

Persisting mental health problems among AIDS-orphaned children in South Africa

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Background: By 2008, 12 million children in sub-Saharan Africa were orphaned by AIDS. Cross-sectional studies show psychological problems for AIDS-orphaned children, but until now no longitudinal study has explored enduring psychological effects of AIDS-orphanhood in the developing world. **Methods:** A 4-year longitudinal follow-up of AIDS-orphaned children with control groups of other-orphans and non-orphans. 1021 children ($M = 13.4$ years, 50% female, 98% isiXhosa-speaking) were interviewed in 2005 and followed up in 2009 with 71% retention (49% female, $M = 16.9$ years), in poor urban South African settlements. Children were interviewed using sociodemographic questionnaires and well-validated standardised scales for assessing depression, anxiety, and post-traumatic stress. Data were analysed using mixed-design ANOVA and backward-stepping regression. **Results:** AIDS-orphaned children showed higher depression, anxiety, and post-traumatic stress disorder (PTSD) scores in both 2005 and 2009 when compared with other-orphans and non-orphans. Backward-stepping regression, controlling for baseline mental health, and sociodemographic cofactors such as age, gender, and type of bereavement, revealed that being AIDS-orphaned in 2005 was associated with depression, anxiety, and PTSD scores in 2009. This was not the case for other-orphaned or non-orphaned children. Age interacted with orphan status, such that there was a steep rise in psychological distress in the AIDS-orphaned group, but no rise with age amongst other-orphans and non-orphans. **Conclusions:** Negative mental health outcomes amongst AIDS-orphaned children are maintained and worsen over a 4-year period. It is important that psychosocial support programmes are sustained, and focus on youth as well as young children. **Keywords:** HIV/AIDS, orphans, adolescents, depression, anxiety, post-traumatic stress.

Introduction

The HIV/AIDS epidemic continues to produce increasing numbers of orphans. UNAIDS estimates 12 million AIDS-orphaned children in sub-Saharan Africa, and 1.9 million in South Africa alone (UNAIDS, 2010). In the developing world, a number of cross-sectional studies have examined mental health impacts of AIDS-orphanhood, demonstrating negative psychological impacts, particularly on internalising problems such as depression and anxiety in sub-Saharan Africa (Bhargava, 2005; Cluver, Gardner, & Operario, 2007; Makame, Ani, & McGregor, 2002; Nyamukapa et al., 2008) and China (Fang et al., 2009). However, cross-sectional evidence may be insufficient to understand the impacts of AIDS-orphanhood.

Longitudinal community-based studies in the developed world demonstrate moderate increases in psychopathology throughout adolescence (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003), with increased exposure to environmental stressors (Copeland, Keeler, Angold, & Costello, 2007). Such stressors are especially pertinent in poor, urban South Africa, where children's distress is associated with high levels of violent crime and social instability

(Ward, Flisher, Zissis, Muller, & Lombard, 2001). In the developed world, theory and limited longitudinal evidence regarding children orphaned by non-AIDS causes suggest a 1–2 year period of intense grief, followed by (for most) a recovery to regular levels of mental health (Dowdney, 2000). However, we have almost no available evidence of long-term effects of AIDS-orphanhood in the developing world. Only two known longitudinal studies, both in the US, examine mental health amongst AIDS-orphaned children: in New Orleans ($n = 106$), AIDS-orphaned children showed more psychological problems than children of healthy parents 2 years post-bereavement (Pelton & Forehand, 2005). In New York, 73 AIDS-orphaned adolescents were compared to 138 with surviving, HIV-positive, parents. At 2-years post-bereavement, orphans showed more psychological problems (Rotheram-Borus, Lee, Lin, & Lester, 2004). However, we should be cautious about transferability of US-based studies of familial HIV/AIDS to sub-Saharan Africa's generalised epidemic, whilst heterosexual HIV-infection in the US is frequently associated with marginalised groups, substance use or partner incarceration (Mellins et al., 2009).

Thus, major gaps in our evidence remain. First, few studies include comparison groups of other-orphaned and non-orphaned children, despite cross-sectional evidence of higher psychological distress amongst

Conflict of interest statement: No conflicts declared.

AIDS-orphaned children than both these groups (Cluver et al., 2007). Second, to our knowledge, no longitudinal studies in the developing world examine enduring psychological impacts of AIDS-orphanhood.

