



Published in final edited form as:

AIDS Care. 2011 September ; 23(9): 1128–1135. doi:10.1080/09540121.2011.554527.

Health of adults caring for orphaned children in an HIV endemic community in South Africa

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Abstract

In South Africa, an estimated 2.5 million children have been orphaned by AIDS and other causes of adult mortality. Although there is a growing body of research on the well-being of South African orphaned children, few research studies have examined the health of adult individuals caring for children in HIV endemic communities. The cross-sectional survey assessed prevalence of general health and functioning (based on Short-Form 36 version 2 scale), depression (based on Center for Epidemiologic Studies-Depression scale), anxiety (using Kessler-10 scale), and post-traumatic stress (using the Harvard Trauma Questionnaire) among a representative community sample of adults caring for children in Umlazi Township, an HIV endemic community in South Africa. Of 1599 respondents, 33% (n=530) were carers of orphaned children. Results showed that, overall, carers reported poor general health and functioning, and elevated levels of depression, anxiety, and post-traumatic stress. Carers of orphaned children reported significantly poorer general health and functioning and higher rates of depression and post-traumatic stress compared to carers of non-orphaned children. In multivariate analyses, orphan carer and non-orphan carer differences in general health were accounted for by age, gender, education, economic assets, and source of income, but differences in depression were independent of these co-factors. Interventions are needed to address physical and mental health of carers in general. Greater health problems among orphan carers appeared to be fully explained by socioeconomic characteristics, which offer opportunities for targeting of programs. More research is needed to understand determinants of mental health disparities among orphan carers, which were not explained by socioeconomic characteristics.

Keywords

South Africa; general health and functioning; mental health; depression; anxiety; post traumatic stress; HIV/AIDS; orphan carer

Introduction

In South Africa, 2.5 million children have been orphaned by AIDS and other causes of adult mortality (UNICEF, 2007), and numbers of orphaned children are projected to increase steadily in the coming decade (UNAIDS, 2008). Supporting orphaned children will pose long-term challenges to families and communities, especially because institutional care for orphaned children is uncommon in South Africa. It has been argued that the large number of orphaned children will have a major impact on families and households, and might

particularly affect the capacity of adult carers to support a potentially increasing number of children per household (Madhavan, 2004).

Little is known about the adults who provide care to orphaned children in South Africa. Some researchers have suggested that adults who are most likely to care for orphaned children in sub-Saharan Africa are themselves vulnerable to health, social, and economic problems (Bachman DeSilva et al., 2008; Heuveline, 2004; Ssengonzi, 2007) and this carer-family dynamic can exacerbate vulnerabilities of the orphaned children (Cluver & Operario, 2008). A review of studies on carers of orphaned children showed a limited body of research on the health outcomes of carers (Kuo & Operario, 2009). The existing literature reveals an emerging concern around the possible negative impacts of care provision for these carers, with a number of studies documenting poor health outcomes including elevated levels of stress, chronic illness, and poor nutritional outcomes (Hansell et al., 2002; Oburu & Palmerus, 2003; Rotheram-Borus et al., 2002; Ssengonzi, 2007; Strug & Burr, 2003). More information is urgently needed on carer health since such information can inform strategies to support carers, a group that plays a substantial role in supporting orphans.

The challenges associated with caring for orphaned children might exacerbate some of the health and psychological risks in the general adult population in South Africa. Data from South Africa's first nationally representative study on prevalence of psychiatric disorders documents concerning levels of lifetime prevalence for anxiety disorders (15.8%) and major depression (9.8%) (Stein et al., 2007), and Demographic and Health Surveys have identified chronic and acute health problems besides HIV/AIDS that are prevalent in adults which account for substantial mortality (Timaues & Jasseh, 2004). This base rate for health and psychological problems provides motivation to further evaluate whether carers of orphaned children face even greater physical and mental health outcomes. Building a stronger understanding of whether orphan carers face health disparities and the risk and protective factors for these outcomes will be critical for the design of health policies and interventions in South African communities that have been highly affected by HIV.

The research aims of this paper are to: (a) assess levels of self-reported general health and functioning and prevalence of depression, anxiety, and post-traumatic stress among carers of children in an AIDS-endemic community in South Africa; and (b) evaluate whether orphan carers reported increased levels of health and psychological problems compared with non-orphan carers.

