

Psychological distress among AIDS orphans in rural Uganda

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Abstract

More than 11 million children under 15 years in sub-Saharan Africa have lost at least one parent to AIDS. In Uganda, about 2 million children are orphans, with one or both parents dead. The objective of this study was to investigate the psychosocial consequences of AIDS orphanhood in a rural district in Uganda and to identify potential areas for future interventions. The study was conducted in a randomly selected sub-county in Bushenyi District in Uganda. The study population consisted of 123 children aged 11–15 years whose parents (one or both) were reported to have died from AIDS and 110 children of similar age and gender living in intact households in the same neighbourhood. Symptoms of psychological distress were assessed using the Beck Youth Inventories of Emotional and Social Impairment (BYI). The standardized interview also included questions concerning current and past living conditions. A multivariate analysis of factors with possible relevance for BYI outcome showed that orphan status was the only significant outcome predictor. Orphans had greater risk (vs. non-orphans) for higher levels of anxiety (odds ratios (OR) = 6.4), depression (OR = 6.6), and anger (OR = 5.1). Furthermore, orphans had significantly higher scores than non-orphans on individual items in the Beck Youth Depression Inventory that are regarded as particularly “sensitive” to the possible presence of a depressive disorder, i.e. vegetative symptoms, feelings of hopelessness, and suicidal ideation. High levels of psychological distress found in AIDS orphans suggest that material support alone is not sufficient for these children.

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Introduction

Although HIV most often infects adults of reproductive age, the illness has important consequences for younger family members dependent on these adults for parental support. In sub-Saharan Africa, more than 11 million children under the age of 15 have lost at least one parent to AIDS, representing one-third of the total number of children who have been orphaned world

wide. More than half of those orphaned by AIDS in sub-Saharan Africa are between the ages of 10 and 15. The orphan crisis in sub-Saharan Africa is expected to increase dramatically within the coming years. By 2010, there will be approximately 20 million children in sub-Saharan Africa who have lost at least one parent to AIDS (Bhargava & Bigombe, 2003; UNAIDS, 2003).

In an estimated total population of 23 million, 1.05 million people living in Uganda are now estimated to have HIV, and about 120,000 have already developed AIDS. Nearly 80% of those infected with HIV are between the ages of 15 and 45 years. In Uganda, about 2 million children under the age of 18 years are orphans,

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with one or both parents dead. These children experience orphanhood at an age when parental guidance and socialization is most desirable (Uganda AIDS Commission, 2003). Little is known about the psychosocial consequences of AIDS orphanhood, in Uganda or in other low-income countries. Concerns about the socio-economic impact of AIDS on children in low-income countries have overshadowed the psychological impact, in so far as physiological and safety needs may seem to require more immediate attention than psychosocial problems. Nevertheless, due to the severity of the epidemic in Africa, many African children face recurrent losses among family members and guardians, as well as the loss of familiar surroundings and schooling. Thus, the psychological impact may well be recurrent also (Makame, Ani, & Grantham-McGregor, 2002).

The experience of loss and bereavement is generally difficult for young children (Siegel & Gorey, 1994), with psychological reactions developing sometimes months or years following these events (Goodman, 2001). Children's mourning behaviour tends to fluctuate, making it difficult for adoptive parents and teachers to recognize symptoms and to provide appropriate support (Foster, 2002). Psychological well-being is, nevertheless, a prerequisite for sustainable programs seeking to provide material and educational support to AIDS orphans. Interrupted schooling may have long-term effects on household poverty and may increase the risk for HIV infection (Gilborn, 2002). Also, although the extended family remains the principle orphan-care unit, some relatives may exploit the children's labour and fail to meet their educational and medical needs (Bedri, Kebede, & Negassa, 1995; Foster et al., 1995). Thus, the growing magnitude of AIDS orphanhood in Africa has implications for current and future mental health.

Despite the need for a comprehensive assessment of these children's vulnerability, previous studies of AIDS orphans in Uganda/East Africa have primarily focused upon orphans' living circumstances, rather than upon psychological health (Foster, 2002). One study conducted in Zimbabwe did however show that orphans have a number of emotional and behavioural concerns, including stigmatization, exploitation, and problems at school (Foster, Makufa, Drew, Mashumba, & Kambeu, 1997). Sengendo and Nambi's study in Uganda (1997) found that children confronted with an ill parent felt sad and helpless, and upon adoption, many felt angry and depressed. Likewise, Makame et al. (2002) found higher levels of negative mood and pessimism in AIDS orphans compared to non-orphans, utilizing selected items from the Beck Depression Inventory for Adults (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

The overall pattern of results across studies indicates that AIDS orphanhood may be accompanied by an increased risk for the development of depressive symptoms. Although symptoms of depression, guilt,

and anger are part of the normal bereavement process, bereavement is especially complicated when a child loses a parent in AIDS (Siegel & Gorey, 1994). AIDS is a stigmatising disorder, and discussion of the illness is often avoided. Moreover, a large number of AIDS orphans lose more than one family member to AIDS, and children may even themselves worry about becoming ill. No previous study has assessed AIDS orphans' psychological status using an instrument covering a broad range of symptoms and one that is developed specifically for use in children.