Third, no known studies follow AIDS-bereaved children for more than 2 years. We know little about whether orphanhood-associated psychological distress is relatively short-term or whether it is lasting. We also lack knowledge regarding how AIDS-orphanhood predicts mental health trajectories over time compared to other groups – it is possible that multiple HIV/AIDS-related stressors are barriers to recovery from bereavement-related distress. Despite high population HIV-prevalence in South Africa, levels of stigma remain widespread and profound. This results in increased community stigma and bullying of orphaned children (Cluver & Orkin, 2009). Studies of HIV-infected mothers have shown high levels of depression linked to their diagnosis and AIDS-related illness, which may impact on children's mental health both directly and via reduced parenting capacity (Rochat et al., 2006). Familial AIDS often causes enduring household-level poverty, due to high medical bills, unemployment related to chronic illness, and multiple deaths (UNAIDS., 2008). Additionally, new evidence shows severe educational difficulties for children in AIDS-affected families, including school dropout due to financial constraints and reduced attendance and achievement due to caregiver illness (Cluver, Operario, Lane, & Kganaka, in press). Many of these stressors are chronic, and impact on multiple levels of children's lives.

Finally, most developing world studies have concentrated on orphaned *children* (aged 5–17), with no known research focusing on mental health impacts of AIDS-orphanhood during the transition into late adolescence and young adulthood.

This longitudinal study aims to address these research gaps: first, assessing whether psychological distress in 2005 has changed 4 years later amongst AIDS-orphaned, other-orphaned and non-orphaned children; second, testing whether any increase in psychological distress is greater for AIDS-orphaned children than other groups whilst controlling for sociodemographic covariates; and third, testing whether age interacts with orphanhood status in predicting psychological distress.¹

Methods

Participants

In 2005, 1025 children were interviewed in Xhosa-speaking peri-urban settlements around Cape Town. Sampling included household door-to-door visits in 10

settlements, 9 schools, 18 community organisations, and additional purposive recruitment of street-children and child-headed households, aiming to include important groups who are often excluded from surveys. The UN definition of orphanhood was used – i.e. loss of one or both parents among children up to age 18 (Skinner et al., 2006; UNAIDS., 2004); 425 children were AIDS-orphaned, 241 other-orphaned, and 278 non-orphaned. Eighty-one were excluded from analyses due to orphanhood by unknown causes. Controls were selected by alphabetical allocation from school registers, shelters, and matched by close locality (see Cluver et al. (2007) for further information on sampling procedures).

Four-year longitudinal follow-up achieved retention of 723 children (71%, 269 AIDS-orphaned, 228 other-orphaned, 180 non-orphaned, and 46 children excluded from analyses due to uncertainty of the orphanhood status); 477 children had moved homes, 111 had moved city or province, and 6 had died (excluding street-children). Follow-up challenges included high mobility amongst orphans – most lived in informal settlements with no administrative systems; demolition of one informal settlement from which 189 children had been recruited in 2005; and near-impossibility of tracing street-children due to exceptionally high mobility and mortality. 12 interviews were curtailed due to participants' substance inebriation or police raids. Thirty children were interviewed in external provinces, and three in prison.

Measures

Determining cause of parental death. Death certificates are unreliable sources regarding HIV/AIDS in South Africa, and clinical data is rarely available. Cause of parental death was therefore determined using the 'Verbal Autopsy' method based on child responses. This method has been validated in previous studies of adult mortality throughout Sub-Saharan Africa. In a South African validation study, sensitivity was 89%, specificity 93%, and positive predictive value 76% (Kahn, Tollman, Garenne, & Gear, 2000). Determination of AIDS-related parental death required a conservative threshold of three or more AIDS-defining illnesses (i.e. Kaposi's sarcoma or shingles), and in all cases of uncertain diagnoses, symptoms were reviewed independently by two medical practitioners. Where possible, child reports were corroborated by teachers, social workers, and surviving parents. Cases with unclear cause of death (such as 'bewitchment' or tuberculosis without other AIDS-related symptoms) were excluded from analyses (81 in 2005, 46 in 2009).

Sociodemographic information. Items included age, gender, ethnicity, household composition, internal migration (to/from Cape Town), formal/informal housing, and maternal/paternal/double orphanhood.

