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Posttraumatic Stress Symptoms Among Adults Caring for Orphaned Children in HIV-Endemic South Africa

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Abstract There is growing evidence that mental health is a significant issue among families affected by AIDS-related parental deaths. The current study examined posttraumatic stress symptoms and identified risk factors among adults caring for AIDS-orphaned and other-orphaned children in an HIV-endemic South African community. A representative community sample of adults caring for children (N=1,599) was recruited from Umlazi Township. Of the 116 participants who reported that a traumatic event was still bothering them, 19 % reported clinically significant posttraumatic stress symptoms. Of the 116 participants, caregivers of AIDS-orphaned and other-orphaned children were significantly more likely to meet threshold criteria for PTSD (28 %) compared to caregivers of non-orphaned children (10 %). Household receipt of an old age pension was

identified as a possible protective factor for PTSD symptoms among caregivers of orphaned children. Services are needed to address PTSD symptoms among caregivers of orphaned children.

Keywords Posttraumatic stress · South Africa · Caregivers · Orphans · HIV

Introduction

South African populations may be at risk for posttraumatic stress disorder (PTSD) due to high rates of HIV. However, data on PTSD among South African populations is limited. South Africa recently conducted its first national survey of mental health disorders, documenting 2 % lifetime prevalence of PTSD among the general adult population [1]. These PTSD data were not disaggregated by HIV affected populations. However, an understanding of PTSD among HIV affected populations is needed given that exposure to HIV infection, AIDS-related deaths, and other HIV-related experiences may increase risk for PTSD. In studies with recently diagnosed HIV-positive patients, 15-40 % reported PTSD [2-4]. South African studies show that AIDSorphaned children report significantly higher rates of PTSD compared to non-orphaned children [5, 6]. Further investigation of PTSD among population sub-groups affected by HIV can inform mental health programs, policies, and future intervention research and is particularly crucial given that South Africa has the largest number of people living with HIV of any country in the world [7].

Among populations affected by HIV, data on PTSD is particularly lacking on adults caring for orphaned children (i.e., caregivers). In South Africa, these caregivers play a critical role in supporting 3.4 million orphaned children

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[8], with over half of these children orphaned through AIDS-related parental deaths [9]. Because the majority of caregivers are related to these children [10], and are also grappling with potentially traumatic experiences of familial death, it follows that caregivers may also be at increased risk for PTSD. No studies have specifically examined PTSD among caregivers of AIDS-orphaned children. However, several studies outside of South Africa provide evidence that this population experiences poor mental health [11-16]. However, all of these studies were qualitative or small quantitative studies, limiting our ability to assess the scale of poor mental health among caregivers of AIDS-orphaned children. Together this literature indicates both a need to investigate PTSD among caregivers of AIDS-orphaned children and a need to investigate outcomes using representative community sampling.

PTSD risk among caregivers of AIDS-orphaned children cannot be examined in isolation. Nearly a quarter of South Africans reported exposure to violence such as assault, rape, and political violence [17]. Among adults exposed to political violence, 38-52 % met criteria for PTSD [18, 19] and among adults who were victims of human rights abuses, 42 % met criteria for PTSD [20]. Thus, there is a need to disentangle whether caring for an AIDS-orphaned child is any different from caring for an other-orphaned child or even caring for a non-orphaned child more generally. Given that caregiving takes place in an environment of high PTSD risk, comparisons of PTSD outcomes among caregivers of AIDSorphaned, other-orphaned, and non-orphaned children are needed to isolate whether caring for an AIDS-orphaned child increases risk for PTSD among caregivers. No study to our knowledge has examined the prevalence of PTSD symptoms and identified risk or protective factors for PTSD, or used caregiver comparison groups to disentangle whether caring for an AIDS-orphaned child rather than an other-orphaned child was a risk factor for PTSD.

This paper reports on a representative cross-sectional survey of 1,599 adults caring for children in Umlazi Township in South Africa conducted from 2008 to 2009. Umlazi Township reports high HIV prevalence (42 %) [21], violent crime [22], and orphanhood (30 %) [23]. Study aims included: (a) assessing type and frequency of traumatic events; (b) assessing prevalence of PTSD symptoms; (c) comparing prevalence of PTSD symptoms among caregivers of AIDS-orphaned, other-orphaned, and nonorphaned children; and (d) identifying risk and protective factors for PTSD symptoms. Based on the literature showing elevated risk for PTSD symptoms among orphaned children, it was hypothesized that caregivers of orphaned children would also exhibit higher rates of PTSD symptoms compared to caregivers of non-orphaned children, and that the primary type of traumatic event linked to PTSD symptoms would be familial death.



