

AIDS-Orphanhood and Caregiver HIV/AIDS Sickness Status: Effects on Psychological Symptoms in South African Youth

Lucie D. Cluver,^{1,2} DPHIL, Mark Orkin,³ PHD, Mark E. Boyes,¹ PHD, Frances Gardner,¹ PHD, and Joy Nikelo,⁴

¹Centre for Evidence-Based Intervention, Department of Social Policy and Intervention, University of Oxford, ²Department of Psychiatry and Mental Health, University of Cape Town, ³School of Public and Development Management, University of the Witwatersrand, and ⁴Cape Town Child Welfare

All correspondence concerning this article should be addressed to Dr Lucie Cluver, Centre for Evidence-Based Intervention, Department of Social Policy and Intervention, Oxford University, 32 Wellington Square, Oxford, OX1 2ER, UK. E-mail: lucie.cluver@spi.ox.ac.uk

Received June 1, 2011; revisions received January 6, 2012; accepted January 8, 2012

Objective Research has established that AIDS-orphaned youth are at high risk of internalizing psychological distress. However, little is known about youth living with caregivers who are unwell with AIDS or youth simultaneously affected by AIDS-orphanhood and caregiver AIDS sickness. **Methods** 1025 South African youth were interviewed in 2005 and followed up in 2009 (71% retention). Participants completed standardized measures of anxiety, depression, and posttraumatic stress. Comparison groups were youth who were AIDS-orphaned, other-orphaned, and nonorphaned, and those whose caregivers were sick with AIDS, sick with another disease, or healthy. **Results** Longitudinal analyses showed that both AIDS-orphanhood and caregiver AIDS sickness predicted increased depression, anxiety, and posttraumatic stress symptoms over a 4-year period, independently of sociodemographic cofactors and of each other. Caregiver sickness or death by non-AIDS causes, and having a healthy or living caregiver, did not predict youth symptomatology. Youths simultaneously affected by caregiver AIDS sickness and AIDS-orphanhood showed cumulative negative effects. **Conclusions** Findings suggest that policy and interventions, currently focused on orphanhood, should include youth whose caregivers are unwell with AIDS.

Key words caregiver; HIV/AIDS; mental health; South Africa; youth.

Introduction

The impact of parental HIV/AIDS on youth mental health is only beginning to be understood. By 2009, 17 million children had been orphaned by AIDS—with 15 million in sub-Saharan Africa, and 1.5 million in South Africa alone (UNAIDS, 2010). A growing number of studies have demonstrated heightened internalizing problems among youth orphaned by AIDS, particularly symptoms of depression and anxiety, in the United States (Forehand et al., 2002; Rotheram-Borus, Stein, & Lin, 2001), sub-Saharan Africa (Bhargava, 2005; Cluver, Gardner, & Operario, 2007; Makame, Ani, & McGregor, 2002; Nyamukapa et al.,

2008), and China (Fang et al., 2009). Additionally, in contexts where antiretroviral access remains low, many youth live with AIDS-affected parents or caregivers, although no population estimates are available for this group. The sexually transmitted nature of HIV means that young people may simultaneously experience parental death and AIDS-related illness of the other parent. In sub-Saharan Africa, clustering of high prevalence rates in poor communities mean that orphaned youth are often fostered by family members who are themselves suffering from AIDS-related illness (Kuo & Operario, 2009). We understand very little about whether it is

AIDS-orphanhood per se which causes negative outcomes, or whether risks may also be established during stages of advanced parental illness.

Developmental theory suggests that child and adolescent psychopathology is directly related to extent, chronicity, and magnitude of exposure to environmental stressors (Rutter, 2005), and this is supported by evidence from community-based studies in the developed world (Copeland, Keeler, Angold, & Costello, 2007). The ecological model for child internalizing symptoms (Bronfenbrenner, 1979) suggests that many of the negative proximal effects of HIV/AIDS would apply equally to both AIDS-orphaned youth and youth living with caregivers who are AIDS-sick, and thus similarly affect their mental health. This model also suggests why familial HIV/AIDS may have a greater impact than other familial sickness or death. For example, both orphanhood and severe parental sickness affect the “microsystem” of the family, with children experiencing high levels of anxiety and depression concerning fear of death, loss of parental support, and family conflict (Rutter, 1966), but in the context of HIV this may be compounded by internalized stigma, the debilitating nature of the disease, and witnessing of previous deaths by AIDS. “Meso” and “macro” systems can also be negatively impacted: familial HIV/AIDS increases family poverty through lost employment, medical, and funeral expenses (Booyesen, 2004), and has a greater impact than other illnesses through its chronic and worsening progression and by affecting those of breadwinning age within the family. In addition, AIDS-related stigma can isolate youth from seeking or receiving support from peers, school, and community. AIDS-affected youth also experience higher levels of physical and emotional abuse and bullying victimization than other children (Cluver, Orkin, Boyes, Gardner, & Meinck, 2011) resulting in increased exposure to chronic stressors. Theory also suggests potential cumulative or compounding effects of multiple, related traumas on child internalizing symptoms (Atzaba-Poria, Pike, & Deater-Deckard, 2004), which may be particularly pertinent in the case of a terminal disease transmitted within families through sex and birth.

There is consistent evidence that AIDS-orphaned youth in sub-Saharan Africa experience more internalizing than externalizing symptoms (Cluver & Gardner, 2007; Sherr et al., 2008). However, to date, little research has examined internalizing symptoms among youth living with caregivers who are sick with AIDS. Qualitative evidence of children living with AIDS-affected caregivers, as well as with caregivers suffering other chronic and terminal illnesses, suggests that anxiety may be particularly severe for this group as they anticipate parental death

(Evans & Becker, 2010; Forrest, Plumb, Ziebland, & Stein, 2006; Sherr, et al., 2008). In a recent qualitative study, a 14-year-old boy reported “I don’t concentrate at school. I am worried about my mother. She looks like she’s going to die like my father” (Cluver, Operario, Lane, & Kganakga, 2011). Reviews of the effects of parental cancer on children’s development have shown increased emotional problems amongst adolescents, especially linked to worsening parental physical condition, mental health, and treatment complications (Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004). For both orphaned and affected children, depressive symptomatology and posttraumatic stress may be closely aligned, with youth reporting hopelessness and fear for their own futures, closely linked to the illness and death of their parents, and perhaps similar to symptoms experienced by youth experiencing other stigmatized parental deaths (Black & Harris-Hendricks, 1992).