Outcome measures. Depression was measured using the Child Depression Inventory short form (CDI; Kovacs, 1992), which has comparable results with the full CDI, strong psychometric properties and is widely used in South Africa. Reliability at 2005 was $\alpha = .67$ and at 2009, $\alpha = .69$. Anxiety was measured using the Children's Manifest Anxiety Scale-Revised (Reynolds &

¹ This study was developed in consultation with the National Department of Social Development, Department of Basic Education and Department of Health of the South African government, in order to inform evidence-based policy for AIDS-orphaned children.

Richmond, 1978). The 28-item scale was reduced using factor analysis to 14 items, and showed reliability at both 2005 and 2009 of $\alpha = .80$. The scale has been used in South Africa (Wild, Flisher, Laas, & Robertson, 2006), with good reliability and validity. Post-traumatic stress was measured using the 'Child post-traumatic stress disorder (PTSD) Checklist' (Amaya-Jackson, Newman & Lipschitz, 2000). This 28-item scale measures DSM-IV symptomology in avoidance, numbing, hyperarousal, and reexperiencing, and has been used extensively in South Africa (Seedat, van Nood, Vythilingum, Stein, & Kamminer, 2000). Reliability at both 2005 and 2009 was $\alpha = .94$. The text-based checklist was accompanied by cartoons from the 'Levonn/Andile trauma scale' (Richters & Martinez, 1993), found accessible for Xhosa-speaking Cape adolescents (Ensink, Robertson, Zissis, & Leger, 1997). Overall questionnaire design was assisted by a 'Teen Advisory Group' of 14 AIDS-affected children. In weekend camps, children advised on item acceptability, interviewing methods, and co-designed questionnaires in the style of a teen magazine, including popular music stars, cartoons, and pictures.

Procedure

Ethical protocols were approved in 2005 and 2009 by Oxford University, the University of Cape Town and the Western Cape Education Department. Participation was voluntary, and informed consent was obtained from all participants and caregivers. Response rate was 99.7% in 2005, and 98.3% of those traced in 2009. With interviewers, participants completed 60 min self-report questionnaires. All interviewers were Xhosa-speaking social workers or community health workers, trained in working with AIDS-affected children. No incentives were provided, although participants received refreshments and certificates. Confidentiality was maintained, except where children were at risk of significant harm or requested assistance.

Analysis strategy

As a preliminary check, we noted any differences in baseline sociodemographic characteristics of children lost to follow-up. Data were then analysed in three stages. First, a series of mixed-design ANOVAs were conducted (for each psychological outcome) in order to examine changes in mental health across time for the three orphanhood groups. Mental health scores (depression, anxiety, and PTSD) obtained at the two time-points were entered as a within-subjects factor and orphanhood status was entered as a between-groups variable with three levels (AIDS-orphaned, other-orphaned, and nonorphaned). Second, in order to quantify the relative importance of orphanhood status (while controlling for baseline psychological and sociodemographic covariates) changes in the three mental health outcomes among orphanhood groups were compared. Using backward-stepping regression, the dependent variable was each domain of mental health in 2009; and its value in 2005 is included among potential predictors, where it takes account of initial differences among respondents. Handled in this way, panel data recognise that psychological distress is not a

single event but a process, an often-chronic condition which may be both self-perpetuating and modified by external circumstances. Orphanhood status categories were treated as dummy variables, taking nonorphanhood as the baseline. Third, potential interaction effects of age and orphanhood status were examined by introducing interaction terms into multivariate models.²

Results

Preliminary data check

Prior to analysis, we checked for differences between children lost and retained at follow-up. Those lost were more likely to be male [$\chi^2(1) = 4.18, p = .05$], older [$F(1, 1022) = 17.81, p < .001$], and living in informal (shack) housing [$\chi^2(1) = 6.24, p = .01$]. Moreover, they had higher depression [$F(1, 1022) = 26.52, p < .001$] and anxiety [$F(1, 1016) = 7.20, p = .01$] scores in 2005. Although follow-up of 71% was relatively high after 4 years for this highly mobile and at-risk population, results must be interpreted in light of the fact that some of the most vulnerable children were among those who had died or were unable to be traced.

