Title: Mental Health of Youth Orphaned due to AIDS in South Africa: Biological and Supportive Links to Caregivers

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Title: Mental Health of Youth Orphaned due to AIDS in South Africa: Biological and Social Protection from Caregivers

Youth orphaned due to AIDS have significantly higher levels of depression, anxiety, and post-traumatic stress (PTS) symptoms compared to those orphaned due to other causes and non-orphans. This research explored the biological and social support relationship between the youth and his/her caregiver to identify protective factors that are related to positive mental health outcomes. **Methods:** Using a 2009 cross-sectional data set 254 youth orphaned due to AIDS were purposively selected from the overall sample of 732 youth to further examine their relationship with their caregiver in neighborhoods surrounding Cape Town, South Africa. Multivariate analyses were used to estimate regression models to identify variables that are related to depression, anxiety, and PTS symptoms as well as suicidal tendencies among youth orphaned due to AIDS. **Results:** Caregiver relation was analyzed in several combinations to determine if it was significantly related to mental health outcomes, with only anxiety showing significance. Specifically the anxiety score for those living with a biological parent was significantly higher than those living with a grandparent, other kin, or non-kin. Anxiety was also significantly related to an increased age, lower levels of emotional support, and lower levels of instrumental/financial support (R^2= .153). Age was the only significant variable from the model that was related to depression symptoms (R^2 = .111). PTS symptoms were related to increases in age, lower levels of emotional support, instrumental/financial support, and satisfaction with the caregiver (R^2 = .194). Gender and age were related to suicidal tendencies, specifically boys were 2.26 times more likely to exhibit suicidal tendencies compared to girls and every yearly increase in age results in the youth being 1.22 times more likely to exhibit suicidal tendencies. **Conclusion:** Strengthening the caregiver's ability to provide social support for the child is

critical, irrespective of any biological kin relationship. Interventions should integrate regular mental health screenings and referrals as a standard of care for youth orphaned due to AIDS.

Key Words: Orphans, HIV, AIDS, Mental Health, Caregivers, Social Support

South Africa has over 5 million people living with HIV with 2.1 million children having lost one or more parents due to AIDS. (UNAIDS, 2012). Many children experienced orphan-hood at an early age, and during adolescence (10-19) they may lack parental guidance that supports optimal psychosocial adjustment (Cluver, Operario, & Gardner, 2009; King, De Silva, Stien, & Patel, 2009). This loss can impact the child's well-being throughout their lifetime (Atwine, Cantor-Graae, & Bajunirwe, 2005; Li et al., 2008;).

A study by Cluver, Gardner, and Operario (2007) examined the mental health of over 900 children who were matched in three comparison groups: those orphaned due to AIDS, those orphaned from other causes, and non-orphaned children. Results showed those orphaned due to AIDS had significantly higher levels of depression, anxiety, and post-traumatic stress (PTS) symptoms compared to the other groups. Longitudinal follow-up in 2009 showed significantly worse mental health among those orphaned due to AIDS, compared to the other groups (Cluver, Orkin, Gardner, & Boyes, 2012). Due to persistent mental health problems among these youth orphaned due to AIDS this study purposively chose to further investigate this population using the 2009 cross-sectional data. Isolating this population may lead to a better understanding of protective and risk factors associated with caregiver social support, caregiver relation, and mental health outcomes. Bronfenbrenner's ecological theory is a useful framework for studying children affected by HIV, as a child's primary relationship in their environment is with his/her caregiver (Betanacourt, et al., 2013; Bronfenbrenner, 1986). This relationship is both biological and social, and further understanding how blood relations and social support may lead to protective interventions.

Mental Health and Psychosocial Adjustment

Although children orphaned due to AIDS have much higher rates of psychological stress compared to those orphaned by other causes (Cluver, Orkin, Gardner; & Boyes, 2012; Makame et al., 2002), many studies on orphans and vulnerable children focus on how to best meet financial and educational needs. Only recently have studies emerged examining psychological well-being (Allison, 2012). Additionally children orphaned due to AIDS experience additional issues which may complicate the process of individuation and psychosocial adjustment associated with adolescence (Atwine, et al., 2005; Cluver et al., 2009; King et al., 2009). How a child behaves in grief fluctuates, making it difficult for caregivers to recognize symptoms and to provide appropriate support (Foster, 2002). A trusting, positive relationship with a caregiver can be protective for a child orphaned due to AIDS (Chi & Li, 2013). Having one caring adult who provides support is associated with stronger well-being among youth affected by HIV (Chi & Li, 2013; Daniel et al., 2007).