In the United States, a small number of recent studies have found child psychological distress associated with parental HIV-infection (Bauman et al., 2006; Forehand, et al., 2002; Murphy, Marelich, & Hoffman, 2002; Rotheram-Borus, et al., 2001). In New Orleans, a 2-year study with 105 6- to 11-year-olds showed more distress among AIDS-orphaned children after 2 years than those with HIV-positive or HIV-negative mothers, but no differences at 6 months (Pelton & Forehand, 2005). However, transferability from the United States to sub-Saharan Africa is problematic, due to differential disease epidemiology (Mellins et al., 2009) and better healthcare access, which contrasts with sub-Saharan Africa’s generalized epidemic, overburdened health systems, and home-based palliative care (UNAIDS, 2010). Developing world research examining links between caregiver HIV-status and child outcomes is even scarcer. Qualitative studies in Tanzania and Kenya report distress among youth within AIDS-affected families (Evans & Becker, 2010; Skovdal & Ogutu, 2009). Searches found only two quantitative studies. In South Africa, 30 AIDS-affected children showed greater distress than controls (Gwandure, 2007). The other compared 50 children in Zimbabwe and New York, all with HIV-positive mothers. Zimbabwean children showed more depression, with two-thirds in the clinically significant range (Bauman, et al., 2006). Additionally, no studies worldwide examine long-term outcomes over more than a two-year period. Thus, there remain major gaps in the evidence. To date, no large-scale developing world research examines psychological distress amongst youth with AIDS-sick parents or caregivers (Becker, 2007), or allows comparison of effects of caregivers affected by AIDS, another illness, and healthy

Table 1. Summary of Sample Characteristics (2009)

	Children Orphaned by AIDS (n = 269)	Children Orphaned by Other Causes (n = 228)	Nonorphaned Children (n = 180)	p-value	AIDS-sick Caregiver (n = 103)	Other-sick Caregiver (n = 146)	Healthy Caregiver (n = 436)	p-value
Age (M, SD)	17.2 (2.7)	17.0 (2.6)	16.5 (1.9)	.01	17.0 (2.5)	16.9 (2.3)	16.8 (2.5)	ns
Age range	11–24	12–25	12–22	–	12–23	12–22	11–25	–
Female	52.8	45.2	49.4	ns	59.2	44.5	48.2	ns
Xhosa ethnicity	99.2	97.4	98.2	ns	100	99.3	99.3	ns
Household size (M, SD)	5.1 (2.3)	5.0 (2.1)	5.3 (2.4)	ns	5.2 (2.0)	5.7 (2.2)	4.9 (2.3)	<.01
Informal dwelling	34.5	31.1	30	ns	41.6	27.1	33.5	.02
Migration (at least once)	45.4	46.1	39.3	ns	43.1	47.9	44.8	ns

Note. p-value associated with one-way ANOVA or chi-squared test. Values are represented as percentage unless otherwise specified.

caregivers, or comparison of effects of AIDS-orphanhood with those of caregiver AIDS-sickness.

Accordingly, this study aimed to address these gaps. Using longitudinal data from 2005–2009,¹ the current study aimed to test the following hypotheses based on models of multiple and cumulative child traumas. First, we hypothesized that AIDS-orphanhood and caregiver AIDS-sickness would both predict increases across time in youth internalizing symptoms, independently of each other. Within this hypothesis, other-orphanhood and other-sickness would not predict increases in internalizing symptoms, as these did not represent multiple risk factors including stigma. Second, we hypothesized that there would be a cumulative effect for youth who were “dual-affected” by both AIDS-orphanhood and caregiver AIDS-sickness, over and above the effect of each of these traumas singly. We also made a tentative hypothesis that caregiver AIDS-sickness would be a stronger predictor of increases in youth anxiety than AIDS-orphanhood, based on qualitative evidence of greatest anxiety related to fear for caregivers’ approaching death (Cluver et al., 2011), whilst depression and posttraumatic stress may be equally likely to affect children pre-and postorphanhood (Sherr et al., 2008).

Methods

Participants

In 2005, 1,025 children and adolescents were interviewed in a study examining psychological distress in children from poor peri-urban communities of Cape Town (see Cluver, et al., 2007, for a detailed description of the

sample). Longitudinal follow-up in 2009 achieved a retention rate of 71%, and the current paper focuses on these data. A 4-year follow-up period was chosen in order to assess long-term impacts of familial HIV/AIDS and other sickness on psychological distress. Particular challenges to tracing youth for follow-up included the following: one informal settlement (from which 189 children had been recruited in 2005) had been demolished, with no relocation records. Street children were almost impossible to trace due to exceptionally high mobility and mortality. Several participants lived in unsafe gang-owned houses, and 12 interviews were curtailed due to participants’ substance inebriation or police raids. Three children were interviewed in prison. Thirty children were interviewed in external provinces. Table 1 summarizes socio-demographic information of children followed-up in 2009.

The UN definition of orphanhood was used—i.e., loss of one or both parents among children up to the age of 18 years (Skinner et al., 2006; UNAIDS, 2004). This includes youth in a range of caregiver circumstances, including doubly orphaned, singly orphaned, and living with a surviving parent or “de facto” doubly orphaned by loss of a lone parent. Participants lived with a combination of biological and step-parents, relatives, youth-headed households, and with formal or informal fostering arrangements. Seven hundred and twenty-three youths (aged between 11 and 25 years, 50% female) were re-interviewed in 2009: 269 were AIDS-orphaned, 228 were orphaned due to other causes, and 180 were nonorphaned. For 46 youths it was unclear whether parental death was AIDS-related and these cases were excluded from analyses. Four hundred and thirty-six youths reported living with a healthy caregiver, 103 with a caregiver unwell with AIDS, and 146 with a caregiver who suffered another chronic illness (such as diabetes, breast cancer, or emphysema). For 38 youth caregiver, sickness status was unclear and these cases were excluded from analyses.