The mean age of participants was 13.4 years in 2005 (range: 10–19 years) and 16.9 years in 2009 (range: 12–23 years). AIDS-orphaned children were older ($M1: 13.7, M2: 17.2$) than non-orphans ($M1: 13.0$ and $M2: 16.5$) but not older than other-orphans (Table 1). This was likely a result of the original sampling, in which controls were matched from the same school grade, whilst AIDS-orphaned children were more likely to be delayed in school than non-orphans; $\chi^2(1) = 18.2; p = .01$. There were no gender differences (approximately 50% female), ethnic composition (98% amaXhosa), or migration (40%–45% – Table 1). In 2005, orphans were more likely to live in smaller households [$F(1, 965) = 12.07, p = .001$] and in informal dwellings than non-orphans [$\chi^2(1) = 14.25; p < .001$]. We also examined differences between orphanhood types: at both times AIDS-orphaned children were approximately twice as likely to be maternally bereaved and to be doubly orphaned as other-orphans. Other-orphaned children were more likely to be paternally bereaved; 2005: $\chi^2(2) = 12.80; p = .002$; 2009: $\chi^2(2) = 10.24; p = .02$. In both 2005 [$F(1, 587) = 42.75, p < .001$] and 2009 [$F(1, 373) = 7.58, p = .01$] AIDS-orphaned children were older at first bereavement than other-orphans. Age at first orphanhood and time since orphanhood were not predictors of any mental health outcomes either at 2005 or 2009 (controlling for mental health at 2005 and sociodemographic cofactors).

²This had the additional benefit of addressing the issue of sample-weighting. It is recommended (Winship & Radbill, 1994) that sampling variables and their interactions with predictors be introduced in lieu of weighting; which was achieved here since orphanhood status was also the basis for sampling.

Table 1 Comparison between groups on demographic variables, 2005 and 2009 (standard deviations in parentheses)

	Children orphaned by AIDS (n = 425)		Children orphaned by other causes		Non-orphaned children		<i>p</i> value ^a	
	2005 (n = 425)	2009 (n = 269)	2005 (n = 241)	2009 (n = 228)	2005 (n = 278)	2009 (n = 180)	2005	2009
Age (mean, <i>SD</i>)	13.7 (2.5)	17.2 (2.7)	13.4 (13.4)	17.0 (2.6)	13.0 (2.0)	16.5 (1.9)	< .001	.01
Proportion female	50.6%	52.8%	43.2%	45.2%	46.4%	49.4%	ns	ns
Xhosa ethnicity	98.1%	99.2%	96.7%	97.4%	96.4%	98.2%	ns	ns
Household size (mean, <i>SD</i>)	4.8 (1.9)	5.1 (2.3)	4.6 (1.7)	5.0 (2.1)	5.2 (2.0)	5.3 (2.4)	< .001	ns
Informal dwelling	43.0%	34.5%	43.0%	31.1%	29.1%	30.0%	< .001	ns
Migration	41.4%	45.4%	44.0%	46.1%	40.6%	39.3%	ns	ns
Loss of mother	58.6%	57.6%	28.2%	32.0%	–	–	< .001	< .001
Loss of father	66.1%	63.6%	83.0%	70.2%	–	–	.01	< .001
Loss of both parents	24.9%	45.3%	12.4%	28.5%	–	–	< .001	< .001
Age, first bereavement (mean, <i>SD</i>)	10.1 (3.8)	9.5 (4.5)	7.8 (4.6)	8.1 (4.6)	–	–	< .001	.01

^a*p*-value associated with one-way ANOVA or chi-square test.

Depression

In the first analysis stage, the mixed-design ANOVA for depression revealed an overall within-subjects increase in depression scores between 2005 and 2009; $F(1, 654) = 16.77, p < .001$. The lack of a significant interaction between depression scores and orphanhood status [$F(2, 654) = 1.24, p = .29$] suggests that the change in depression scores were similar in magnitude for all groups (Figure 1). However, a significant between-groups effect of orphanhood status was shown; $F(2, 654) = 18.58, p < .001$. Comparisons using Bonferroni correction revealed that AIDS-orphaned children ($p < .001$) and other-orphans ($p < .02$) had higher depression scores than non-orphans ($M1 = 3.11; M2: 3.93; M1 = 2.48; M2: 3.21; M1 = 2.14; M2: 2.41$ respectively – see Figure 1). In stage 2, backward-stepping regression (controlling for sociodemographic covariates and depression in 2005) showed that being AIDS-orphaned in 2005 predicted depression in 2009 ($p = .05$), but being other-orphaned or non-orphaned did not (Table 2). Other sociodemographic covariates were not significant, apart from age and migration ($p = .01$). Stage 3 tested for interactions with age (Table 3). Being AIDS-orphaned remained a significant predictor. Although age itself was not a predictor in this final model, age interacted strongly with AIDS-orphanhood ($p < .001$), and moderately with other-orphanhood ($p = .05$) to predict psychological distress. Using the *unstandardised* coefficients in the regression equation of the final model allows one to predict depression levels (Figure 2): the *standardised* regression coefficients (Table 3) indicate that contribution of the interaction of age with AIDS-orphanhood ($\beta = .863$) is nearly ten times larger than that with other-orphanhood ($\beta = .092$).