Caregiver Social Support to Youth

Caring for children who are orphaned continues to be a family concern in sub-Saharan Africa with kinship care being preferred (Richter et al., 2009; Freeman & Nkomo, 2006). Bronfenbrenner's ecological theory identifies how social support functions in a child's microsystem (Betanacourt, Meyers-Ohki, Charrow, & Hansen, 2013). Bronfenbrenner (1979) notes: "the availability of supportive settings is, in turn, a function of their existence and frequency in a given culture or subculture" (p. 7). Close relationships with caregivers are known to promote resiliency among children (Betancourt & Khan, 2008; Daniel et al., 2007). A child's development emerges via interactions with their environment (Bronfenbrenner, 1986) and ecological theory provides a framework to better understand the importance of caregiver social support.

Caregiver Biological Relationship with Youth

Caregivers are primarily biological kin (a remaining parent, grandparents, or other extended family) or non-kin, which may include a foster parent or institution (Allison, 2012; Littrell et al., 2011). In South Africa approximately 90% of children orphaned due to AIDS are cared for by biological kin (Allison, 2012; Karimli, et al., 2012). The kinship system is the primary safety net that can become overextended emotionally and financially in high HIV prevalence settings (Heymann & Kidman, 2009; Richter et al., 2009). Few studies examine the correlation between the biological relations of caregivers and a youth's mental health (Cluver et al., 2009; Zhao et al., 2010). This information is useful as new care-giving models are emerging in response to HIV (Chirwa, 2002; Freeman & Nkomo, 2006; Karimli et al., 2012; Nyamukapa et al., 2010). Despite numerous programs focused on psychosocial well-being, there is little evidence to inform programmers and policy makers about the specific variables related to improved mental health of those orphaned due to AIDS (Schenke, 2009).

Little is known about potential protective links between the caregiver's delivery of social support to the youth and the caregiver's biological relationship. Understanding this interplay may between the caregiver's relationship (social and biological) with the child can inform interventions that strengthen the resiliency of children (Atilola, 2014; Betanacourt, et al., 2013; Bronfenbrenner, 1994). This research had two aims: first, to examine how caregiver social support relates to mental health of children orphaned due to AIDS; and second, to examine how the caregiver's specific relationship (biological or non-biological) to the child relates to his/her mental health.

Methods

Study Participants

In 2005, 1025 youth were recruited into a study designed to examine psychological distress in peri-urban communities surrounding Cape Town, South Africa. Participants were recruited from household door-to-door visits in 10 settlements, 9 schools, and 18 community organizations. The study purposively sampled those orphaned due to AIDS (N=425) and compared them to other orphans (N=241) and non-orphaned controls (N=278) to examine in depth the particular vulnerabilities and resilience factors associated with each population (Cluver et al., 2009). In 2009, 71% of the original youth were located and re-interviewed (N=723). Orphan status was re-assessed in 2009 with 266 reporting they were orphaned due to AIDS, 228 other-orphaned, 180 non-orphaned, and 49 excluded from analysis due to uncertainty of orphan status. Of those 266 youth, 254 reported they had a caregiver. Challenges related to locating children from the 2005 data included the high levels of mobility experienced by the youth (Cluver et al., 2012). This research used the 2009 cross-sectional data set, examining in depth the caregiver relationship among those 254 youth orphaned due to AIDS from the overall. All 254 youth were living in neighborhoods formerly designated for Black Africans under apartheid, with high rates of violence, unemployment, population density, HIV prevalence (23-30%), and poverty (Cluver et al., 2010). Ethical approval was obtained by Oxford University, University of Cape Town, and the Western Cape Education Department. Adolescents and caregivers gave voluntary informed consent and assent verbally and in writing.