¹This study was developed in consultation with the National Departments of Social Development, Basic Education and Health of the South African government, aiming to inform evidence-based policy for AIDS-affected youth.

Measures

Determining Cause of Parental Death and Caregiver Sickness

In South Africa, death certificates are unreliable sources of AIDS mortality and clinical data is rarely available. Cause of parental death was therefore determined using the youth-report Verbal Autopsy method (see Lopman et al., 2006), validated in previous studies of adult mortality in South Africa, with sensitivity of 89%, specificity 93%, and positive predictive value 76% (Kahn, Tollman, Garenne, & Gear, 2000). In the current study, determination of AIDS-related parental death required a conservative threshold of three or more AIDS-defining illnesses; e.g., Kaposi's sarcoma or shingles. In all cases of uncertain diagnoses, symptom reports were reviewed independently by two medical practitioners. Where possible, youth reports were corroborated by teachers, social workers, and surviving parents. Where cause of death was unclear (such as "bewitchment" and deaths by tuberculosis with no other AIDS-related symptoms) cases were excluded from analyses (81 in 2005, 46 in 2009).

For determining caregiver illness, self-reported current HIV-status is also unreliable. High levels of stigma in South Africa result in low HIV-testing (8% in the past year; Peltzer, Matseke, Mzolo, & Majaja, 2009), and many people and their families are unaware of their HIV-status. Consequently, caregiver AIDS-sickness was determined using a youth-report verbal symptom checklist, parallel to the Verbal Autopsy method, and intended to define Stage 4 AIDS-illness through identification of HIV-related opportunistic infections such as diarrhea, oral candidiasis, and jaundice. In this study, determination of caregiver AIDS-sickness required either (i) a conservative threshold of three or more AIDS-defining illnesses or (ii) self-identification of symptomatic HIV/AIDS or CD4 count less than 200. Where possible, youth reports were corroborated by caregiver reports, and for uncertain diagnoses, symptoms were reviewed independently by two medical practitioners. Where cause of sickness was unclear (such as cervical cancer which may or may not have been AIDS-related), cases were excluded from analyses (54 in 2005, 38 in 2009).

Sociodemographic Information

Items were derived from the South African Census, and were based on youth reports. Analyses controlled for potential confounders of the effects of familial HIV/AIDS on youth mental health. These included age, as psychopathology tends to increase throughout adolescence (Cicchetti & Cohen, 2006), gender, as girls show higher levels of internalizing disorder both in the developed and

developing worlds (Cluver et al., 2007), formal versus informal housing as a measure of socioeconomic status, household size, and child migration which may increase susceptibility to psychological distress.

Mental Health Measures

Depression was measured using the short form of the Children's Depression Inventory (Kovacs, 1992). This measure has strong psychometric properties, has been widely used in South Africa (Suliman, 2002), and correlates highly with the full version of the Children's Depression Inventory. Internal consistency in the current sample was .67 in 2005 and .69 in 2009. Anxiety was measured using the Children's Manifest Anxiety Scale-Revised (Reynolds & Richmond, 1978), validated for use in South Africa (Boyes & Cluver, in press). The 28-item scale was reduced using factor analysis to 14 items, and internal consistency in the current sample was .80 in both 2005 and 2009. Posttraumatic stress was measured using the Child PTSD Checklist (Amaya-Jackson, 1995). This 28-item scale measures DSM-IV symptomatology in avoidance, numbing, hyper-arousal, and reexperiencing, and has been used extensively in South Africa (Seedat, van Nood, Vythilingum, Stein, & Kaminer, 2000). Internal consistency in the current sample was .94 in both 2005 and 2009, and the text-based checklist was accompanied by cartoons from the Levonn/Andile trauma scale, found accessible for isiXhosa-speaking Cape Flats adolescents (Ensink, Robertson, Zissis, & Leger, 1997). For a detailed description of standardized clinical cut-offs used, see Cluver et al. (2007). We note that Western-validated clinical scores must be interpreted with caution, and to date no clinical cut-offs have been validated in Africa. Measures were all presented in a questionnaire, and design and layout was assisted by a Teen Advisory Group of 14 AIDS-affected youth. During weekend camps, youth advised on item acceptability, interviewing methods, and layout, which was in the style of a teen magazine and included popular music stars and cartoons.

Procedure

Ethical protocols were approved in 2005 and 2009 by the University of Oxford, the University of Cape Town, and the Western Cape Department of Education. Voluntary informed consent was obtained from all participants and their caregivers, with a positive response rate of 99.7% of those referred to the study in 2005, and 98.3% of those who were able to be traced in 2009. For youth in child-headed households, living on the streets or in prison, caregiver consent was obtained from an adult guardian or

social worker. With interviewers, participants completed self-report questionnaires lasting 40–60 min, and participants received refreshments and certificates. All interviewers were isiXhosa-speaking social or community workers, trained in working with AIDS-affected youth. Questionnaires were translated, back-translated, and piloted in isiXhosa and English, and children chose their language of reading and response (many chose a combination of the two). Confidentiality was maintained, except where participants were at risk of significant harm or requested assistance. Where participants reported ongoing abuse, rape, or risk of significant harm, immediate referrals were made to child protection services. Where prior abuse or rape was no longer occurring, referrals were made to support/counselling services, and to HIV testing and treatment services where appropriate.

Analysis Strategy

As a preliminary check, we noted baseline characteristics of youth lost to follow-up, as well as any differences in socio-demographic characteristics. Using interviewers resulted in minimal missing data (less than 1%) and where missing items were identified they were imputed using the mean of responses to other scale items. Linear regressions were conducted to determine whether AIDS-orphanhood and caregiver AIDS-sickness were significant independent predictors of changes in mental health between 2005 and 2009. Depression, anxiety, and PTSD change scores were entered as respective outcome variables. Dummy variables representing AIDS-orphanhood or being orphaned by other causes and having an AIDS-sick caregiver or caregiver with another sickness were entered as predictors in each model (controlling for age, gender, household composition, informal housing, and 2005 mental health scores). Additionally, to determine whether there was a cumulative effect of exposure to familial AIDS, a series of regressions including a dummy variable representing “dual-affected” children (being both AIDS-orphaned and living with an AIDS-sick caregiver) were conducted. To avoid multicollinearity, dummy variables representing “AIDS-orphaned only” and “AIDS-sick caregiver only” were used in these analyses.