Anxiety

First, a mixed-design ANOVA for anxiety revealed no overall within-subjects effect of anxiety across time [$F(1, 661) = .17; p = .68$]; however, the interaction

between anxiety and orphanhood group was approaching significance; $F(2, 661) = 2.87, p = .05$. Comparisons indicated that for AIDS-orphaned children the change in anxiety scores between 2005 and 2009 was approaching significance [$t(259) = 1.83, p = .07$]. In contrast, for both other-orphans [$t(225) = .63, p = .53$] and non-orphans [$t(177) = -1.66, p = .11$] no changes in anxiety across time were found (Figure 1). Additionally, a significant between-group effect of orphanhood group was shown; $F(2, 661) = 9.29, p < .001$. Comparisons using Bonferroni correction revealed that AIDS-orphaned children had higher anxiety scores ($p < .001; M1 = 5.59; M2 = 6.07$) than other-orphans ($M1 = 4.89, M2 = 5.06$) and non-orphans ($M1 = 5.08, M2 = 4.62$). There were no differences between non-orphans and other-orphans (Figure 1). Second, backwards-stepping regression (controlling for sociodemographic covariates and anxiety in 2005) showed that being AIDS-orphaned in 2005 was a significant predictor of anxiety in 2009 ($p = .05$), but being other-orphaned or non-orphaned was not. Other sociodemographic covariates were not significant, apart from age, and anxiety at 2005 ($p = .01$). In stage 3, testing for age-orphanhood interactions, showed that age ($p < .001$) and anxiety in 2005 ($p < .001$) predicted anxiety in 2009, whilst AIDS-orphanhood in 2005 did not, but that the *interaction* of age with AIDS-orphanhood ($p < .001$) was a significant predictor. There was no interaction between age and other-orphanhood or non-orphanhood. Other sociodemographic covariates were not significant.

Post-traumatic stress disorder

First, a mixed-design ANOVA for PTSD revealed an overall within-subjects increase in PTSD scores between 2005 and 2009; $F(1, 641) = 35.24, p < .001$. The lack of a significant interaction between PTSD scores and orphanhood status [$F(2, 641) = .88, p = .42$] suggests that changes in PTSD scores were similar in magnitude for all groups (Figure 1). However, a significant between-groups effect of

