):1-22.
35. McDaniel A, Zulu E. **Mothers, fathers and children: regional patterns in child-parent residence in sub-Saharan Africa.** *African Population Studies* 1996, **11**:1-28.
36. Bledsoe C. **Children are like bamboo trees: potentiality and reproduction in sub-Saharan Africa.** In *population, Economic Development and the Environment.* Edited by Kiessling K, Landberg H. Oxford: Oxford University Press; 1994;105-138.
37. Aspaas HR **AIDS and orphans in Uganda: a geographical and gender interpretation of household resources.** *The Socio-Demographic Impact of AIDS in Africa Conference.* Durban: IUSSP; February 1997.

38. Hunter S, Kaijage F, Maack P *et al.* **Using rapid research to develop a national strategy to assist families affected by AIDS in Tanzania.** *Health Trans Rev* 1997, **7** (Suppl):393-420.
39. Goody E. *Parenthood and social reproduction: Fostering and occupational roles in West Africa.* Cambridge, Cambridge University Press, 1982.
40. Caldwell JC. **The impact of the African AIDS epidemic.** *Health Trans Rev* 1997, **7** (Suppl 2):169-188.
41. Bandawe CR, Louw J. **The experience of family foster care in Malawi: A preliminary investigation.** *Child Welfare* 1997, **76**:535-547.
42. Foster G. **The capacity of the extended family for orphans in Africa.** *Psych Health & Med* 2000, **5**:55-62.
43. Rutayuga JBK. **Assistance to AIDS orphans within the family/kinship system and local institutions: a program for east Africa.** *AIDS Education and Prevention* 1992, **4** (Suppl):57-68.
44. Burman S. **Intergenerational family care: Legacy of the past, implications for the future.** *J Southern African Studies* 1996, **22**:585-598.
45. Robson E. **Invisible carers: young people in Zimbabwe's home-based health care.** *Area* 2000, **32**:59-69.
46. Drew RS, Foster G, Chitima J. **Cultural practices associated with death in the north Nyanga district of Zimbabwe.** *J Soc Devt in Africa* 1996, **11**:79-86.
47. Poulter C. *A psychological and physical needs profile of families living with HIV/AIDS in Lusaka, Zambia: Research Brief No. 2.* Lusaka: UNICEF; December 1997.
48. Mmari GJ. **Cultural practice as a function of HIV transmission.** *IXth International Conference on AIDS and STD in Africa*, Kampala, December 1995, (abstract WeC263).
49. School of Social Work, Harare. *Family coping and AIDS in Zimbabwe: a study.* Harare: Journal of Social Development in Africa; 1994.
50. Drew RS, Foster G, Chitima J. **Economic status and cultural practices of orphaned families in the North Nyanga District of Zimbabwe.** *IXth International Conference on AIDS and STD in Africa.* Kampala, December 1995 (abstract TuD678).
51. WHO/UNICEF *Action for Children Affected by AIDS.* New York: United Nations Children's Fund; 1994.
52. Carey F **AIDS and orphans.** *Africans on Africa*, 1995, **3**:18-22.
53. Foster G, Makufa C, Drew R *et al.* **Supporting children in need through a community-based orphan visiting programme.** *AIDS Care* 1996, **8**:389-403.
54. Beers C *et al.* **AIDS: the grandmother's burden.** In: *The Global Impact of AIDS.* Edited by Fleming AF *et al.* New York: Liss; 1988 171-174.
55. McKerrow N. *Responses to orphaned children: a review of the current situation in the Copperbelt and Southern Provinces of Zambia: Research Brief No. 3.* Lusaka: UNICEF; December 1997.
56. Ntozi JPM. **Effect of AIDS on children: the problems of orphans in Uganda.** *Health Trans Rev* 1997, **7** (Suppl): 23-40.
57. Foster G, Makufa C, Drew R *et al.* **Factors leading to the establishment of child-headed households: the case of Zimbabwe.** *Health Trans Rev* 1997, **7** (Suppl. 2):155-168.