Measures

Determining parental death. In South Africa, death certificates and clinical data are unreliable regarding AIDS therefore the "Verbal Autopsy" technique was used to determine parental death. This technique was validated in previous studies of adult mortality in South Africa (Kahn, Tollman, Garenne, & Gear, 2000). Stage 4 AIDS-illness was identified using a

conservative threshold of youth identifying three or more AIDS-defining illnesses. When diagnoses were unclear, symptoms were reviewed independently by two medical professionals and substantiated by teachers and surviving parents where possible. A total of 46 orphaned children were excluded from the 2009 data because cause of death could not be determined.

Mental health measures. Depression, anxiety, and PTS symptoms as well as suicidal tendencies were measured using standardized scales all previously used with vulnerable children in Cape Town (Wild, Flisher, Laas, & Robertson, 2006 July). The 10-item Child Depression Inventory short-form (Kovacs, 1992) has been frequently used in South Africa (Cluver, Orkin, Boyes, Gardner, & Nikelo, 2012). The short form exhibits good psychometric properties and has comparable results with the full CDI (Kovacs, 1992). Internal consistency was .78. Anxiety was measured by Children's Manifest Anxiety Scale-Revised (Reynolds &Richmond, 1978). The 28-item scale shows good reliability and validity (Gerard & Reynolds, 1999) and has been used in South Africa (Wild, Flisher, Laas, & Robertson, 2006 July). Internal consistency was .83. PTS was measured by Child PTSD Checklist, a 29-item scale developed from the DSM-IV criteria and has been used extensively in South Africa (Seedat et al., 2004). This scale was accompanied by drawings from the Levonn/Andile PTSD scale (Richters, Martinez, & Valla, 1990), to improve accessibility for Xhosa speaking adolescents (Cluver et al., 2007). Internal consistency was .94. The scales were totaled and cut-offs avoided as there are no clinical cut-offs validated in Africa (Cluver et al., 2012). All analyses used the total continuous scores these three scales. Suicidal tendencies were measured by Mini-International Psychiatric Interview for Children and Adolescents (Sheehan, Shytle, & Milo, 2004) with internal consistency of .64 as a continuous variable in the current sample. In this paper the five question scale was dichotomized

with youth who answered yes to one or more of these questions being identified as having suicidal tendencies.

Caregiver social support measures. Caregiver social support was measured using the Social Support Scale (Adolescent Pathways Project, 1992) which was developed to 1) measure social support within microsystems; 2) be appropriate for poor, inner-city adolescents; and 3) be brief (Seidman et al., 1995). The scale identifies six sources of social support identified and has been used in Cape Town (Van der Merwe & Dawes, 2000). The internal consistency was .80 for the caregiver social support subscale. Youth reported caregiver social support in three domains (emotional, instrumental/financial, and satisfaction).

Caregiver relation. Youth were asked if they had a parent, guardian or caregiver staying with and taking care of them at home, which resulted in 25 descriptors that were collapsed into four categorical variables (parent, grandparent, other-kin, non-kin) which in multivariate analysis will be summarize into domains with the non-kin variable as the reference category.

Statistical Analyses Plan

Data were analyzed using SPSS with gender differences being assessed using independent sample t-tests for continuous variables and chi-square for categorical background characteristics. Data analyses included stepwise multiple regression analyses (MRA), using the enter block method, to estimate the regression models that relate to depression, anxiety, and PTS symptoms among the 254 youth. Logistic regression was conducted to estimate a regression model to show the probability of reporting suicidal tendencies among these 254 youth. In all, 10 factors were entered using enter block method, block one entered age, gender, age of first orphanhood, type of orphan (double or mother only), parent caregiver, grandparent caregiver, other kin caregiver), block two entered the remaining four variables to show perceived caregiver

support (having a person, emotional support, instrumental/financial support, and perceived satisfaction). Regression results are shown in Tables 2-5.

Findings

Descriptive Characteristics

The mean age of male and female participants was 17.0 years, with an age range of 11-24. The mean age of first orphan-hood was 9.1 years for girls and 9.6 years for boys. The mean household size was 5 and the majority of males (64%) and females (55%) lived in a home of brick/concrete. Less than half lived with a parental caregiver (female=41%, male=38%). Thirty-one percent females and 35% males reported losing their mother to AIDS. Thirty-three percent females and 42% males reported losing their father to AIDS. Additionally 36% of the females and 17% of the males reported losing both parents to AIDS. The results of the descriptive analyses are shown in Table 1 and revealed a significantly higher rate of suicidal tendencies among girls (36%) compared to boys (23%). No other background characteristics were significantly different.