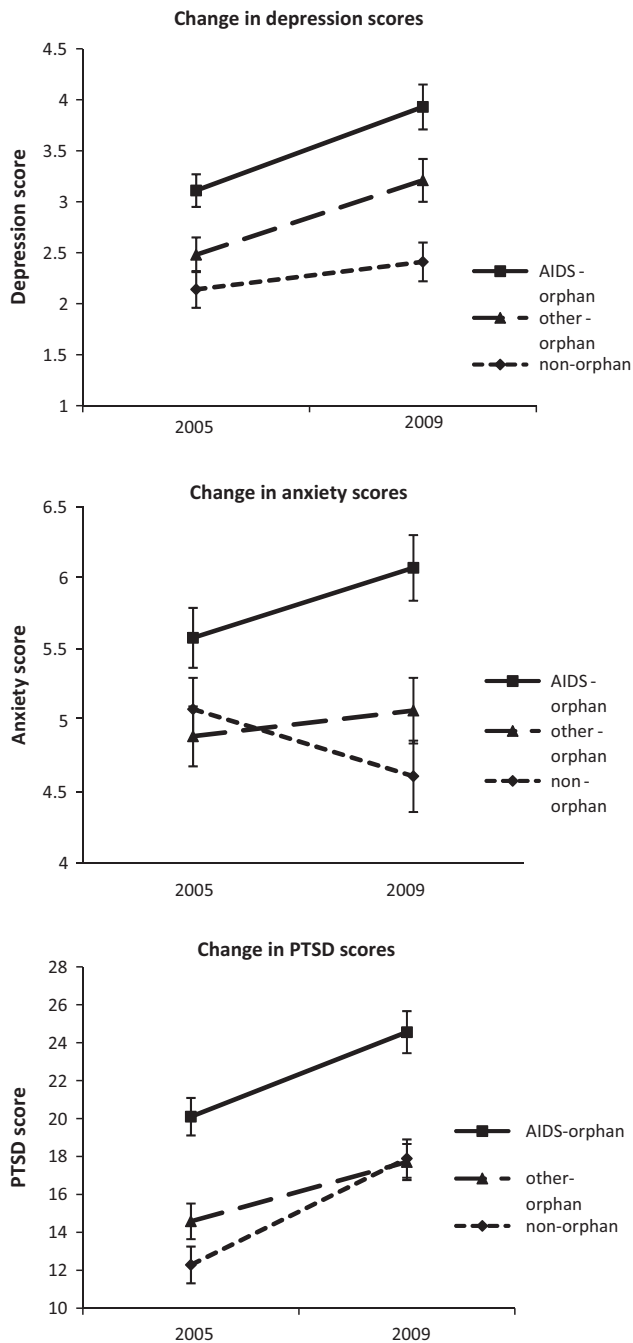


Figure 1 Changes in mental health outcomes between 2005 and 2009 as a function of orphanhood group

orphanhood status was shown; $F(2, 641) = 25.70$, $p < .001$. Comparisons using Bonferroni correction revealed that AIDS-orphaned children had more PTSD symptoms ($p < .001$; $M1 = 20.10$; $M2 = 24.57$) than other-orphans ($M1 = 14.58$, $M2 = 17.71$) and non-orphans ($M1 = 12.28$, $M2 = 17.89$). There were no differences between non-orphans and other-orphans (Figure 1). Second, backward-stepping regression (controlling for sociodemographic covariates and PTSD in 2005) showed that being AIDS-orphaned in 2005 was a significant predictor of PTSD in 2009, ($p = .01$), but being other-orphaned or non-orphaned was not (Table 2). Other sociodemographic covariates were not significant, apart from age, and PTSD at 2005 ($p = .01$). In stage 3, testing for age-orphanhood interactions showed that age of itself was not a significant predictor, but 2005 levels of PTSD, and being AIDS-orphaned were. Additionally, the interaction of age with AIDS-orphanhood was highly significant ($p < .001$). There was no interaction of age and other-orphanhood or non-orphanhood. Other sociodemographic covariates were not significant.

Discussion

Cross-sectional studies in the developing world have demonstrated psychological distress associated with AIDS-orphanhood, and now this longitudinal study allows us to examine these impacts over time. First, we determined whether AIDS-orphaned adolescents and young adults were still experiencing more severe mental health problems than other groups over a 4-year post-orphanhood period. Findings clearly showed that they were. From the literature on vulnerable children it might have been expected that widespread exposure to community violence and other stressors amongst the whole sample would have reduced differences between orphanhood groups. However, AIDS-orphanhood retained significant predictive value, despite heightened risks for all participants. Although orphanhood by non-AIDS causes was often due to homicide or road traffic accidents, both of which would be expected to raise distress, other-orphanhood did not – with the exception of depression – have long-lasting deleterious

Table 2 Multivariate regression showing predictors of psychological outcomes, including orphanhood status and sociodemographic cofactors

	Depression		Anxiety		Post-traumatic stress	
	Unstandardised ^a	Standardised	Unstandardised	Standardised	Unstandardised	Standardised
Intercept	-.510		-.588		1.864	
Orphanhood by AIDS	.673*	.101*	.752*	.104*	5.279***	.161***
Mental health in 2005	–	–	.155***	.228***	.262***	.237***
Age	.206***	.163***	.240***	.176***	.713**	.116**
Migration to Cape Town ^b	.717*	.105*	–	–	–	–

*Denotes significance at $< .05$ level ** $< .01$ level *** $< .001$ level.

^a'Standardised' and 'unstandardised' refer to regression coefficients.

^bThe other covariates – gender, housing type, household size, orphanhood by non-AIDS causes, and maternal/paternal/double orphanhood – were not significant for any of the three dependent variables.