- 58.Ntozi JPM. **Widowhood, remarriage and migration during the HIV/AIDS epidemic in Uganda.** *Health Trans Rev*, 1997, **7** (Suppl):125-144.
- 59.SafAIDS/CFU. *Orphans on farms: Who cares? An Exploratory Study into Fostering Orphaned Children on Commercial Farms in Zimbabwe.* Harare: Southern Africa AIDS Information Dissemination Service/ Commercial Farmers Union; 1996
60. Nalugoda F, Wawer MJ, Konde-Lule JK *et al.* **HIV infection in rural households, Rakai District, Uganda.** *Health Trans Rev*, 1997, **7** (Suppl. 2):127-140.
- 61.Over M. 1998 **Coping with the impact of AIDS.** *Finance and Development.*
- 62.Konde-Lule JK, Ssengonzi R, Wawer M,*et al.* **The HIV epidemic and orphanhood, Rakai District, Uganda.** *IX th International Conference on AIDS and STD in Africa.* Kampala, December 1995 (abstract TuD670).
- 63.Drew RS, Foster G, Chitima J. **Poverty - a major constraint in the community care of orphans: A study from the North Nyanga District of Zimbabwe.** *SafAIDS News*, 1996, **4**:14-16.
- 64.Foster G. **HIV and AIDS: Orphans and sexual vulnerability.** In *Sexually Exploited Children: Working to Protect and Heal.* Edited by Kilbourn P, McDermid M. Monrovia:MARC; 1998 216-232.
- 65.World Bank. *Lessons in designing safety nets PREM notes: Nr 2.* Washington DC: World Bank; 1998.
- 66.Rugalema G. **It is not only the loss of labour: HIV/AIDS, loss of household assets and household livelihood in Bukoba District, Tanzania.** In *AIDS and African Smallholder Agriculture.* Edited by Mutangadura G, Jackson H, Mukurazita D. Harare: Southern Africa AIDS Information Dissemination Service; 1999 41-52.
- 67.USAID. *USAID Responds to HIV/AIDS: Report on the Fiscal Years 1995 and 1996 HIV/AIDS Prevention Programmes of the United States Agency for International Development.* Washington, DC: United States Agency for International Development; 1996.
- 68.Barnett T, Blaikie P. *AIDS in Africa: its present and future impact.* London: Belhaven Press: 1992.
- 69.Foster G. **Responses in Zimbabwe to children affected by AIDS.** *SafAIDS News*, 2000, **8**:2-7.
- 70.Foster G, Makufa C, Drew R *et al.* **Perceptions of children and community members concerning the circumstances of orphans in rural Zimbabwe.** *AIDS Care* 1997, **9**:391-406.
- 71.Ledward A. *Age, Gender and Sexual Coercion: their Role in Creating Pathways of Vulnerability to HIV Infection.* Masters dissertation, M Sc Medical Anthropology. London: University of London; 1997.
- 72.Foster S. *ADZAM - a Study of Adult Diseases in Zambia - Final Report.* London: Overseas Development Agency; 1995.
- 73.Nampanya-Serpell N. *Children orphaned by HIV/AIDS in Zambia: risk factors from premature parental death and policy implications,* Ph D Dissertation. Baltimore: University of Maryland; 1998.
- 74.Haworth A, Mulenga M, Mwewa L *et al.* **On being an orphan on the streets of Lusaka, Zambia.** *Xth International Conference on AIDS and STD in Africa.* Abidjan, December 1997 (abstract C346).
- 75.Lungwangwa G, Macwan'gi M. *Street Children in Zambia: A Situation Analysis.* Lusaka: UNICEF; 1996.
- 76.Njoroge M; Ngugi E; Waweru A **Female sex workers (FSWs) AIDS orphans multi prolonged problem in Kenya: a case study.** *XII International Conference on AIDS.* Geneva, July 1998 (abstract 60116).