Results

Prior to analyses we checked for differences between youths lost and retained at follow-up. The former were more likely to be male [$\chi^2(1) = 4.18, p = .04$; Cramer's phi (V) = .06], older [$F(1, 1022) = 17.81, p < .001$; partial $\eta^2 = .02$], and living in informal (shack) housing

[$\chi^2(1) = 6.24, p = .01$; $V = .08$]. Moreover, youths lost to follow-up had higher depression [$F(1, 1022) = 26.52, p < .001$; partial $\eta^2 = .03$] and anxiety [$F(1, 1016) = 7.20, p = .01$; partial $\eta^2 = .01$] 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 unable to be traced.

Proportions of youth scoring above the clinical cut-offs for psychological disorders in 2009 are summarized in Figure 1. The highest levels of depression, anxiety, and posttraumatic stress disorder were reported by youth whose caregivers were sick with AIDS (26%, 29%, and 60%, respectively) and by AIDS-orphaned youth (23%, 22%, and 54%, respectively). Youth whose caregivers were sick with other causes showed lower levels of all disorders (16%, 16%, and 40%, respectively), as did other-orphaned youth (14%, 14%, and 36%, respectively), youth with healthy caregivers (13%, 14%, and 39%), and nonorphaned youth (7%, 10%, and 38%). High levels of PTSD in all groups reflect those shown in other studies in this area (Ensink et al., 1997; Seedat et al., 2000).

Initial cross-sectional analyses revealed that being AIDS-orphaned in 2009 predicted depression ($\beta = .13, p = .001$), anxiety ($\beta = .10, p = .015$), and PTSD ($\beta = .09, p = .019$) scores in 2009 (after controlling for 2005 depression, anxiety, and PTSD scores, respectively). Similarly, having an AIDS-sick caregiver in 2009 predicted depression ($\beta = .11, p = .001$), anxiety ($\beta = .12, p = .001$), and PTSD ($\beta = .11, p = .002$) scores in 2009 (after controlling for 2005 depression, anxiety, and PTSD scores respectively). Being non-orphaned, orphaned by non-AIDS causes, living with a caregiver sick with another illness, or living with a healthy caregiver were not significant predictors of any 2009 mental health outcomes in the cross-sectional analyses.

Longitudinal analyses revealed that, as hypothesized, AIDS-orphanhood was associated with increased symptomatology for all psychological outcomes between 2005 and 2009 (see Table II and Figure 2). Being orphaned by another cause predicted increased depression scores between 2005 and 2009 ($\beta = .08, p = .042$), but was not associated with changes in anxiety or PTSD over time. Being nonorphaned was not associated with changes in any of the psychological outcomes. Similarly, having an AIDS-sick caregiver in 2009 predicted depression ($\beta = .11, p = .001$), anxiety ($\beta = .12, p = .001$), and PTSD ($\beta = .11, p = .002$) scores in 2009 (after controlling for 2005 depression, anxiety, and PTSD scores respectively). Again, longitudinal analyses revealed that, as hypothesized, having an AIDS-sick caregiver was associated with

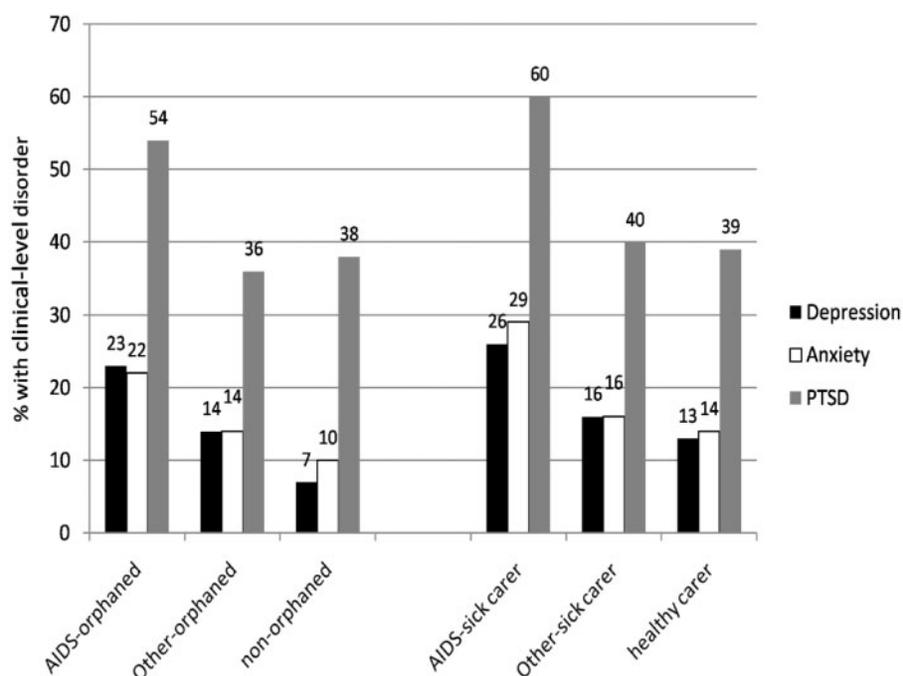


Figure 1. Proportion of children scoring within the clinical range for depression, anxiety, and PTSD as a function of orphanhood status and caregiver sickness status (2009).