The aim of the present study was to conduct a comprehensive assessment of the current psychological status of AIDS orphans using an instrument developed for children, the Beck Youth Inventories of Emotional and Social Impairment (BYI) (Beck, Beck, & Jolly, 2001). The study concerns children within a restricted age range (11–15), i.e. that corresponding to middle childhood. Orphans who are younger than 11 may not be able to express their feelings as well as older orphans, and orphans who are older than 15 might face additional challenges, due to the onset of sexual activity and the risk of HIV infection. Most estimates of AIDS orphanhood concern children under 15 years old (Foster & Williamson, 2000). We hypothesized that orphans would have lower self-esteem and higher levels of psychological distress than non-orphans, controlling for other factors such as low socioeconomic status.

A secondary aim of the study was to identify background factors related to current symptom levels that might potentially be targeted in future intervention programs for orphans. We hypothesized that orphans with additional stressors, e.g. AIDS mortality among other relatives, increased household burdens, perceived neglect, or poor communication with elders, would have more symptoms of psychological distress than orphans without such stressors (Siegel & Gorey, 1994; Siegel, Mesagno, & Christ, 1990).

Methodology

Study area and sample

The study was conducted in Bugongi sub-county in Bushenyi District. Bushenyi is a district that is generally representative of districts affected by the HIV/AIDS epidemic in Uganda and has a current HIV prevalence of about 6.2%. The district is located in the south-western part of the country, is approximately 5396 km², and has a population of 738,355. The main language spoken is Runyankore, and the main source of income is subsistence farming (Mugaju, 1999). The study population consisted of 123 children between the ages of 11–15 years whose parents were reported to have died from AIDS and 110 children of similar age (± 1 year) and

gender who were living with both their parents and in the same neighbourhood as the index children. An “orphan” was defined as a child having one or both parents dead due to AIDS.

Study design and data collection

Measures

The Beck Youth Inventories (Beck et al., 2001) were chosen for the assessment of psychological distress, because they are particularly suitable for use in younger children as young as 7 years. It was developed as a self-report instrument, providing a systematic assessment across five inventories, i.e. Self-concept, Anxiety, Depression, Anger, and Disruptive behaviour, respectively. The inventories include items that represent children's automatic thoughts, as well as emotional, behavioural, physiological, and cognitive symptoms. The BYI is not a diagnostic instrument as such, but is widely used as a diagnostic aid in clinical settings, and may help clinicians determine, for example, whether a child with repeated complaints of abdominal pain might instead be suffering from a depression. The BYI has been used in a variety of clinical and non-clinical settings, and its reliability and validity has been shown to be robust (Beck et al., 2001). However, the BYI is a recent development (2001), and to date, no BYI studies have been conducted outside the United States. The BYI Depression Inventory is nevertheless similar to the Beck Depression Inventory for Adults, an instrument with extensive international usage (e.g. Richter, Werner, Heerlein, Kraus, & Sauer, 1998). Reliability was assessed in this study but not validity.

Each inventory (Self-concept, Anxiety, Depression, Anger, Disruptive behaviour, respectively) contains 20 statements concerning thoughts, feelings, and behaviours that represent that particular underlying dimension. “Self-concept” taps aspects concerning self-confidence and positive self-worth. “Anxiety” reflects children's specific worries, fears including loss of control, and physiological symptoms associated with anxiety. “Depression” reflects both the vegetative and behavioural symptoms of depression. “Anger” reflects unfair treatment, feelings of anger, and hatred. “Disruptive Behaviour” identifies thoughts and behaviours associated with conduct disorder and oppositional-defiant behaviour (Beck et al., 2001). For the purpose of this study, the BYI was administered in the form of a standardized interview. The children were asked how frequently the statements had been true for them during the previous 2 weeks, including the day of the interview. Each statement was answered either as never (0), sometimes (1), often (2), and always (3). A total raw score for each inventory was obtained by adding the scores obtained for each item (max. = 60). A mean summary score was also calculated for each inventory.

Higher scores indicate higher levels of that construct. The internal consistency (alpha) coefficients for the separate BYI inventories were satisfactory (0.70–0.85) except Disruptive Behaviour (alpha = 0.32). The separate inventories were also significantly intercorrelated, except Self-Concept which was not reliably related to Anxiety and Anger ($p = 0.08$ and 0.07 , respectively).