77. Muller O, Abbas N. **The impact of AIDS mortality on children's education in Kampala Uganda.** *AIDS Care* 1990, **2**:77-80.
78. Rossi MM, Reijer P. **Prevalence of orphans and their education status.** Research report, 1995. Quoted in *Situation Analysis of Orphans in Zambia, Volume 1, Bibliography: An Annotated Review of Literature Relevant to the Situation of Orphans & Vulnerable Children in Zambia*; Joint USAID / UNICEF / SIDA / Study Fund Project; 1999.
79. Conroy R, Tomkins A, Landsdown R, Elmore-Meehan M. **Identifying emerging needs among AIDS orphans in Kenya.** Annual Scientific Review, University of Nairobi, January 2000.
80. Ware H **Effects of maternal education, women's roles and child care on child mortality.** *Pop Dev Rev* 1984, **10** (Suppl):191-214.
81. Oni JB. **Fostered children's perception of their health care and illness treatment in Ekita Yoruba households, Nigeria.** *Health Trans Rev* 1995, **5**:21-34.
82. Bledsoe CH, Ewbank DC, Isiugo-Abanihe UC. **The effect of child fostering on feeding practices and access to health services in rural Sierra Leone.** *Soc Sci Med* 1988, **27**:627-636.
83. Foster G. **Today's children - challenges to child health promotion in countries with severe AIDS epidemics.** *AIDS Care* 1998, **10** (Suppl. 1): S17-S23.
84. Ryder RW, Kamenga M, Nkusu M *et al.* **AIDS orphans in Kinshasa, Zaire: incidence and socio-economic consequences.** *AIDS* 1994, **8**:673-679.
85. Hunter SS, Bulirwa E, Kisseka E **AIDS and agricultural production: report of a land utilisation survey, Masaka and Rakai Districts of Uganda.** In *Land Use Policy* 1993, 241-258.
86. Nduati RW, Muita JW, Olenja *et al.* **A survey of orphaned children in Kibera Urban Slum, Nairobi.** *IXth International Conference on AIDS.* Berlin, July 1993 (abstract WS-D26-4).
87. Ankrah EM. **AIDS: A research problematic.** *Soc Sci Med* 1989, **293**:265-279.
88. Naerland V *AIDS-learning to be more helpful.* Kampala: Redd Barna; 1993.
89. Kirya SK. **AIDS-related parental death and its effect on orphaned children's self-esteem and sociability at school.** *XI International Conference on AIDS.* Vancouver, July 1996 (abstract Th.D. 4871).
90. Forsyth BWC, Damour L, Nagler S *et al.* **The psychological effects of parental human immunodeficiency virus infection on uninfected children.** *Arch Pediatr Adolesc Med* 1996, **150**:1015-1020.
91. Saler L, Skolnick N. **Childhood parental death and depression in adulthood: roles of surviving parent and family environment.** *Am J Orthopsychiatr* 1992, **62**:504-516.
92. Richter LM, Swart-Kruger J. **AIDS-risk among street children and youth: Implications for intervention.** *S Afr J Psych*, 1995, **25**:31-38.
93. Anarfi J. **Vulnerability to sexually transmitted disease: street children in Accra.** *Health Trans Rev* 1997, **7** (Suppl): 281-306.
94. Sharpe U, Ssentongo R, Ssenyonga A *et al.* **Orphans sexual behaviour in Masaka diocese, Uganda., IXth International Conference on AIDS.** Berlin, July 1993 (abstract WS-D26-5).
95. Ministry of Labour and Social Affairs and UNICEF (Uganda). *Operational Research on the Situation of Orphans within Family and Community Contexts in Uganda.* Kampala: Ministry of Labour and Social Affairs and UNICEF; 1993.

96.Schietinger H. *Psychosocial Support for People Living with HIV/AIDS: Discussion Papers on HIV/AIDS Care and Support No. 5*. Arlington, VA: Health Technical Services (HTS) Project for USAID, June 1998.