Table II. Summary of Regression Weights for AIDS-Orphanhood, Caregiver AIDS-Sickness, Orphanhood by Other Causes, and Having a Caregiver with Another Sickness as Associated with Changes in Depression, Anxiety, and PTSD Scores Between 2005 and 2009

	Depression		Anxiety		PTSD	
	<i>B</i>	β	<i>B</i>	β	<i>B</i>	β
AIDS-orphanhood	.98**	.13**	.81**	.10**	3.48**	.09**
Orphanhood by other causes	.62*	.08*	.37	.04	-.73	-.02
Caregiver AIDS-sickness	1.13**	.11**	1.32***	.12***	5.51**	.11**
Caregiver with another sickness	.07	.01	.33	.03	-.40	-.01
R^2	.36***		.30***		.37***	
<i>F</i> (<i>df</i>)	32.59*** (11, 649)		25.09*** (11, 656)		34.28*** (11, 638)	

Note. All analyses control for 2005 depression, anxiety, and PTSD scores (as appropriate), as well as gender, age, household size, migration, and formal/informal housing; * $p < .05$; ** $p < .01$; *** $p < .001$.

increased symptomatology for all outcomes between 2005 and 2009. Having a caregiver with another sickness, or a healthy caregiver, were not significant predictors of changes in any psychological scores over time. The fact that AIDS-orphanhood and caregiver AIDS-sickness were significant predictors in the analyses, even though they were entered into the analyses simultaneously, indicates that they are independent predictors of increases in psychological distress across time.

Potential cumulative effects of AIDS-orphanhood and caregiver AIDS-sickness on changes in psychological symptoms were examined by entering dummy variables of AIDS-orphaned only, living with an AIDS-sick caregiver

only, and being ‘dual-affected’ into a series of linear regressions (controlling for 2005 depression, anxiety, and PTSD scores, respectively). After controlling for AIDS-orphanhood and caregiver AIDS-sickness, being “dual-affected” was a significant predictor of increased depression ($\beta = .13$, $p < .001$), anxiety ($\beta = .12$, $p < .001$), and PTSD ($\beta = .17$, $p < .001$) between 2005 and 2009 (Table III).

Discussion

Longitudinal analyses showed that AIDS-orphanhood and caregiver AIDS-sickness both independently predicted

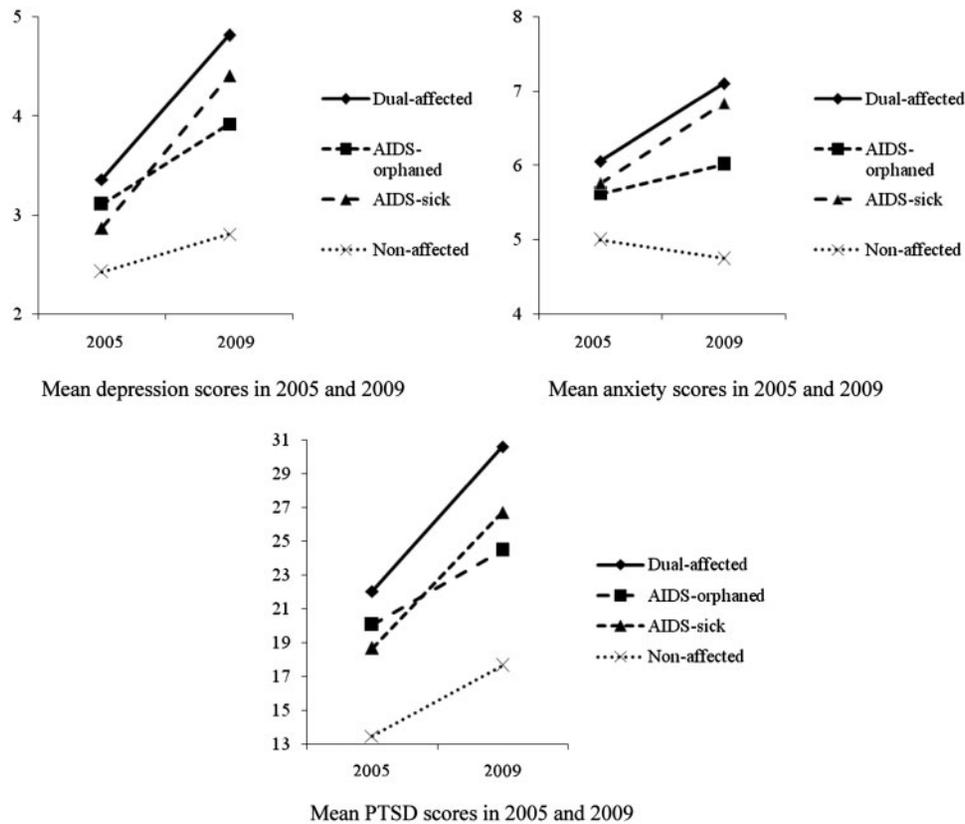


Figure 2. Change in depression, anxiety, and PTSD scores as a function of orphanhood status and caregiver sickness status. *Note.* Being dual-affected refers to being both AIDS-orphaned and living with an AIDS-sick caregiver. Being non-affected refers being neither AIDS-orphaned nor living with an AIDS-sick caregiver (however, these children may be orphaned by non-AIDS causes or be living with a caregiver who is sick with an illness unrelated to HIV/AIDS).

Table III. Summary of Regression Weights for being AIDS-Orphaned Only, Having an AIDS-Sick Caregiver Only, and Being “Dual-Affected” as Associated with Changes in Depression, Anxiety, and PTSD Scores Between 2005 and 2009

	Depression		Anxiety		PTSD	
	<i>B</i>	β	<i>B</i>	β	<i>B</i>	β
AIDS-orphaned only	.70*	.08*	.67*	.07*	2.98*	.07*
AIDS-sick caregiver only	1.22*	.07*	1.46*	.08*	2.16	.03
Dual-affected	1.71***	.13***	1.74***	.12***	11.11***	.17***
<i>R</i> ²	.35***		.29***		.37***	
<i>F</i> (<i>df</i>)	35.26*** (10, 650)		27.35*** (10, 657)		38.19*** (10, 639)	

Note. All analyses control for 2005 depression, anxiety, and PTSD scores (as appropriate), as well as gender, age, household size, migration, and formal/informal housing; **p* < .05; ***p* < .01 ****p* < .001.

worsening in mental health symptoms over a 4-year period. The similar standardized beta weights for both groups suggest that living with an AIDS-sick caregiver is associated with comparable levels of psychological distress to that of AIDS-orphanhood. Findings also showed a significant cumulative effect for depression, anxiety, and PTSD—i.e., that dual-affected youth are at a higher risk for poor mental health outcomes than those singly affected; and

the latter are at a higher risk than those with healthy, living parents.