Table 3 Multivariate regression with interaction terms of age and orphanhood status, controlling for sociodemographic cofactors

	Depression		Anxiety		Post-traumatic stress	
	Unstandardised	Standardised	Unstandardised	Standardised	Unstandardised	Standardised
Intercept	2.292		-.246		15.057	
Mental health in 2005	.131**	.106**	.160***	.236***	.209***	.193***
AIDS-orphanhood	-4.328***	-.660***	-	-	-16.821**	-.517**
Age ^a	-	-	.204***	.142***	-	-
Age * AIDS-orphanhood	.324***	.863***	.055***	.130***	1.297***	.701***
Age * other-orphanhood	.037*	.092*	-	-	-	-
Adjusted R square	.069		.109		.101	

*Denotes significance at < .05 level ** < .01 level *** < .001 level. '–' denotes nonsignificant predictor.

^aThe other covariates – gender, housing type, household size, maternal/paternal/double orphanhood and the interaction age * nonorphanhood – were not significant for any of the three dependent variables.

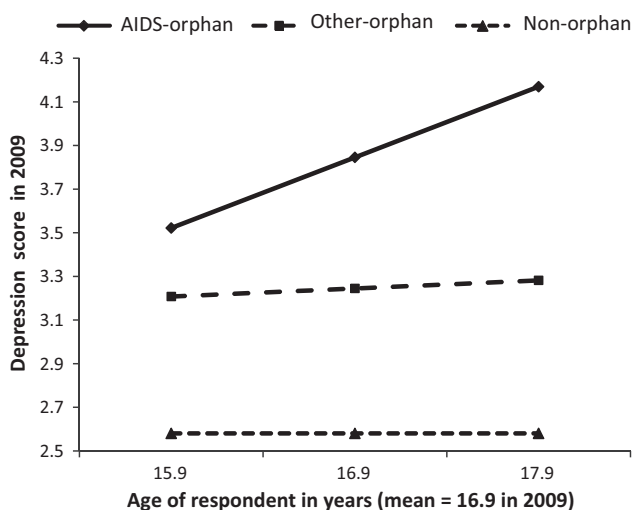


Figure 2 Interactions of age and orphanhood status by depression in 2009

mental health effects. These findings provide empirical context for calls in the international literature for a focus on the psychosocial support needs of orphaned and vulnerable children (Skinner et al., 2006, <http://www.jlica.org>).

Second, effects of AIDS-orphanhood were retained over time when controlling for sociodemographic cofactors (such as gender, migration, and maternal/paternal/double orphanhood), and baseline levels of all three mental health outcomes. Findings showed no significant sociodemographic covariates apart from age (for anxiety and PTSD) and migration (for depression). Psychological distress in 2005 predicted symptoms in 2009, as we would generally expect from longitudinal studies of adolescent mental health. But the important finding here is that, even when controlling both for psychological distress at 2005 and sociodemographic cofactors, AIDS-orphanhood *independently* predicted an increase in depression, anxiety and PTSD symptoms.

Third, we investigated whether older age predicted increased psychological distress differently amongst different orphanhood groups. One might have expected that all children's psychological distress would increase with age, given increased exposure to

community and other violence, cessation of child welfare grants, and progression from school into unemployment (around 80% amongst youth in our study areas). However, increasing age of itself was associated with increasing distress across all categories of children only in the instance of anxiety; whereas AIDS-orphanhood (but not other-orphanhood or non-orphanhood) interacted with increased age to magnify the rise in levels of depression, anxiety and PTSD. In other words (with the exception of anxiety), growing up predicts increased mental health problems for AIDS-orphaned youth, but not for other-orphans and non-orphans.

These findings have implications for our understanding of the long-term impacts on children of parental death by a chronic, highly stigmatised disease. Studies amongst bereaved children (by causes other than HIV/AIDS) in the developed world have found common symptoms of grief, distress and dysphoria in the year post-bereavement, followed for most by resilience to long-term psychiatric distress (Dowdney, 2008). This study suggests that the negative psychological impacts of parental bereavement by HIV/AIDS may be more enduring, and more severe, than the impacts of other bereavement. Findings also demonstrate that AIDS-orphanhood exacerbates psychological distress over time, and interacts with age to predict greater increase in distress for older AIDS-orphaned youth. These two effects suggest that the impact of AIDS-orphanhood gets worse, not better, with time and with the developmental process of growing up. This may represent a similar psychological impact to that shown amongst adults who experienced childhood exposure to other chronic and extreme stressors such as war, terrorism or abuse (Heim & Nemeroff, 2001). It is possible that, whilst bereavement by causes other than AIDS often functions as a single major stressor from which the majority of children recover, AIDS-orphanhood represents an ongoing set of associated social and economic stressors which amplify and sustain distress.