Symptoms of depression were of particular interest because they potentially have the most serious implications in terms of mental health. The severity of a depression may be particularly associated with the presence of vegetative symptoms, feelings of hopelessness, and suicidal ideation (Beck et al., 2001). Thus, four items from the Depression Inventory were selected a priori for further analysis (orphans vs. non-orphans): items #5 and #9 assessing vegetative symptoms (“Do you have trouble sleeping?”, “Does your stomach hurt?”), and items #4 and #20 indicating hopelessness and suicidal ideation (“Do you wish that you were dead?”, “Do you think that your life will be bad?”).

Information was also collected from all children on the following putative stressors: whether or not the children were required to carry out household chores, frequency of going to bed hungry, perceived differential treatment in the home, perceived ease of communication with parents or guardians, whether or not they headed households, loss of other close relatives to the AIDS epidemic, the children's own current health status, ease of access to health services (“taken to the clinic quickly when ill”), school attendance, and for orphans, whether or not they participated in support groups for orphans (“contact with other orphans”). In this part of Uganda, health is an important issue. Most people in this district live 5–10 km from a health facility with a community health worker. Thus, a child who is taken to a clinic quickly is regarded as receiving proper care by his parents or guardians, and conversely, delay can be a sign of neglect. Household size (including the participating child) was noted. Socioeconomic class (I, II, or III) was assigned on the basis of the parent's or guardian's occupation, according to Ugandan norms concerning occupational status. Groups I and II consisted of teachers, traders, nurses or any other professionals while group III consisted of peasants. Children who headed households were also allocated to group III. For the purpose of data analysis, age was stratified into two subcategories, i.e. 11–12 years vs. 13–15 years, based on the a priori notion that children within these groups would be more homogenous as to “maturity”, i.e. Ugandan children at the age 13 are more similar to 14- and 15-year olds than they are to 11- and 12-year olds.

The BYI plus the additional questions were translated from English to Runyankore by two native speakers working separately and independently, and then back-translated into English by two other Runyankore speakers. The two English translations were then

checked against each other by a native English speaker for inter-translator reliability and checked against the original English language inventory in order to ensure correctness. Differences between the two English translations were reconciled, and one final translation was used for the protocol. The interview protocol was pre-tested for one day with children of similar ages who were not part of the study in order to ensure that the questions were readily comprehensible.

Recruitment

One sub-county out of 29 in the District was randomly selected for the study site. It is located in the interior parts of the district and the socioeconomic standard (i.e. primarily subsistence farming) is typical of the district at large. All the parishes in the selected sub-county were involved in the study. Selection of the orphaned children was done using a multistage procedure. A list of children orphaned by AIDS in each parish was obtained from the respective local village community leaders. In these communities, the village leaders have the responsibility for keeping records of the village residents, including deaths. In villages of this size, information about serious illnesses and circumstances surrounding deaths are well known. The potential participants in the study were then selected randomly from these lists. These were then followed up in their homes or schools and interviews carried out. None of the potential participants refused to be interviewed, and all the parents and guardians consented to their children's participation in the study. Children were included in the study if their age was between 11 and 15, if they were known to have lost one or both of their parents to AIDS, and if they were aware that their parent(s) had died of AIDS. We excluded any child who clinically had AIDS based on physical observation, any child who resided with a sibling that had already been recruited in the study, and any child orphaned for reasons other than AIDS. Control children were selected by choosing a child from the next household who was of the same sex, having maximally a one-year age difference, and who was living with both parents. In this district where destabilizing wars and internal conflicts have been scarce, it is common for children between the ages of 7 and 16 to live with both parents. Between 3 and 6 households were visited in order to obtain an eligible control for every orphaned child in the study. The actual sero-status of the participating children was not known. It was assumed to be negative by absence of overt physical signs of AIDS and also by relying on the interviewer's clinical skills. All children completed the interview protocol and answered all the items in the Beck inventory.

Assessment procedures

All the interviews were conducted privately by the first author. A counselor was recruited as a research assistant and was readily available to ensure that professional and

sensitive contact was maintained with the children. Any child who became distressed was given immediate counseling by the counselor. Informed consent was at all times given by the guardians/parents on the morning of the day of the interview. The study was approved by the Research and Ethics Committee, Mbarara University, Uganda.

Data analysis and statistics

Independent sample *t*-tests were used for between-group comparisons of continuous variables, e.g. Beck summary scores. Fisher's exact tests were used for between-group comparisons of category variables, e.g. individual item analysis.