Participants

This study examined data from a cross-sectional survey of adults who provided primary child care in the home (i.e., caregivers), defined as the adult responsible for the majority of day-to-day active care of the children (e.g., preparing children for school, emotional support, and possibly economic support). Participants could be related to the child in any way (i.e., surviving biological parent of the child, other relative, unrelated surrogate parent). Participants were eligible if: (a) they were 18 years or older; (b) provided primary care to one or more children; and, (c) both caregiver and child(ren) lived in the household at least four nights a week for the past 4 weeks [24]. If multiple primary caregivers existed within a single household, one eligible primary caregiver was randomly invited to participate.

Participants were predominantly Black African (99 %), isiZulu speakers (98 %), female (86 %), and an average of 39.39 years old (SD = 14.73). Less than a quarter of participants (23 %) completed the secondary education standard of Grade 12 and 54 % lived in informal dwellings (i.e., buildings made from cardboard, corrugated iron, plastic, etc.). Participants were responsible for 4,039 children, with an average of 2.49 children per caregiver (SD = 1.61). Roughly one-third (33 %) of participants were caregivers of orphaned children. Of those respondents who were caregivers of orphaned children, 22 % (n = 359) were caregivers to at least one AIDS-orphaned child, and 11 % (n = 171) were caregivers of other-orphaned child (e.g., children whose parents died of other non-AIDS related causes). For other-orphaned children, over 90 % of their parents died from violent or unexpected deaths shootings, stabbings, or car accidents. Cause of AIDS-related parental death was determined using the verbal autopsy measure where the primary caregiver, family member, or other relation to the deceased uses eight signs and symptoms related to HIV to verify cause of death. The verbal autopsy method has shown a sensitivity as high as 83 % and a specificity of 75 % of predicting death due to AIDS in settings that lack medical records [25, 26]. Caregivers of AIDSorphaned, other-orphaned, and non-orphaned children showed socio-economic and demographic differences in age, education, social support, source of income, and receipt of social welfare grants (e.g., monetary grants based on economic and other health or social needs targeting vulnerable groups such as the elderly, children, people living with disabilities) but no differences with regard to gender, ethnicity, language or a variety of household-descriptive variables (including food insecurity, potable water, etc.). A summary of participant characteristics is shown in Table 1.



Table 1 Differences between caregiver subgroups on number of traumatic events and socio-demographic variables

	All caregivers $(N = 1,599)$	Caregivers of AIDS-orphaned children $(n = 359)$	Caregivers of other-orphaned children $(n = 171)$	Caregivers of non-orphaned children $(n = 1,069)$	p Value ^a
Number or reported potentially traumatic of life threatening events	2.61 (2.05)	2.89 (3.01)	2.98 (3.27)	2.46 (3.02)	ns
Age (M, SD)	39.39 (14.73)	44.24 (16.36)	39.39(14.68)	37.77 (13.80)	<.001
Female (%)	86	90	87	85	ns
Education (M, SD)	Grd. 8 (3.85)	Grd. 7 (4.11)	Grd. 8 (3.63)	Grd. 8 (3.76)	<.001
African (%)	99	99	100	99	ns
isiZulu language (%)	98	98	98	98	ns
Social support (M, SD)	63.64 (13.23)	60.23 (13.86)	64.02 (13.56)	64.71 (12.78)	<.001
Number of children (M, SD)	2.2 (1.59)	3.22 (1.80)	3.00 (1.57)	2.21 (1.41)	<.001
Salaries as main household income (%)	65	55	57	70	<.001
Flush toilet (%)	45	46	50	45	ns
Household food insecurity (%)	62	63	64	61	ns
Piped water (%)	78	80	84	76	ns
Potable water (%)	99	99	99	99	ns
Formal dwelling (%)	46	49	47	46	ns
Old age pension (%)	16	28	18	11	<.001
Disability grant (%)	9	10	9	8	ns
Housing grant (%)	5	8	4	5	<.01
Child support grant (%)	74	70	74	75	ns
Foster care grant (%)	4	9	4	2	<.001

^a p Values are associated with one-way ANOVA or χ square test

Measures

Participants reported on PTSD symptoms using a three part assessment. All measures were administered verbally by the trained research team to ensure that literacy was not a barrier. First, participants reported potentially traumatic or life threatening events using the life events checklist (LEC) [27]. Then, participants who reported at least one event on the LEC went on to specify if events were still bothering them. Finally, participants answered the Harvard Trauma Questionnaire (HTQ) [28]. The HTQ includes 30-items. The first 16-items are based on DSM criteria for PTSD symptoms and the last 14-items assess the impact of trauma on ability to function in daily life. The results presented in this paper focus on the 16 PTSD symptoms assessed in the HTQ. Symptoms are scored on a scale ranging from one point (not at all) to four points (extremely). The HTO was developed specifically for use in diverse cultural settings [28] and is culturally validated among South African populations [4], leading to the choice of this tool in this study. The HTQ has been administered in a number of South African studies [29, 30].