These findings provide the first empirical evidence from the developing world to support the argument that the negative experience of AIDS-orphanhood is not only defined by parental death, but is equally experienced during a caregiver’s AIDS-symptomatic illness (Richter, Foster, & Sherr, 2006). It provides preliminary evidence

to suggest that anxiety levels may be even higher among youth with AIDS-affected caregivers than those orphaned by AIDS. Findings suggest that policy and programming targeted only at orphaned youth may be too late to address vulnerabilities already established in the pre-orphanhood period—i.e., that interventions should be focused not only at orphanhood, but rather at the larger group of AIDS-affected youth (Rotheram-Borus et al., 2006).

Findings also show that psychological impacts of caregiver AIDS-illness and AIDS-orphanhood are experienced not only during childhood, but endure into adolescence and early adulthood in this longitudinal sample. Thus, psychological impacts of living in an AIDS-affected family are both severe and influencing a developmentally wide age range. Finally, evidence of cumulative effects of being dual-affected suggests a group especially vulnerable to psychological distress. This study also adds to growing evidence for psychological effects of familial AIDS and HIV infection (Rochat et al., 2006). It is important that future research examines the impact of stages of caregiver HIV/AIDS on children, such as diagnosis, disclosure and AIDS-illness, and interactions between family illness and stage of youth development. These findings also support theoretical models of child psychological response to multiple disadvantages. Instead of an approach conceptualizing “orphanhood” as a unique state of high vulnerability, we could instead consider a model of exposure to AIDS-related trauma to predict youth internalizing symptomatology. It is likely that exposure to traumas such as caregiver sickness and death, and to HIV-compounded associated risk factors such as poverty and stigma are functioning both as risks and by reducing availability of resilience-promoting factors (Rutter, 2007). These findings also support models of “cumulative” trauma, suggesting that parental death and caregiver AIDS-illness compound each other’s effects.

It is also important to identify potential mechanisms, or pathways, by which caregiver AIDS-sickness may cause psychological distress. Among AIDS-orphaned children, stigma, hunger, and bullying have been shown to mediate distress (Cluver & Orkin, 2009). There is strong evidence throughout sub-Saharan Africa that familial AIDS-sickness and death leads to deepened household poverty, through loss of primary breadwinners, medical, and funeral expenses (Booyesen, 2004). There is also consistent evidence of increasing levels of stigma, both toward HIV-positive people and towards their families (Maughan-Brown, 2010), which may compound effects of consistently low rates of testing and access to antiretrovirals in South Africa (Aarif Adam & Johnson, 2009). In sub-Saharan Africa, terminal AIDS-care is often provided

at home, by family members, with little support from overburdened health services. Qualitative evidence suggests that youth undertake practical and emotional responsibility for palliative care (Skovdal & Ogutu, 2009). Future research could valuably examine impacts of becoming a “Young Carer,” as well as other potential pathways, on children’s mental health.

However, the theoretical models used in this study also suggest that negative impacts of trauma in one area of a young person’s life can be “buffered” by creating or boosting protective factors in another. Thus, it is essential that further research identifies resilience promoting factors in both the pre-orphanhood and orphanhood stages. For example, studies have found positive emotional responses of children to parental disclosure of HIV-positive status prior to severe illness (Rochat, Bland, Coovadia, Stein, & Newell, 2011). To date, however, there is almost no evidence for effective interventions with these groups. A recent Cochrane review (King, De Silva, Stein, & Patel, 2009) found no studies of psychosocial support interventions for AIDS-affected children. Since then, one study in Uganda has shown positive effects of support groups and intensive medical care for orphaned children (Kumakech, Cantor-Graae, & Maling, 2009), but the resource-intensive nature of this intervention may make replication difficult. There are a number of ongoing intervention trials that will provide valuable evidence in coming years.

This study has a number of limitations. First, although all scales had been previously used in this population, no standardized psychological scales and no clinical cut-off scores for this age group have been validated in Africa. Second, while this is the largest known sample to date of youth with AIDS-sick caregivers, it did not allow subgroup analyses of the effects of movements between orphanhood and sickness groups over time (notably AIDS-sick caregiver to AIDS-orphanhood). Future research could benefit from large, longitudinal studies. Third, due to low levels of HIV-testing, most youth participants did not know their own HIV-status and this study was unable to conduct HIV-antibody testing; however no participants were perinatally infected. Although most emotional distress associated with HIV-status occurs after illness and diagnosis (Rochat et al., 2006) there may be neurocognitive impacts, such as cognitive delays, associated with undiagnosed and asymptomatic HIV-infection, and these may have affected youth responses (Antinori et al., 2007). Fourthly, although it is always important to be cautious regarding attributed direction of causality, in this case reverse causality (i.e. youth distress causing parental HIV-infection) is unlikely. While we control for potential sociodemographic cofactors, future research may identify yet other

factors affecting caregiver HIV-infection and child psychopathology.

Finally, although validated for postmortem use, the verbal autopsy method has not been validated as a symptom checklist for determining AIDS-sickness. However, we used a conservative cut-off of 3+ AIDS-defining symptoms, and it is likely that any bias would be negative—i.e., youth unaware of caregiver symptoms (such as vaginal tumors). Thus, “false negatives” would have had the effect of reducing group differences between youth with AIDS-sick and other-sick caregivers, which in this study nevertheless remained highly significant. This study took place within a very high-violence, high-poverty urban area. Indeed, by 2009, 75% of participants had witnessed a fatal stabbing or shooting. This high level of violence exposure is reflected in high overall levels of PTSD and other symptoms among youth in these communities (Ensink, et al., 1997). Again, we might expect that this would have reduced group differences in psychological outcomes, yet they remained highly significant.