The relationship between Beck scores and predictor variables (e.g. orphanhood status) was examined in the total sample using multivariable logistic regression, with BYI scores as the outcome variable. BYI scores were dichotomized as "high" vs. "low" on the basis of median-split. Potential multi-collinearity among independent variables was first examined by generating a bivariate correlation matrix (Spearman rank) for those variables selected a priori as predictors of BYI outcome in the total sample: age group, sex, socioeconomic group, household size, orphanhood status, school attendance, currently performing chores, additional relatives died in AIDS, current health problems, and taken to the clinic quickly when ill. Multivariable logistic regression was then performed for each Beck inventory separately, with all independent variables entered simultaneously.

The relationship between predictor variables and outcome within the orphan group was examined in a similar manner. For this analysis, the independent variables were a priori selected for inclusion on the basis of the following criteria: (a) variables representing basic demographic information, i.e. age group, gender, socioeconomic status, and household size, and (b) variables representing aspects of the orphan's circumstances that could be targeted in an intervention. Variables such as "other relatives died in AIDS" were excluded. Variables in the second set were further restricted to those for which the minimum number of persons in any given category was 15.

Statistical analyses were conducted using SPSS for windows version 11.5 (SPSS, 2002). Statistical significance was a priori accepted at *p* value <0.01.

Results

Demographic and background characteristics

Table 1 shows the demographic and background characteristics of the 233 children included in the study. Orphans and non-orphans differed solely on household size, with orphans residing in households with fewer

Table 1
Demographic and background characteristics of orphans and non-orphans (number and % except where stated otherwise)

Characteristics	Orphans (n = 123)	Non-orphans (n = 110)
Age, mean years (SD)	13.9 (1.1)	13.7 (0.9)
<i>Gender</i>		
Males	73 (59.3)	72 (65.5)
Females	50 (40.7)	38 (34.5)
<i>Socio-economic group</i>		
Group I + II	29 (23.6)	25 (22.7)
Group III	94 (76.4)	85 (77.3)
Number of persons in household, mean (SD)	5.1 (2.0)	6.7 (1.4) ^a
<i>Attending school</i>		
Yes	118 (95.9)	103 (93.6)
No	5 (4.1)	7 (6.4)
<i>Death of parent</i>		
Father	65 (52.8)	—
Mother	13 (10.6)	—
Both	45 (36.6)	—
<i>Current household type</i>		
“Single” mother household	51 (41.5)	—
“Single” father household	5 (4.1)	—
Siblings-only household	15 (12.2)	—
Other adult relatives	50 (40.7)	—
New family	2 (1.6)	—
Both parents	—	110 (100.0)
<i>In contact with other orphans</i>		
Yes	93 (75.6)	—
No	30 (24.4)	—
<i>Other relatives (not parent) also died of AIDS</i>		
Yes	89 (72.4)	69 (62.7)
No	34 (27.6)	41 (37.3)

^aIndependent *t*-test, $t(219.5) = -7.1$, $p < 0.001$.

occupants, $p < 0.001$. Most orphans were living with their widowed mothers (41.5%) or with other relatives in an extended family setting, usually grandparents, aunts and uncles (40.7%). Eight of the orphans (6.5%) were taking care of their younger siblings, as heads of households.

Orphans and non-orphans perceptions of their living conditions

The results of the questions concerning living conditions are shown in Table 2. Orphans vs. non-orphans

Table 2
Orphans and non-orphans' perceptions of their circumstances and living conditions (number and %)

Items	Orphans (n = 123)	Non-orphans (n = 110)
<i>Performing household chores</i>		
Never, sometimes	44 (35.8)	36 (32.7)
Often, always	79 (64.2)	74 (67.3)
<i>To bed hungry</i>		
Never	96 (78.0)	98 (89.1)
Sometimes	21 (17.1)	12 (10.9)
Often	6 (4.9)	—
Always	—	—
<i>Contented with living conditions</i>		
Yes	88 (71.5)*	110 (100.0)
No	35 (28.5)	—
<i>Treated as other children in the home</i>		
Yes	100 (81.3)*	109 (99.1)
No	19 (15.4)	1 (0.9)
<i>Talk to parents/guardians</i>		
Yes	86 (71.0)	91 (82.7)
No	7 (5.8)	—
Sometimes	28 (23.1)	19 (17.3)
<i>Any health problems currently</i>		
Yes	33 (26.8)	29 (26.4)
No	90 (73.2)	81 (73.6)
<i>Taken to the clinic quickly when ill</i>		
Yes	76 (61.8)	79 (71.8)
No	47 (38.2)	31 (28.2)

*Orphans vs. non-orphans, yes vs. no, Fisher's exact, $p < 0.001$.

were less frequently “contented with their living conditions” and felt less frequently that they were “treated just like any of the children” in that home.