[Insert Table 1 Here]

Mental Health Outcomes

Depression symptoms. MRA showed a significant relationship between age, perceived satisfaction with caregiver support, and depression symptoms. Older youth and those who were less satisfied with their caregiver social support were more likely to report depression symptoms ($F(10,231) = 2.760$, $p<.01$). Increased age ($B=.205$, $p<.05$) and lower levels of caregiver satisfaction ($B=-.181$, $p<.05$) related to depression symptoms. Both accounted for 11.1% of the variance in depression symptoms ($R^2 =.111$).

Anxiety symptoms. Regressions showed three variables significantly related to anxiety symptoms, these were increased age (B=.153, p<.05), having a biological parent as the caregiver (B=.339, p<.05), and lower levels of caregiver satisfaction (B= -.200, p<.05). Increased age, having a biological parental caregiver, and low levels of satisfaction with the support the caregiver provides were significantly related to anxiety symptoms (F(10,231)=3.994, p<.001) in this model. These three variables accounted for 15.3% of the variance in anxiety (R^2=.153). Additionally an independent t-test showed that those with a caregiver who was sick with AIDS was significantly related to higher anxiety symptoms among youth (t=-3.259, p<.01).

Post-traumatic stress symptoms. MRA showed that increased age, higher levels of emotional support, and lower levels of satisfaction with caregiver support related to PTS symptoms (F (10, 219) = 5.038, p<.001). As youth age they are more likely they reported PTS symptoms (B=.160, p<.05). Higher levels of caregiver emotional support (B=.214, p<.05), and lower levels of satisfaction with caregiver support (B=-.304, p<.05) were related to higher PTS symptoms. All three variables accounted for 19.4% of the variance in PTS symptoms (R^2 =.194).

Suicidal tendencies. The results of the logistic regression (Table 5) revealed two factors significantly related to suicidal tendencies. These factors were age (Wald (df=1) = 10.289, p<.01) and gender (Wald (df=1) = 6.267, p<.05). Boys were 2.25 times more likely to exhibit suicidal tendencies compared to girls. Additionally, every yearly increase in age resulted in the youth being 1.22 times more likely to exhibit suicidal tendencies. Bivariate analysis showed girls had significantly higher numbers of reported suicidal tendencies, however in the multivariate analysis the impact of gender is reversed. This indicates an interaction effect may

be operating, which may suggest gender is a moderator in the regression model and further research is needed.

Caregiver relation. With each group MRA were run to identify significance in biological/non-biological relationships to the youth's mental health. This allowed for a full examination between the biological relation to the primary caregiver and mental health. Anxiety was the only outcome that showed a significant difference when the caregiver was analyzed as four groups, specifically the anxiety score was significantly higher for those living with a biological parent compared to those living with a grandparent, other kin, or non-kin. All other mental health outcomes (suicidal tendencies, depression and PTS symptoms) did not show any significance when analyzed with caregiver relationship regardless of how the caregiver relation variable was analyzed (e.g. 4 groups, 3 groups, or 2 groups).

[Insert Table 2-5 here]

Discussion and Implications

Biological caregiver relationships were not related to the mental health in the majority of these analyses. The transfer of social support from caregiver to the child is important and not necessarily linked to a biological relationship. All caregivers occupy a central and critical role and programs should recognize that reality and reinforce the caregiver relationship in all family strengthening efforts (Richter et al., 2009). However, it is important to note that youth in this study who were living with a parent had significantly higher anxiety symptoms than those not living with a parent. Further analysis uncovered a significant relation between anxiety symptoms and having a parent sick with AIDS, reinforcing findings from a South African study where 60% of adult caregivers were experiencing moderate-to-high anxiety which may influence the child as she/he cares for the remaining parent, however further analyses is needed (Casale, Wild, Cluver,

& Kuo, 2014; Kuo & Operario, 2011). These results indicate the need for stronger supportive services to target those youth who are living with their remaining parent.