Methods

A cross-sectional survey was conducted in Umlazi Township from August 2008 to March 2009. The field site is located in KwaZulu Natal (KZN) province which has the highest antenatal HIV prevalence at 37.4% (South African National Department of Health *The National HIV and Syphilis Prevalence Survey*, 2008) and highest rates of orphanhood at 19.8% (Shishana et al., 2005) in South Africa. Within KZN, Ethekwini municipality, where Umlazi is located, has the highest antenatal HIV prevalence at 41.6 percent (Smith, 2008).

Sampling

Participants were identified through multi-stage cluster sampling. First, Umlazi was split into geographic clusters based on Geographical Information System mapping of South African census enumeration areas (EAs). Second, EAs were randomly sampled and in each sampled EA, all households were visited and screened for eligibility. Third, household members identified the primary child carer in the home and this carer was invited to participate if: (a) they were 18 years or older; (b) provided care to one or more children; and, (c) both carer and child(ren) lived in the household at least four nights a week for the past

four weeks (Statistics South Africa *Census 2001 Questionnaire*, 2001). If multiple primary carers existed within a single household, one eligible carer was randomly invited to participate. The carer could be related to the child in any way (*i.e.*, carers could be the biological parents of the child but could also be aunts, grandparents, non-relatives).

A total of 2,070 households were contacted through this approach and screened for eligibility. Recruiters were unable to make contact with 160 households after three visits (7.7% of households). Of eligible households, there was a 99.3 percent response rate resulting in a sample of 1599 adult carers. Research protocols were approved by ethical review committees at Oxford University and University of KwaZulu Natal.

Measures

The survey questionnaire was translated and back-translated into isiZulu and piloted to ensure coherency and cultural validity. A team of trained enumerators fluent in isiZulu administered the questionnaire.

Eligible participants reported whether they were the primary carer for one or more orphaned child. 'Orphan' was defined in accordance with the UNAIDS, UNICEF, and USAID definition as a child under age 18 whose mother and/or father has died (UNICEF, 2004). Carers provided general demographic information about age, education, employment, household composition, household economic assets, and access to social grants.

General health and functioning was measured using the Short Form-36 version two scale (SF-36v2), a 36-item generic measure of health status for adults (Ware, 2000, 2004). The SF-36 has been used in over 7,000 studies, in varying populations and cultural settings, and has been translated into 60 languages including isiZulu (Ware et al., 2007) and used in South Africa (Benitha & Tikly, 2007; O'Keefe & Wood, 1996). Scores are transformed to a 0 to 100 scale with higher scores indicating better health. There are two sub-component scores – the physical health component score and the mental health component score (Ware, et al., 2007). The SF-36v2 showed strong internal reliability in this sample ($\alpha=0.95$)

Depression was measured using the Centre for Epidemiologic Studies Depression scale (CES-D), a 20-item measure designed to assess levels of depressive symptomology (Radloff, 1977). The CES-D is one of the most widely used self-report depression instruments and has been administered in various settings including South Africa (Hamad, Fernald, Karlan, & Zinman, 2008; Myer et al., 2008; Pretorius, 1991; Smit et al., 2006). Scores range from 0 to 60, with a score of 16 or more used to indicate clinical depression (Radloff, 1977). The CES-D showed high internal reliability in this sample ($\alpha=0.92$).

Anxiety was measured using the Kessler scale (K10) which assesses the level of anxiety using 10-items (Kessler et al., 2002). K10 has been administered in various settings including Burkina Faso (Baggaley et al., 2007). Scores range from 10 to 50, with higher scores indicating higher levels of psychological distress (Kessler, et al., 2002). Scores in the range of 10 to 15 indicate low or no risk, 16 to 29 indicate moderate risk, and 30 to 50 indicate high risk for an anxiety disorder (Andrews & Slade, 2001). The K10 showed good internal reliability in this sample ($\alpha=0.85$).

Post-traumatic stress disorder (PTSD) was assessed using the Harvard Trauma Questionnaire (HTQ), a 30-item questionnaire. HTQ is scored using an algorithm for determining clinically significant levels of PTSD (Mollica, McInnes, & Sarajlic, 1999). HTQ has been administered in South Africa (Myer, et al., 2008; Smit, et al., 2006; Ward, Flisher, Zissis, Muller, & Lombard, 2001). The HTQ showed good internal reliability in this sample ($\alpha=0.97$).

Analyses

Data was analyzed using SPSS version 17. Bivariate analyses comparing health and psychological differences between orphan and non-orphan carer groups were conducted using Chi square tests for categorical variables and t-tests for continuous variables. If carer groups reported statistically significant differences in health, multivariate regressions were used to further assess whether differences persisted after adjusting for conceptually relevant sociodemographic co-factors that showed a bivariate association with each health outcome at $p < 0.25$ (Hosmer & Lemeshow, 1989).