BYI raw scores for orphans and non-orphans

Table 3 shows the BYI summated scores for the orphan and non-orphaned children. Although no significant differences were found between the two groups on Self-Concept, the children differed significantly on all other Beck inventories. Further, separate analyses of the four items from the Depression Inventory yielded significant comparisons (orphans vs. non-orphans). Question #4, “Do you wish that you were dead?” was endorsed by 12.2% of the orphans vs. 2.7%

Table 3
Beck Youth Inventory means (SD) out of 60 for orphans and non-orphans

	Orphans (<i>n</i> = 123)	Non-orphans (<i>n</i> = 110)	<i>t</i> (df)
Self-concept	43.79 (6.7)	43.34 (4.6)	<i>t</i> (217.5) = 0.60
Anxiety	18.22 (9.4)	9.80 (4.2)	<i>t</i> (173.1) = 9.03, <i>p</i> < 0.001
Depression	14.73 (6.9)	8.55 (4.0)	<i>t</i> (200.0) = 8.50, <i>p</i> < 0.001
Anger	14.67 (6.3)	9.05 (3.9)	<i>t</i> (205.3) = 8.31, <i>p</i> < 0.001
Disruptive behaviour	5.09 (4.5)	3.72 (3.5)	<i>t</i> (226.9) = 2.61, <i>p</i> < 0.01

of the non-orphans ($p < 0.01$). Question #5, “Do you have trouble sleeping?” was endorsed by 18.7% of the orphans vs. 4.5% of the non-orphans ($p < 0.001$). Question #9, “Does your stomach hurt?” was endorsed by 34.4% of the orphans vs. 9.1% of the non-orphans ($p < 0.001$). Question #20 “Do you think that your life will be bad?” was endorsed by 32.5% of the orphans vs. 5.5% of the non-orphans ($p < 0.001$).

BYI outcome in relationship to background characteristics, total sample

No multi-collinearity was found among the independent variables selected for multivariable logistic regression analysis in the total sample (results not shown), indicating that all variables could be entered into the analysis. Table 4 shows the odds ratios (OR) for Beck outcomes in relation to these background characteristics. Odds ratios for high BYI outcomes are shown, e.g. high levels of self-concept, high levels of anxiety, etc. When all background factors were simultaneously adjusted for each other, orphanhood was the only variable significantly related to psychological distress, in that orphans (vs. non-orphans) were more likely to have above-median scores for Anxiety, Depression, and Anger.

BYI outcome in relation to background characteristics for the orphan group

No multi-collinearity was found among the independent variables selected for multivariable logistic regression analysis within the orphan group (results not shown), indicating that all variables could be entered into the analysis. Table 5 shows the OR for BYI outcome in relation to background characteristics and living circumstances within the orphan group. When all background variables were simultaneously adjusted for each other, the following relationships were obtained: Depression scores were higher in orphans living in smaller (1–5) vs. larger (6–11 persons) households; Self-concept scores were higher in orphans currently in contact with other orphans vs. orphans without such

contact; Anger scores were higher in orphans who were performing chores sometimes/always (vs. seldom/never).

Discussion

Levels of psychological distress among orphans

The current findings indicate that AIDS orphans had higher levels of psychological distress than non-orphans, when other factors were controlled. This is consistent with previous studies using other methods of measurement (Makame et al., 2002; Nyambedha, Wandibba, & Aagaard-Hansen, 2003; Sengendo & Nambi, 1997). Orphans had higher levels of anxiety and depression symptoms and more frequently endorsed those BYI items that are considered to be especially sensitive for the detection of depressive disorder in children (Beck et al., 2001). Because adolescent depression is associated with an increased risk of depression in adulthood, and in conjunction with conduct problems may be particularly associated with severe affective and non-affective outcomes (e.g. Fombonne, Wostear, Cooper, Harrington, & Rutter, 2001), these findings are noteworthy. Thus, although the provision of material support (i.e. food, shelter, and clothing) for orphans may be adequate, the current results indicate that additional efforts may be needed in order to ensure the psychological well-being of these orphans.

Factors related to increased levels of psychological distress within the orphan group

Few of the background factors hypothesized to be additional stressors within the orphan group predicted BYI outcome. Some subcategories had relatively few individuals, and larger samples may be required in order to study this adequately. Sample selection of the orphans was, however, done randomly and without knowledge of the specific family situation. Consequently, the background characteristics of these orphans are presumably generally representative of AIDS orphans residing in rural districts in Uganda. In the