This study has some notable strengths. To our knowledge, it is the first study in the developing world to compare youth with AIDS-sick, other-sick, and healthy caregivers on psychological outcomes. It is the first known study to include both youth with AIDS-sick caregivers and AIDS-orphaned youth with nonaffected comparison groups, and it is the first longitudinal study of the mental health impacts on AIDS-affected youth in the developing world. The study uses standardized psychometric tools, which were piloted with AIDS-affected youth. Findings of this study demonstrate severe and negative psychological impacts of having an AIDS-sick caregiver, comparable in effect to that of AIDS-orphanhood, and worsening across time. It also demonstrates a new, particularly high-risk group of dual-affected youth. There is clearly a need for further research, policy attention, and interventions for both AIDS-orphaned youth, and for this hitherto hidden group of youth with AIDS-sick caregivers.

Acknowledgments

The authors wish to thank our fieldwork team: Somaya Latief, Naema Latief, Joy Nikelo, Julia Limba, Nomhle Panyana, Daphne Makasi, and Themabela Molwana. We would also like to thank Cape Town Child Welfare, the Western Cape Education Department, Pollsmoor Prison, The Homestead Shelter, Dr F. Fosby, and South African Airways. Most importantly, we thank all the participants, and their families.

Funding

This study was supported by grants from the Nuffield Foundation (grant number OPD/35198) and the Economic and Social Research Council (grant number RES-062-23-2068).

Conflicts of interest: None declared.

References

- Aarif Adam, M., & Johnson, L. (2009). Estimation of adult antiretroviral treatment coverage in South Africa. *South African Medical Journal*, *99*(9), 661–667.
- Amaya-Jackson, L. (1995). *Child PTSD Checklist*. North Carolina: Duke Treatment Service.
- Antinori, A., Arendt, G., Becker, J., Brew, B., Byrd, D., Cherner, M., . . . Wojna, V. E. (2007). Updated research nosology for HIV-associated neurocognitive disorders. *Neurology*, *69*(18), 1789–1799.
- Atzaba-Poria, N., Pike, A., & Deater-Deckard, K. (2004). Do risk factors for problem behaviour act in a cumulative manner? An examination of ethnic minority and majority children through an ecological perspective. *Journal of Child Psychology and Psychiatry*, *45*(4), 707–718.
- Bauman, L., Foster, G., Silver, E. J., Berman, R., Gamble, I., & Muchaneta, L. (2006). Children caring for their ill parents with HIV/AIDS. *Vulnerable Children and Youth Studies*, *1*(1), 56–70.
- Becker, S. (2007). Global perspectives on children’s unpaid caregiving in the family: Research and policy on ‘young carers’ in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy*, *7*(1), 23–50.
- Bhargava, A. (2005). AIDS epidemic and the psychological well-being and school participation of Ethiopian orphans. *Psychology, Health and Medicine*, *10*(3), 263–275.
- Black, D., & Harris-Hendricks, K. (1992). Father kills mother: Post-Traumatic Stress Disorder in the children. *Psychotherapy and Psychosomatics*, *57*, 152–157.
- Booyesen, F. (2004). Income and poverty dynamics in HIV/AIDS-affected households in the Free State province of South Africa. *South African Journal of Economics*, *72*(3), 522–545.
- Boyes, M., & Cluver, L. (in press). Performance of the Revised Children’s Manifest Anxiety Scale in a sample of children and adolescents from poor urban communities in Cape Town. *European Journal of Psychological Assessment*.

- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge: Harvard University Press.
- Cicchetti, D., & Cohen, D. J. (2006). *Developmental psychopathology* (2nd ed.). Hoboken, N.J.: Wiley.
- Cluver, L., & Gardner, F. (2007). Mental health of children orphaned by AIDS: A review of International and Southern African research. *Journal of Child and Adolescent Mental Health*, 19(1), 1–17.
- Cluver, L., Gardner, F., & Operario, D. (2007). Psychological distress amongst AIDS-orphaned children in urban South Africa. *Journal of Child Psychology and Psychiatry*, 48(8), 755–763.
- Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2011). Educational shortfalls among ‘Young Carers’ in the South African AIDS Epidemic. *Journal of Adolescent Research*, Advance online publication. doi:10.1177/0743558411417868
- Cluver, L., & Orkin, M. (2009). Stigma, bullying, poverty and AIDS-orphanhood: Interactions mediating psychological problems for children in South Africa. *Social Science and Medicine*, 69(8), 1186–1193.
- Cluver, L., Orkin, M., Boyes, M. E., Gardner, F., & Meinck, F. (2011). Transactional sex amongst AIDS-orphaned and AIDS-affected adolescents predicted by abuse and extreme poverty. *Journal of Acquired Immune Deficiency Syndromes* 58, 336–343.
- Copeland, W., Keeler, G., Angold, A., & Costello, E. J. (2007). Traumatic events and posttraumatic stress in childhood. *Archives of General Psychiatry*, 64, 577–583.
- Ensink, K., Robertson, B., Zissis, C., & Leger, P. (1997). Post-traumatic stress disorder in children exposed to violence. *South African Medical Journal*, 87(11), 1526–1530.
- Evans, J., & Becker, S. (2010). *Children caring for parents with HIV and AIDS: Global issues and policy responses*. Bristol: Policy Press.
- Fang, X., Li, X., Stanton, B., Hong, Y., Zhang, L., Zhao, G., . . . Lin, D. (2009). Parental HIV/AIDS and psychosocial adjustment among rural Chinese children. *Journal of Pediatric Psychology*, 34(10), 1053–1062.
- Forehand, R., Jones, D., Kotchick, B., Armistead, L., Morse, E., Simon Morse, P., & Stock, M. (2002). Noninfected children of HIV-infected mothers: A 4-year longitudinal study of child psychosocial adjustment and parenting. *Behavior Therapy*, 33, 579–600.
- Forrest, G., Plumb, C., Ziebland, S., & Stein, A. (2006). Breast cancer in the family—children’s perceptions of their mother’s cancer and its initial treatment: Qualitative study. *British Medical Journal*, 332(7548), 998–1003.
- Gwandure, C. (2007). Home-based care for parents with AIDS: Impact on children’s psychological functioning. *Journal of Child and Adolescent Mental Health*, 19(1), 29–44.
- Kahn, K., Tollman, S., Garenne, M., & Gear, J. (2000). Validation and application of verbal autopsies in a rural area of South Africa. *Tropical Medicine and International Health*, 5, 824–831.
- King, E., De Silva, M., Stein, A., & Patel, V. (2009). Interventions for improving the psychosocial well-being of children affected by HIV and AIDS. *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD006733. doi:10.1002/14651858.CD006733.pub2
- Kovacs, M. (1992). *Children’s Depression Inventory*. Niagra Falls, NY: Multi-health Systems.
- Kumakech, E., Cantor-Graae, E., & Maling, S. (2009). Peer-group support intervention improves the psychosocial well-being of AIDS orphans: Cluster randomized trial. *Social Science and Medicine*, 68(6), 1038–1043.
- Kuo, C., & Operario, D. (2009). Caring for AIDS-orphaned children: A systematic review of studies on caregivers. *Vulnerable Children and Youth Studies*, 4(1), 1–12.
- Lopman, B., Barnabas, R., Boerma, T., Chawira, J., Gaitskell, K., Harrop, T., . . . Gregson, S. (2006). Creating and validating an algorithm to measure AIDS mortality in the adult population using verbal autopsy. *Public Library of Science Medicine*, 3(8), 1273–1281.
- Makame, V., Ani, C., & McGregor, S. (2002). Psychological well-being of orphans in Dar El-Salaam, Tanzania. *Acta Paediatrica*, 91, 459–465.
- Maughan-Brown, B. (2010). Stigma rises despite antiretroviral roll-out: A longitudinal analysis in South Africa. *Social Science & Medicine*, 70(3), 368–374.
- Mellins, C., Elkington, K., Bauermeister, J., Brackis-Cott, E., Dolezal, K., McKay, M., . . . Abrams, E. J. (2009). Sexual and drug use behavior in perinatally HIV-infected youth: Mental health and family influences. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48(8), 810–819.
- Murphy, D., Marelich, W., & Hoffman, D. (2002). A longitudinal study of the impact on young children