The HTQ was scored using the algorithm method, which assessed whether respondents exhibit a minimum threshold

of clinically significant PTSD symptoms based on responses to questions for three symptom clusters: re-experiencing of the event; avoidance or numbing; and hyperarousal. Respondents were categorized as having clinically significant levels of PTSD if they had a score of three or four points on: one of the four questions on re-experiencing symptoms; three of the seven questions on avoidance and numbing symptoms; and two of the five questions on hyperarousal symptoms [31].

Original psychometric testing showed that the HTQ has excellent consistency reliability ($\alpha=0.89$) [31]. Another study of the reliability and validity of the HTQ in Sri Lankans experiencing the tsunami disaster (n=127) showed excellent internal consistency ($\alpha=0.94$) and construct validity [32]. The cultural validity of the tool was tested in South African populations [33]. The construct validity of the HTQ has been established through comparisons with other tools including the Mini-International Neuropsychiatric Interview (MINI) [4]. In this study population, internal consistency for the entire HTQ was $\alpha=0.97$ and for the first 16 items used in this analysis was $\alpha=0.96$.

In addition to measuring health outcomes, the questionnaire gathered data on possible risk and protective factors: demographic (e.g., age, gender, education, ethnicity, language); care provision (e.g., social support for the carer,



number of children in the household); as well as household economic (e.g., main household source of income, housing type); and policy factors (e.g., receipt of old-age pension, disability, child support, and foster care grants) which were selected based on South African literature that suggested each might be a potentially important factor in mental health outcomes [34, 35]. Social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), a 12-item scale assessing support from family, friends, and significant others. Scores range from 12 to 84 points, with higher scores indicating higher levels of perceived social support [36, 37]. The MSPSS has been used in various cultural settings, including South Africa [38, 39]. Validation studies shown good internal consistency reliability $(\alpha = 0.77-0.98)$ in a variety of samples, including adolescents in South Africa [39], individuals with psychiatric illnesses [40, 41], and other developing country populations [42]. The remainder of items to assess risk and protective factors were drawn from the South Africa National Census [43], South Africa General Household Survey [44], South Africa Demographic and Health Survey [45], and the KwaZulu-Natal Income Dynamics Study (KIDS) 2004 questionnaire [46] to ensure the use of culturally appropriate and pre-tested questions.

Procedures and Data Analysis

Participants were identified using a representative community sample. The research site was split into geographic clusters based on Geographical Information System mapping of census enumeration areas (EAs). Of 51 existing EAs, twenty-three were randomly sampled and in each EA, every household was visited and screened for eligibility. Then, household members identified the primary caregiver in the household. Study aims and procedures were explained. If the primary caregiver indicated an interest in participation, the participant was provided a copy of the informed consent document. This consent document was also read out loud by a member of the research team and questions answered before informed consent was obtained. A total of 2,070 households were screened for eligibility, with a response rate of 99 %, resulting in a final sample of 1,599 caregivers. No incentives were provided. It is likely that the high response rate was due to the extensive process of community buy-in in preparation for the study as well as the high rate of unemployment in the community which meant that many caregivers were available to participate. Surveys were administered by the local research team who were fluent in isiZulu and trained in research and ethical protocols.

Data were analyzed using SPSS version 17. Descriptive statistics were used to summarize caregiver demographics, traumatic events, and PTSD symptoms. Chi square tests were conducted to assess whether caregivers of orphaned children

were more likely to meet criteria for PTSD compared to caregivers of non-orphaned children. ANOVAs were conducted to compare differences in PTSD symptom scores between caregivers of AIDS-orphaned, other-orphaned, and non-orphaned children. Multivariate logistic regressions identified factors independently associated with PTSD in caregivers of orphaned children. Variables were entered into regression models using forward block-wise entry, with variables ordered by those most proximal to the individual followed by those that were more distal. In the first block, a dichotomous variable for orphan versus non-orphan caregivers was entered. In the second block, variables that were most proximally associated with the provision of childcare were entered (number of children in the household, social support for the caregiver). In the third block, household characteristics were entered (source of income, dwelling type). In the fourth block, policy-related variables were entered (old age pension, disability grant, child support grant, and foster care grant). Caregiver demographic variables were entered (age, gender, education) in the final block to minimize the suppression of effects for other socio-economic variables due to potentially strong demographic predictors of PTSD. All study procedures were approved by ethical review committees at Oxford University and University of KwaZulu Natal.