Additionally these data strongly indicate that access to regular mental health assessment and support is critical for all youth orphaned due to AIDS, and this need increases as the youth ages. A stepped care approach (1. screen, 2. intervene, and 3. refer) can identify the need for further mental health support/referrals (Beaglehole et al., 2008). Stepped care provides screening at the lowest appropriate service level with linkages to more specialized services (Thornicroft & Tansella, 2004). As older youth are less likely to be in school, programs should use health and community care workers at health facilities and/or community service organizations to implement rapid screening/referrals. Additionally health/community workers could provide basic therapeutic interventions with limited training/support (Beaglehole et al., 2008). This may improve access among youth at the community level, as mental health services in South Africa are available but not widely accessible. There is a very limited number of trained psychiatric nurses practicing (Atwine, et al., 2005), and this cadre could be identified to provide higher level care after a community screen. Improving access to services is important as HIV and depression are leading causes of morbidity among youth ages 10-24 globally (Tylee et al., 2007).

While this information can help programs and policy makers, there are also important limitations that must be recognized. First, although the scales have been used with this population previously, they lack validated clinical cut-off for youth in Africa. Additionally cross-sectional data limits any references to causality between the variables. Thirdly, the findings may not be generalizable due to non-representative sampling methods, however the large number of youth orphaned due to AIDS helps to control for background characteristics.

Fourthly, the data were collected retrospectively and findings do not distinguish when metnal health distress was experienced in relation to orphan-hood, important in the context of the multiple losses associated with HIV (Cluver et al., 2009). Fifthly, the study did not collect data from the caregivers about their relationships, which would be useful to compare with the child's perception. Future research should collect information from the child and his/her caregiver to more deeply understand the relationship's protective nature on mental health.

Findings from this study show that satisfaction with caregiver support was significant for positive mental health, and interventions should continue to focus on strengthening caregiver's ability to provide positive support to youth orphaned due to AIDS irrespective of the caregiver's blood relation. This research supports the international policy and programmatic continued shift towards strengthening families and caregivers so they are able to care for youth orphaned due to AIDS (United States Government, 2012; UNICEF, 2010). Educating caregivers about the importance of protective and supportive care should continue to be a focus of all international policies and programs. Strengthening families to care for orphaned children and adolescents should continue to reach beyond biological parents to include other relatives and community caregivers.

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Table 1: Description of Participants

Youth orphaned due to AIDS (N=254)	Female	Male	λ^2 p	t-test p
Gender N (%)	131 (52%)	121 (48%)		
Age M(SD)	17.0 (2.7)	17.0 (2.6)		.87
Age of first orphanhood M(SD)	9.1 (4.0)	9.6 (4.3)		.42
Under 15 N (%)	23 (17%)	22 (18%)	.96	
15-19	68 (52%)	64 (52%)		
20-25	40 (31%)	35 (29%)		
Household size M(SD)	5.0 (2.2)	5.5 (2.4)		.14
Home is brick or concrete N (%)	72 (55%)	77 (64%)	.20	
Other	59 (48%)	44 (36%)		
Mother deceased	41 (31%)	42 (35%)	.21	
Father deceased	44 (33%)	51 (42%)		
Both deceased	34 (36%)	20 (17%)		
Unknown	12 (9%)	8 (7%)		
Parent caregiver N(%)	53 (41%)	46 (38%)	.77	
Grandparent caregiver	27 (21%)	22 (18%)		
Kin caregiver	44 (34%)	48 (40%)		
Non-kin caregiver	7 (5%)	5 (4%)		
Depression Symptoms M(SD)	4.1 (3.5)	3.7 (3.4)		.37
Anxiety Symptoms M(SD)	5.8 (3.7)	6.0 (3.7)		.69
PTS Symptoms M(SD)	23.8 (15.3)	25.9 (19.3)		.35
Suicidal Tendencies N(%)	47 (36%)	28 (23%)	.04*	