- of maternal HIV serostatus disclosure. *Clinical Child Psychology and Psychiatry*, 7(1), 55–70.
- Nyamukapa, C., Gregson, S., Lopman, B., Saito, S., Watts, H., Monasch, R., & Jules, M. C. (2008). HIV-associated orphanhood and children's psychosocial distress: Theoretical framework tested with data from Zimbabwe. *American Journal of Public Health*, 98(1), 133–141.
- Pelton, J., & Forehand, R. (2005). Orphans of the AIDS epidemic: An examination of clinical level problems of children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(6), 585–591.
- Peltzer, K., Matseke, G., Mzolo, T., & Majaja, M. (2009). Determinants of knowledge of HIV status in South Africa: Results from a population-based HIV survey. *BMC Public Health*, 9(1), 174.
- Reynolds, C., & Richmond, B. (1978). What I think and feel: A revised measure of children's anxiety. *Journal of Abnormal Child Psychology*, 6, 271–280.
- Richter, L., Foster, G., & Sherr, L. (2006). *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*. Toronto: Bernard Van Leer Foundation.
- Rochat, T., Bland, R., Coovadia, H., Stein, A., & Newell, M. (2011). Towards a family-centred approach to HIV treatment and care for HIV-exposed children, their mothers and their families in poorly resourced settings. *Future Virology*, 6(6), 687–696.
- Rochat, T., Richter, L., Doll, H., Buthelezi, N., Tomkins, A., & Stein, A. (2006). Depression among pregnant rural South African women undergoing HIV testing. *Journal of the American Medical Association*, 295(12), 1376–1378.
- Rotheram-Borus, M., Lester, P., Song, J., Lin, Y., Leonard, N., Beckwith, L., . . . Lord, L. (2006). Intergenerational benefits of family-based HIV interventions. *Journal of Consulting and Clinical Psychology*, 74, 622–627.
- Rotheram-Borus, M., Stein, J. A., & Lin, Y. (2001). Impact of parent death and an Intervention on the adjustment of adolescents whose parents have HIV/AIDS. *Journal of Consulting and Clinical Psychology*, 69(5), 763–773.
- Rutter, M. (1966). *Children of sick parents*. Oxford: Oxford University Press.
- Rutter, M. (2005). Environmentally mediated risks for psychopathology: Research strategies and findings. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(1), 3–18.
- Rutter, M. (2007). Resilience, competence, and coping. *Child Abuse and Neglect*, 31, 205–209.
- Seedat, S., van Nood, E., Vythilingum, B., Stein, D., & Kammer, D. (2000). School survey of exposure to violence and posttraumatic stress symptoms in adolescents. *Southern African Journal of Child and Adolescent Mental Health*, 12, 38–44.
- Sherr, L., Varrall, R., Mueller, J., Richter, L., Wakhweya, A., Adato, M., . . . Chandan, U. (2008). A systematic review on the meaning of the concept 'AIDS Orphan': Confusion over definitions and implications for care. *AIDS Care*, 20(5), 527–536.
- Skinner, D., Tsheko, N., Mtero-Munyati, S., Segwabe, M., Chibatamoto, P., Mfecane, S., . . . Chitiyo, G. (2006). Towards a definition of orphaned and vulnerable children. *AIDS and Behavior*, 10(6), 619–626.
- Skovdal, M., & Ogotu, V. (2009). "I washed and fed my mother before going to school": Understanding the psychosocial well-being of children providing chronic care for adults affected by HIV/AIDS in Western Kenya. *Globalisation and Health*, 5(8), doi:10.1186/1744-8603-5-8
- Suliman, S. (2002). *Assessing post-traumatic responses among South African Adolescents: a comparison of different methods*. Unpublished manuscript, University of Cape Town, Cape Town.
- UNAIDS. (2004). *Children on the Brink 2004: A joint report of new orphan estimates and a framework for action*. New York: UN.
- UNAIDS. (2010). *Report on the global AIDS epidemic*. Geneva: UN.
- Visser, A., Huizinga, G., van der Graaf, W., Hoekstra, H., & Hoekstra-Weebers, J. (2004). The impact of parental cancer on children and the family: A review of the literature. *Cancer Treatment Reviews*, 30, 683–694.