Table 4
Multivariable-adjusted OR^a (95% confidence interval) for BYI outcome

Predictors	Self-concept	Anxiety	Depression	Anger	Disruptive behaviour
<i>Age group</i>					
11–12	2.3 (1.0–5.8)	1.0 (0.4–2.5)	1.9 (0.7–4.8)	1.7 (0.7–4.1)	1.3 (0.6–3.0)
13–15 ^b					
<i>Gender</i>					
Male	1.4 (0.8–2.4)	2.0 (1.1–3.9)	1.1 (0.6–2.1)	2.2 (1.2–4.2)	1.3 (0.7–2.3)
Female ^b					
<i>Socioeconomic group</i>					
III	0.7 (0.4–1.4)	1.4 (0.7–2.9)	0.8 (0.4–1.6)	0.4 (0.2–0.9)	0.7 (0.4–1.4)
I + II ^b					
<i>Household size</i>					
1–5	0.9 (0.5–1.7)	1.7 (0.9–3.3)	2.0 (1.0–3.8)	1.3 (0.7–2.5)	1.3 (0.7–2.4)
6–11 ^b					
<i>Orphan status</i>					
Yes	1.7 (1.0–3.1)	6.4 (3.4–12.1)*	6.6 (3.5–12.7)*	5.1 (2.7–9.6)*	1.6 (0.9–2.9)
No ^b					
<i>Attending school</i>					
Yes ^b					
No	0.3 (0.1–1.3)	0.7 (0.2–3.0)	1.5 (0.4–6.3)	3.3 (0.8–14.3)	1.0 (0.3–3.6)
<i>Currently doing chores</i>					
Yes	1.1 (0.6–1.9)	1.6 (0.8–3.1)	1.0 (0.5–2.0)	1.2 (0.6–2.2)	0.5 (0.3–1.0)
No ^b					
<i>Other relatives died in AIDS</i>					
Yes	0.9 (0.5–1.7)	1.1 (0.6–2.2)	2.2 (1.1–4.4)	2.2 (1.1–4.3)	1.0 (0.5–1.7)
No ^b					
<i>Current health problems</i>					
Yes	0.8 (0.4–1.5)	1.0 (0.5–2.0)	1.2 (0.6–2.5)	0.7 (0.3–1.4)	0.9 (0.5–1.7)
No ^b					
<i>Taken to clinic quickly when ill</i>					
Yes ^b					
No	0.6 (0.3–1.1)	1.6 (0.8–3.1)	2.3 (1.2–4.7)	1.6 (0.8–3.0)	1.2 (0.6–2.1)

* $p < 0.001$.

^aMultivariable logistic regression, OR are adjusted for all independent variables simultaneously.

^bReference group.

current sample, loss of the father alone was more common, albeit no differences in BYI scores were found between orphans who had lost a mother vs. those who had lost a father (data not shown). Prevalence of AIDS orphanhood due to father's death alone (6.3%) and mother's death alone (2.8%) among children under 15 years in Masaka produced similar findings (Kamali et al., 1996).

Within the orphan group, higher scores on the Depression inventory were related to smaller household size. The extended family system is an important source of solace and care giving in this setting. Smaller families may not be able to provide emotional support, especially if adults are grieving or over-burdened with having to care for other ill relatives. Such factors may play an

important role in determining the extent to which children successfully cope with bereavement (Siegel & Gorey, 1994).

Within the orphan group, access to support groups (i.e. contact with other orphans) was predictive of higher levels of self-concept. Support groups for orphans may diminish feelings of stigmatization and shame. However, contact with other orphans was not associated with lower levels of anxiety and depression, contrary to expectation.

Potential areas for future intervention programs

One of the purposes of this study was to identify potential needs and problem areas that could be targeted

Table 5
Multivariable-adjusted OR^a (95% confidence interval) for BYI outcome on orphans (*n* = 123)

Predictors	Self-concept	Anxiety	Depression	Anger	Disruptive behaviour
<i>Age group</i>					
11–12	5.8 (1.1–31.9)	1.1 (0.3–4.1)	0.5 (0.2–2.0)	0.6 (0.2–1.9)	0.8 (0.3–2.7)
13–15 ^b	1.0	1.0	1.0	1.0	1.0
<i>Gender</i>					
Male	0.9 (0.4–2.4)	2.1 (0.8–5.1)	0.8 (0.3–2.5)	2.2 (0.9–5.4)	1.6 (0.7–3.6)
Female ^b					
<i>Socioeconomic group</i>					
III	0.5 (0.2–1.3)	1.0 (0.4–2.8)	0.9 (0.3–2.5)	0.3 (0.1–1.0)	0.7 (0.3–1.7)
I + II ^b					
<i>Household size</i>					
1–5	0.5 (0.2–1.3)	2.1 (0.8–5.2)	3.8* (1.5–9.9)	1.6 (0.7–4.2)	2.0 (0.9–4.7)
6–11 ^b					
<i>Living with siblings only</i>					
Yes	2.8 (0.5–15.2)	2.2 (0.4–11.8)	1.4 (0.3–7.1)	1.7 (0.4–7.8)	0.2 (0.1–0.9)
No ^b					
<i>Current health problems</i>					
Yes	0.5 (0.2–1.5)	1.2 (0.4–3.6)	2.4 (0.7–7.7)	1.4 (0.5–4.1)	0.6 (0.2–1.7)
No ^b					
<i>Currently doing chores</i>					
Yes	0.9 (0.4–2.4)	1.3 (0.5–3.3)	2.9 (1.1–7.6)	4.4* (1.7–11.7)	0.9 (0.4–2.1)
No ^b					
<i>Treated as other children</i>					
Yes ^b					
No	1.1 (0.3–4.2)	1.8 (0.4–7.7)	4.1 (0.7–22.8)	6.0 (1.0–34.2)	3.1 (0.8–11.8)
<i>Taken to clinic quickly</i>					
Yes ^b					
No	0.9 (0.3–2.4)	2.0 (0.7–5.8)	3.1 (1.0–9.6)	0.8 (0.3–2.4)	1.2 (0.5–2.9)
<i>Contact with other orphans</i>					
Yes ^b					
No	0.1* (0.1–0.4)	0.7 (0.2–2.2)	0.7 (0.2–2.5)	3.0 (0.9–9.9)	0.7 (0.3–2.0)