*p<.05

Table 2: Regression of Depression Symptoms

Depression Symptoms	Step 1					Step 2				
	B	Beta	SEB	t	P	B	Beta	SEB	t	P
Gender	-.595	-.084	.456	-1.307	.193	-.612	-.087	.452	-1.353	.177
Age	.273	.205	.087	3.146	**.002***	.252	.189	.087	2.892	**.004***
Orphaned (Mother Dead or Double)	-.968	-.135	.587	-1.648	.101	-1.032	-.144	.587	-1.751	.081
Caregiver Biological Relationships**										
Parent	.500	.069	1.138	.439	.661	.567	.078	1.133	.501	.617
Grandparent	.204	.023	1.162	.175	.861	.399	.045	1.164	.343	.732
Other Kin	.648	.089	1.105	.586	.558	.634	.087	1.115	.569	.570
Caregiver Social Support Relationships										
Presence						-.857	-.054	1.143	-.750	.454
Emotional						.146	.019	.704	.207	.836
Instrument/Financial						.233	.032	.656	.355	.723
Satisfaction						-1.539	-.181	.774	-1.988	**.048***
R Squared					.078					.111

*p<.05; **reference category is non-kin

Table 3: Regression of Anxiety Symptoms

Anxiety Symptoms	Step 1					Step 2				
	B	Beta	SEB	t	p	B	Beta	SEB	t	p
Gender	.087	.012	.474	.184	.854	.044	.006	.460	.096	.924
Age	.254	.183	.090	2.818	**.005***	.213	.153	.089	2.400	**.017***
Orphaned (Mother Dead or Double)	-.494	-.066	.611	-.808	.420	-.452	-.060	.600	-.754	.452
Caregiver Biological Relationships**										
Parent	2.620	.347	1.184	2.213	**.028***	2.559	.339	1.153	2.219	**.028***
Grandparent	1.665	.179	1.209	1.377	.170	1.706	.183	1.185	1.439	.151
Other Kin	1.896	.249	1.150	1.649	.101	1.554	.204	1.135	1.369	.172
Caregiver Social Support Relationships										
Presence						-2.102	-.127	1.164	-1.806	.072
Emotional						.739	.094	.717	1.032	.303
Instrument/Financial						-.533	-.070	.668	-.798	.426
Satisfaction						-1.772	-.200	.788	-2.248	**.026***
R Squared					.083					.153

*p<.05; ; **reference category is non-kin

Table 4: Regression of PTS Symptoms

PTS Symptoms	Step 1					Step 2				
	B	Beta	SEB	t	p	B	Beta	SEB	T	p
Gender	1.560	.045	2.288	.682	.496	1.060	.031	2.175	.487	.627
Age	1.296	.201	.430	3.010	**.003***	1.030	.160	.414	2.485	**.014***
Orphaned (Mother Dead or Double)	-2.262	-.064	2.914	-.776	.438	-1.725	-.049	2.797	-.617	.538
Caregiver Biological Relationships**										
Parent	1.616	.046	5.558	.291	.771	1.170	.033	5.292	.221	.825
Grandparent	-4.902	-.112	5.696	-.861	.390	-4.458	-.102	5.456	-.817	.415
Other Kin	-.856	-.024	5.399	-.159	.874	-2.824	-.079	5.220	-.541	.589
Caregiver Social Support Relationships										
Presence						-7.995	-.101	5.596	-1.429	.155
Emotional						8.059	.214	3.383	2.382	**.018***
Instrument/Financial						-4.745	-.130	3.140	-1.511	.132
Satisfaction						-12.773	-.304	3.788	-3.372	**.001***
R Squared					.087					.194

*p<.05; **reference category is non-kin

Table 5: Logistic Regression Relations to Suicidal Tendencies

Factor	B	Wald	p	Odds-ratio
Gender	.814	6.267	**.012***	**2.256**
Age	.201	10.289	**.001***	**1.223**
Orphaned (Mother Dead or Double)	.287	.487	.485	1.333
Caregiver Biological Relationships				
Parent	.303	.163	.686	1.354
Grandparent	.775	.926	.336	2.170
Other Kin	-.218	.088	.766	.805
Caregiver Social Support Relationships				
Presence	.624	.714	.398	1.867
Emotional	.596	1.634	.201	1.815
Instrument/Financial	.032	.005	.943	1.033
Satisfaction	.625	1.591	.207	1.869

*p<.05