Results

Demographic characteristics

Participants were predominantly Black African (99.9%) with a small percentage of individuals who were Colored (0.1%). The majority of participants were isiZulu speakers (98.1%) with the remainder speaking isiXhosa (1.6%), Sedepi (0.13%), and Sesotho (0.1%). On average, participants were 39.4 years old ($SD=14.7$) and the majority were female (86.4%). Less than a quarter of participants completed the secondary education standard of Grade 12 (22.8%), and even fewer completed tertiary education (1.8%). Participants reported a mean of 5.5 individuals living in the household ($SD=2.6$). The majority lived in informal dwellings (53.9%) (*i.e.*, buildings made with cardboard, corrugated iron, plastic, etc.) and the remainder lived in formal dwellings (46.1%) (*i.e.*, buildings made with brick, concrete, etc.). The majority of households had some source of income (99.3%); salaries and social welfare grants ranked as the top sources of income. Overall, 33.1% ($n=530$) of participants were carers of orphaned children; the other 66.9% ($n=1069$) did not care for orphaned children (see Table 1).

General Health and Functioning

Participants reported an average SF-36v2 score of 71.8 ($SD=17.7$) on a 100-point scale with this score falling in the third quartile of the standardized scale. Participants reported a mean physical health component score of 73.2 ($SD=21.8$) and a mean mental health component score of 70.3 ($SD=16.1$). When carers were disaggregated into orphan and non-orphan carers, orphan carers reported significantly poorer SF-36v2 scores ($M=68.41$, $SD=19.02$) than non-orphan carers ($M=73.42$, $SD=16.70$), $t(1593) = 5.38$, $p < 0.01$. Analyses of SF-36v2 physical and mental health component scores showed similar patterns (see Table 2).

Depression

One-third of the sample (30.3%) reported scores which met the threshold criteria ($CES-D \geq 16$) for clinically significant depression. When carers were disaggregated into orphan and non-orphan carers, orphan carers were significantly more likely to meet the threshold criteria for clinically significant depression (35.2%) than non-orphan carers (27.9%), $\chi^2(1, N = 1599) = 8.75$, $p < 0.01$ (see Table 2).

Anxiety

The majority of carers met the clinical threshold range for moderate anxiety (63.8%) and a smaller percentage met the threshold range for high anxiety (8.8%). When carers were disaggregated into orphan and non-orphan carers for comparison, there were no significant differences in K10 scores between groups, $\chi^2(1, N = 1599) = 1.61$, $p = 0.45$ (see Table 2).

Post-traumatic Stress

A minority of carers met the threshold for post-traumatic stress disorder (PTSD) (2.3%). However, when post-traumatic stress was compared amongst orphan carers and non-orphan

carers, orphan carers were significantly more likely to be classified as meeting the clinical threshold criteria for PTSD (4.5%) than non-orphan carers (1.00%), $\chi^2(1, N = 1599) = 12.28, p < 0.01$ (see Table 2).

Poor General Health and Depression among Orphan Carers

Multivariate regressions assessed whether there were significant differences in levels of general health and functioning and depression between orphan and non-orphan carers after adjusting for sociodemographic co-factors. Post-traumatic stress was excluded from multivariate analyses because of sample size limitations on this measure. Multivariate linear regressions were conducted with general health and functioning, physical health and functioning sub-component score, mental health and functioning sub-component score as the dependent variables. Multivariate logistic regressions were conducted with depression as the dichotomous dependent variable. Unadjusted and adjusted models for each of these four dependent variables are presented in Table 3.

In unadjusted models, orphan carers reported significantly poorer general health and functioning ($\beta = -0.13$), poorer overall physical health ($\beta = -0.14$), poorer overall mental health ($\beta = -0.11$), and were likely to meet the clinical threshold for depression (OR = 1.39, 95% CI = 1.12 – 1.75), compared with non-orphan carers. After adjusting for age, gender, education, economic assets, and main source of income, carer type (orphan versus non-orphan carer) was no longer significantly associated with general health and functioning, overall physical health, and overall mental health. However, orphan carers were significantly more depressed than non-orphan carers in the adjusted model (OR = 1.32, 95% CI = 1.02 – 1.71).