* $p < 0.01$.

^aMultivariable logistic regression, OR are adjusted for all independent variables simultaneously.

^bReference group.

for intervention at the district level. The current data indicate that one potential target area may be additional support to small families, in order to ensure that children in such families receive needed social and emotional support. More importantly, the data suggest that access to mental health services may be an increasing necessity for all orphans, regardless of family situation. Unfortunately, mental health services are still not a priority within the health care services in Uganda, as is the case in most low-income countries, and the number of health workers specializing in mental health is still quite few. A potential strategy for providing some type of mental health care for children, and particularly for AIDS orphans, involves training of psychiatric

nurses, as in South Africa (Pillay & Lockhat, 1997). Community awareness could be increased by including issues concerning AIDS orphans on the agenda of village meetings, religious sermons, and at other community gatherings.

Methodological concerns and limitations

Little is known about the reliability and the validity of the BYI when used in an African setting, though internal reliability of four inventories was satisfactory. It was not possible to conduct an external validation of the BYI instrument, as no other sources of information about these children were available. The low reliability shown

on the Disruptive Behaviour Inventory may be due to the administration method employed; children may have been more reluctant to report poor conduct in a face-to-face interview than they would in an anonymous self-report. Also, this inventory was also administered last, and some children may have had concentration difficulties at this time.

A limitation in the current study is that HIV serology prior to parental death was not available. Most deaths in low-income countries do not occur while under medical care and HIV serology prior to death is available in only a limited number of cases. Identification of children regarded as AIDS orphans thus relied heavily on the local community's knowledge of the signs and symptoms characteristic of the terminal stages of the disease. Reports from the local leaders served as the primary source of information about the cause of parental death, and information was corroborated by the orphaned children. It was also unknown whether any of the control children's parents were HIV positive, and also whether the children were aware of this. However, any such potential illness in control children's parents would have had the effect of attenuating the actual differences that were obtained between the orphans and non-orphans.

Also, the actual date of parental death and hence the duration of orphanhood could not be ascertained. Thus, at the time of the interview, children were potentially in varying phases of the bereavement process. Nevertheless, despite this potential heterogeneity within the orphan group, levels of anxiety, depression, and anger were high in comparison to the non-orphans. Also, although it is not known how long ago the parents had died, the loss appeared to be still fresh in their minds, insofar as 67.5% of the orphans reported that they still cried when they thought about their parents. It should be noted that the study was not designed to be able to detect whether the psychological distress associated with orphanhood was due to parental death per se, or parental death in AIDS. Although surprisingly little research has been done on this topic thus far, the stigma associated with the illness, the risk for recurrent losses and the risk for own infection would, in all likelihood, intensify the difficulties children generally encounter when confronted with parental death (Siegel & Gorey, 1994). Thus, due to the nature of the illness and the extent of the epidemic in Uganda, emotions normally associated with bereavement may become intensified in AIDS orphans.

Conclusions

Finally, as orphaned children approach adolescence, they join the ranks of the highest risk group for HIV infection in Africa. Young people (15–24 years) account

for 50% of the new HIV cases in high prevalence areas, with girls affected at younger ages. Orphans tend to begin sexual activity earlier than their peers and are especially vulnerable to coercive and transactional sex, unwanted pregnancy, and infection with HIV and other sexually transmitted infections (Gilborn, 2002). The double tragedy of parental-to-offspring transmission, whereby AIDS orphans themselves in turn are highly susceptible to HIV infection, could well emerge as a new "variant" of maternal-to-child transmission. Moreover, due to their increased vulnerability to transactional sex and prostitution, these innocent victims of the AIDS epidemic run the risk of spreading the epidemic further in the near future (Gilborn, 2002). Thus, the problems associated with AIDS orphanhood would appear to have increasingly far-reaching implications. Programs directed towards the sustainability of recovery from the AIDS epidemic may well need to consider the psychological well-being of AIDS orphans as one of their top priorities.