Further, this study also suggests that the transition from adolescence into adulthood may be particularly stressful for AIDS-orphaned youth. It is possible that this reflects a reduction in family and

foster family support as children become young adults, as found in studies of fostering (Minty, 1999). It also may reflect a reduction in NGO, school, and welfare service support, often targeted at 'children' rather than older groups. Finally, it may be that the development of adult relationships and identity are particularly difficult when parent/s have died of a highly stigmatised, sexually transmitted disease. A recent study of orphaned youth aged 19–24 in Rwanda suggested loss of confidence in others and in religious beliefs (Thurman et al., 2006).

These findings expand upon the two US-based, 2-year longitudinal studies of AIDS-orphaned mental health. All three studies showed greater emotional distress amongst AIDS-orphaned children, suggesting that long-term negative impacts of familial HIV/AIDS may exist across cultures, and in epidemics characterised by very different social risk factors. There is a clear need for research to examine the differential impacts of AIDS-orphanhood in other parts of the developing world, and as orphans progress through adulthood.

This study has a number of limitations. First, although strenuous attempts were made to find participants after 4 years, 295 children were not traceable or had died. Analyses of 2005 data suggest that those lost to follow-up were more vulnerable for emotional distress, and that therefore our findings of increased psychological distress in 2009 may be an underestimate. Second, to date, there are no standardised or validated psychological scales for children in sub-Saharan Africa. All psychological measures should be interpreted with caution in different cultural contexts. However, all scales had been extensively used in South Africa, and all showed adequate reliability in this sample. Finally, due to low levels of HIV-testing in South Africa, most participants did not know their own HIV-status, and this study was unable to conduct HIV-antibody testing. Whilst most emotional distress associated with HIV-status occurs after a diagnosis (Rochat et al., 2006), there may be neurocognitive impacts associated with undiagnosed and asymptomatic HIV-infection (Antinori et al., 2007).

This study also has a number of strengths. It is the first known study in the developing world to examine psychological impacts of AIDS-orphanhood longitu-

dinally. It has robust comparison groups of other-orphaned and non-orphaned adolescents, with good follow-up rates over 4 years, despite high levels of mobility amongst all children. Finally, the oversampling of child-headed households, non school-attending children and street-children (although this last group were especially difficult to follow-up) ensured inclusion of groups often omitted in school-based or community-based sampling.

Findings suggest a number of tentative implications for interventions within sub-Saharan Africa. Whilst most psychosocial interventions currently focus on younger children and under-18s, we may need psychosocial support programming for AIDS-affected older adolescents and young adults. Moreover, sustained interventions may be needed in order to mitigate long-term problems. A 2009 Cochrane systematic review of interventions for improving psychosocial well-being of HIV/AIDS-affected children found no studies for inclusion. Authors concluded that current practice is based on anecdotal knowledge, descriptive studies and situational analyses (King, De Silva, Stein, & Patel, 2009). This study suggests that, when developing rigorous evaluations of interventions, it is important to test effects not only in the short-term, but over a number of years.

Acknowledgements

This study was supported by grants from The Nuffield Foundation and the Economic and Social Research Council. The authors wish to thank our fieldwork team: Somaya Latief, Naema Latief, Joy Nikelo, Julia Limba, Nomhle Panyana, Daphne Makasi and Thembele Molwana. We would also like to thank Cape Town Child Welfare, the Western Cape Education Department, Pollsmoor Prison, The Homestead Shelter and South African Airways. Most importantly, we thank all the participants, and their families, for welcoming us again.

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Key points

- Cross-sectional studies have identified greater psychological distress for AIDS-orphaned children. But to date we lack data on long-term impacts of AIDS-orphanhood in the developing world.
- This study shows that the psychological distress associated with AIDS-orphanhood (depression, anxiety and PTSD) is maintained over 4 years.
- AIDS-orphanhood exacerbates the increase in psychological distress over 4 years, but other-orphanhood and nonorphanhood do not.
- Clinical implications include the need to focus interventions not just on *children* who are AIDS-orphaned, but also on older adolescents and young adults.
- Interventions may need to be long-term to address long-term or ongoing negative impacts.

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Accepted for publication: 11 July 2011

Published online: 30 August 2011