Discussion

This is the largest known study to date on carers of AIDS-orphaned, other-orphaned, and non-orphaned children in South Africa that uses representative sampling and validated measures to compare health differences in these groups. This study highlights poor general health and functioning, depression, anxiety, and post-traumatic stress among adults caring for children in an HIV endemic community. Although we observed problem levels of health and psychological functioning in adult carers generally, we found that orphan carers faced greater health problems compared to non-orphan carers. Greater physical health problems in orphan carers were accounted for by socioeconomic characteristics; however, greater psychological problems in orphan carers were independent of socioeconomic characteristics. Findings provide support to prior speculations that adults who assume care for orphaned children in South African might themselves have greater health and psychological challenges.

Findings suggest that this vulnerable family dynamic for households affected by parental death and orphanhood in South Africa is related to key sociodemographic factors including age, education, economic assets, and main source of income. These factors strongly accounted for the association between carer type and self-reported health, offering one explanation for why orphan carers experienced health disparities. A number of studies corroborate that age, gender, education, and economic assets function as fundamental risk and protective factors for health. For example, there is extensive literature documenting the inverse correlation between age and health (for example, see Crimmins, Hayward, & Saito, 1994; House et al., 1994; Kim et al., 2009; Knight, Ofstun, Teng, Lazarus, & Curhan, 2003; Mirowsky & Ross, 1992; Mojtabai & Olfson, 2005). There is also extensive literature documenting the positive association between education and health (for example, see Feldman, Makuc, Kleinman, & Cornoni-Huntley, 1989; Guralnik, Land, Fillenbaum, &

Branch, 1993; Ross & Wu, 1995; Winkleby, Jatulis, Frank, & Fortmann, 1992). Studies also show a relationship between gender and health (for example, see Emslie et al. 2002; Grotvedt and Stavem 2005; Kolip 2005) although the directionality of the relationship varies. In this study, females consistently reported poorer self-reported health; Numerous studies show a positive correlation between economic status and health (for example, see Adler et al., 1994; Adler & Ostrove, 2006; House et al., 1990; Kaplan, Haan, & Syme, 1987; Marmot, Ryff, Bumpass, Shipley, & Marks, 1997; Williams, 1990). Together, all of these factors – age, gender, education, economic assets, and main source of income – may be linked into a wider process of social exclusion related to AIDS related stigma, income inequality, as well as racial and class disparities in South Africa. This social exclusion may increase the vulnerabilities that orphan carers experience and requires not only design of interventions to address the specific risk factors that may be related to poor health, but expansion of social programs and policies to address deprivations. These findings are consistent with other studies which highlight the diversity of carers and the need to contextualize the challenges associated with orphan care in sub-Saharan Africa within a particular social, economic, and historical milieu (Abebe & Aase, 2007; Madhavan, 2004).

Policy makers and practitioners may need to prioritize strategies to address the physical and mental health needs of adults caring for children in high HIV prevalence and socio-economically deprived communities. In addition, policies and interventions need to specifically address the physical and mental health disparities experienced by orphan carers more generally. Addressing mental health needs may meet a number of challenges that reflect the neglect towards mental health in developing countries. Spending on mental health resources in the global South is severely under-resourced with 90 percent of global mental health resources located in high-income countries. Countries in the global South spend less than one percent of their total health budgets on mental health and mental health professionals in these areas are inadequate for service needs (World Health Organization 2005). To an extent, this is the result of a lack of prioritization but also reflects wider shortages in health personnel and inadequate health systems. However, recent studies suggest that these needs can be met through low-cost interventions at the community level; interventions can be affordable and feasible even in human resource and financially scarce environments (Bass, Neugebauer, & K., 2006; Patel et al., 2003; Ran et al., 2003). In sum, prioritizing carer mental health needs would constitute an important shift towards broader strategies that strengthen family resilience rather than a narrow focus on poverty-alleviation strategies, a shift that Abebe & Aase (2007) have also highlighted as necessary for long-term responses to support AIDS-orphaned children and their families.

That sociodemographic differences among orphan and non-orphan carers fully accounted for orphan and non-orphan carer disparities in general health and functioning and reduced the significance of disparities for depression also clearly pointed towards the need for a policy approach towards addressing mental health. The analyses suggested that orphan carers needed more support, and that support might be targeted towards female, older, less educated, and poorer carers. Such support may also have positive implications for the children under their care.

This study has several limitations. First, data was based on self-report, which may be less reliable than clinician-based assessments of health. Second, findings may be specific to Umlazi but certainly may reflect some of the dynamics of high HIV and socio-economically deprived communities within South Africa. Finally, due to cross-sectional nature of the study, this study cannot determine causality or temporal order so it is not possible to conclude whether or how caring for a child affects health and psychological well-being.