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References

- Beck, J. S., Beck, A. T., & Jolly, J. B. (2001). *Manual for the Beck Youth Inventories of emotional and social adjustment*. San Antonio, TX: The Psychological Corporation.
- Beck, AT., Ward, C. H., Mendelson, M., Mock, J., & Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry*, 4, 561–571.
- Bedri, A., Kebede, S., & Negassa, H. (1995). Sociodemographic profile of children affected by AIDS in Addis Ababa. *Ethiopia Medical Journal*, 33(4), 227–234.
- Bhargava, A., & Bigombe, B. (2003). Public policies and the orphans of AIDS in Africa. *British Medical Journal*, 326, 1387–1389.
- Fombonne, E., Wostear, G., Cooper, V., Harrington, R., & Rutter, M. (2001). The Maudsley long-term follow-up of child and adolescent depression. 1. Psychiatric outcomes in adulthood. *British Journal of Psychiatry*, 179, 210–217.
- Foster, G. (2002). Beyond education and food: psychosocial well-being of orphans in Africa. *Acta Paediatrica*, 91, 502–504.
- Foster, G., Makufa, C., Drew, R., Mashumba, S., & Kambue, S. (1997). Perceptions of children and community members concerning circumstances of orphans in rural Zimbabwe. *AIDS Care*, 9(4), 391–405.
- Foster, G., Shakespeare, R., Chinemana, F., Jackson, H., Gregson, S., & Mashumba, S. (1995). Orphan prevalence

- and extended family care in a peri-urban community in Zimbabwe. *AIDS Care*, 7(1), 3–17.
- Foster, G., & Williamson, J. (2000). A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS*, 14(Suppl. 3), S275–S284.
- Gilborn, L. Z. (2002). In the public eye—beyond our borders, the effects of HIV infection on children in Africa. *Western Journal of Medicine*, 176, 12–14.
- Goodman, R.F. (2001). *Children and grief: what they know, how they feel, how to help*. New York: University School of Medicine. <http://www.aboutourkids.org/>.
- Kamali, A., Seeley, J. A., Nunn, A. J., Kengeya-Kayondo, J. F., Ruberantwari, A., & Mulder, D. W. (1996). The orphan problem: experience of a sub-Saharan Africa rural population in the AIDS epidemic. *AIDS Care*, 8(5), 509–515.
- Makame, V., Ani, C., & Grantham-McGregor, S. (2002). Psychological well being of orphans in Dar El Salaam, Tanzania. *Acta Paediatrica*, 91, 459–465.
- Mugaju, J. (1999). District rural health systems: case studies of Bushenyi, Kisoro and Sembabule. In M. Kisubi, & J. Mugaju (Eds.), *Rural health providers in south-west Uganda* (pp. 119–140). Kampala: Fountain Publishers Ltd.
- Nyambedha, E. O., Wandibba, S., & Aagaard-Hansen, J. (2003). Changing patterns of orphan care due to the HIV epidemic in western Kenya. *Social Science & Medicine*, 57, 301–311.
- Pillay, A. L., & Lockhat, M. R. (1997). Developing community mental health services for children in South Africa. *Social Science & Medicine*, 45, 1493–1501.
- Richter, P., Werner, J., Heerlein, A., Kraus, A., & Sauer, H. (1998). On the validity of the Beck Depression Inventory. *Psychopathology*, 31, 160–168.
- Sengendo, J., & Nambi, J. (1997). The psychological effect of orphanhood: a study of orphans in Rakai district. *Health Transit Review*, 7(Suppl.), 105–124.
- Siegel, K., & Gorey, K. (1994). Childhood bereavement due to parental death from acquired immunodeficiency syndrome. *Developmental and Behavioral Pediatrics*, 15, S66–S70.
- Siegel, K., Mesagno, F., & Christ, G. (1990). Parent guidance prevention program for bereaved Children. *American Journal of Orthopsychiatry*, 60, 168–175.
- SPSS. (2002). *SPSS 11.5 for windows*. Chicago: SPSS Inc.
- Uganda AIDS Commission. (2003). *The HIV/AIDS epidemic: prevalence and impact*. <http://www.aidsuganda.org/>.
- UNAIDS. (2003). *UNICEF fact sheet: children orphaned by AIDS in sub-Saharan Africa*. <http://www.unaids.org/html/>.