A number of areas have been identified for future research. Additional studies are needed to explore modifiable risk and protective factors and the causal mechanisms of how these factors influence carer health. Longitudinal data is needed to establish an understanding of the causal pathways through which risk and protective factors impact upon health. Both qualitative and quantitative cross-sectional data are needed to examine how specific dynamics of the provision of child care and family relationship impact carer health. In sum, this study establishes an important baseline of information regarding an understudied population. This information will be vital to supporting carers specifically but relates also to efforts to bolster the well-being of children and families living in HIV affected communities.

Acknowledgments

We would like to thank carers in Umlazi; Professor Alan Whiteside, Dr. Timothy Quinlan, Mr. S'bo Radebe, Dr. Cathy Connolly, and Dr. Soraya Seedat for their expertise; Councilor Sthenjwa Nyawose, Ms. Mphume Sithole, and Sifiso Nzama for their support; and Reggie Khanyile, Feziwe Mhlongo, Siyabonga Msomi, Nomvula Mohoto, Silindile Nyawose, Gugu Ndlovu, and Thokozani Nzimande for their dedication as researchers. This research was supported by Award Number F31MH081820 to Dr. Caroline Kuo and T32 MH078788 to Dr. Larry Brown from the National Institute of Mental Health, the Leverhulme Trust Grant F08-599C to Dr. Don Operario, and the Health Economics and HIV/AIDS Research Division at University of KwaZulu Natal. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Mental Health or the Leverhulme Trust.

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Table 1

Sociodemographic Characteristics

	All carers (n=1599)
African (%)	99.9
isiZulu language (%)	98.1
Age (M, SD)	39.4 (14.7)
Female (%)	86.4
Education (M, SD)	Grd. 8 (3.9)
No schooling (%)	5.7
Some primary (%)	14.6
Completed primary (%)	4.1
Some secondary (%)	51.1
Completed secondary (%)	22.8
Tertiary %)	1.8
Number of people in household (M, SD)	5.5 (2.6)
Salaries as main household income (%)	64.9
Dwelling Type	
Informal dwelling (%)	53.9
Formal dwelling (%)	46.1
Carer type	
Carers of orphaned children (%)	33.1
Carers of non-orphaned children (%)	66.9

Table 2

Differences in Health Outcomes for Orphan versus Non-orphan Carers (n=1599)

	All Orphan Carers (n=530)	Non-orphan Carers (n=1069)	P-Value ¹
General Health and Functioning (M, SD)	68.41 (19.02)	73.42 (16.70)	<.01
Physical Health Subscore (M, SD)	68.90 (22.82)	75.25 (20.94)	<.01
Mental Health Subscore (M, SD)	67.92 (17.40)	71.53 (15.26)	<.01
Depression (n, %)	186 (35.16%)	298 (27.93%)	<.01
Anxiety (n, %)	392 (74.10%)	767 (71.81%)	ns
Post-traumatic Stress (n, %) ²	16 (4.51%)	6 (1.00%)	<.01

Column sums may not add to n=1599 due to missing values

¹ *p*-values associated with T-tests for continuous variables and chi-square tests for categorical variables

² Valid responses for post-traumatic stress measure is n=958

Table 3
Orphan vs. Non-orphan Carer Differences in Health Adjusting for Socio-demographic Co-factors

	General Health and Functioning (β)		Physical Health Subscore (β)		Mental Health Subscore (β)		Depression (OR, 95% CI)	
	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model	Unadjusted Model	Adjusted Model
Carer type (Orphan vs. Non-orphan carer)	-0.13**	-0.04	-0.14**	-0.04	-0.11**	-0.03	1.39** (1.12-1.75)	1.32* (1.02-1.71)
Age		-0.27**		-0.26**		-0.26**		1.39 (0.97-1.99)
Gender		-0.09**		-0.09**		-0.08**		1.98** (1.51-2.60)
Education		0.14**		0.14**		0.12**		0.82 (0.63-1.07)
Economic Asset Index		0.07*		0.12**		-0.002		0.97 (0.67-1.42)
Main source of income (salaries vs. other)		0.16**		0.15**		0.15**		0.55** (0.42-0.71)

* Denotes significance at $p < 0.05$ level.

** Denotes significance at $p < 0.01$ level

+ Adjusted model controls for all variables shown as well as social support, household hunger, potable water, type of housing, social welfare grants, ethnicity, and language.

++ 95% Confidence Interval