Results

More than half of the participants (60 %, n=958) reported experiencing, witnessing, and/or hearing of any traumatic or life threatening event happening to someone they knew based on the LEC. The most frequently reported events were transport accidents (40 %), natural disasters (33 %), physical assaults (32 %), unexpected death of someone close (30 %), assaults by a weapon (30 %), fires or explosions (24 %), life threatening injuries or illnesses (19 %), and sudden or violent deaths (13 %). Details on the type and frequency of events reported are summarized in Table 2.

Out of the sub-sample of participants (n = 958) who reported experiencing, witnessing, and/or hearing of one or more traumatic or life threatening event(s), 116 (12 %) participants indicated that the event(s) were potentially traumatic or "still bothering or upsetting them." Among these 116 participants, the unexpected death of someone close to them (53 %), physical assault (11 %), and sexual assault (10 %) were the most frequently reported events. A fifth of these 116 participants (19 %, n = 22) were classified as meeting the threshold for clinically significant PTSD symptoms based on the algorithm scoring method. Symptom severity did not vary by number of reported traumatic events.

Of the 116 participants that reported events still bothering them, caregivers were disaggregated into caregivers of



Table 2 Type and frequency of events as reported with the life events checklist (N = 1,599)

Trauma type	Experienced event	Witnessed event	Heard of event	Sum number of events	% of the total sample
Transport accident	103	92	435	630	39
Natural disaster	204	99	228	531	33
Physical assault	105	136	269	510	32
Unexpected death of a someone close to them	24	146	312	482	30
Assault by a weapon	55	66	353	474	30
Fire or explosion	54	82	246	382	24
Life threatening injury or illness	28	72	205	305	19
Sudden or violent death	21	39	147	207	13
Accident at work	28	25	149	202	13
Sexual assault	24	5	143	172	11
Exposure to war	21	14	57	92	6
Uncomfortable sexual experience	12	5	53	70	4
Another life threatening experience	5	11	42	58	4
Captivity	4	0	47	51	3
Serious injury, harm or death that you caused	2	2	26	30	2

orphaned and non-orphaned children for comparison. Caregivers of orphaned children were significantly more likely to be classified as meeting the threshold criteria for clinically significant PTSD symptoms (28 %) than caregivers of non-orphaned children (10 %) ($\chi^2 = 5.83$, p = 0.016). Caregivers were also disaggregated into caregivers of AIDS-orphaned, other-orphaned, and non-orphaned children for comparison. Caregivers of other-orphaned children were significantly more likely to be classified as meeting the threshold criteria for clinically significant PTSD symptoms (35 %) than caregivers of AIDS-orphaned children (25 %) and non-orphaned children (10 %) $\chi^2 = 6.66$, (p = 0.04).

Multivariate hierarchical logistic regression models are summarized in Table 3. Each model was significant (p < 0.01). In the unadjusted model, those caring for orphaned children were significantly more likely to report PTSD symptoms (Model 1, OR = 3.47, 95 % CI = 1.24–9.67). This relationship remained significant in the three subsequent models which adjusted for variables related to care provision (Model 2, OR = 2.97, 95 % CI = 1.03-8.57), household factors (Model 3, OR = 2.98, 95 % CI = 1.03-8.66), and policy variables (Model 4, OR = 3.12, 95 % CI = 1.02-9.56). In the final model, there was a trend towards significance (p = 0.06)between caring for an orphaned children and PTSD symptoms (Model 5, OR = 3.01, 95 % CI = 0.96-9.47) [47]. The final model also identified households receiving an old age pension as a possible protective factor for PTSD symptoms. Caregivers had an 89 % higher odds for reporting PTSD symptoms if their households did not receive an old age pension (OR = 0.11, 95 % CI [0.01–1.05]) but this was a trend towards significance (p = 0.055).

Discussion

The current study identifies PTSD as a public health issue of importance among caregivers of orphaned children in HIV endemic communities. Our findings indicate 1 % (22/1,599) of this representative sample reported symptoms indicative of PTSD. A large majority 60 % (n = 958) reported a traumatic or life threatening event. Out of the sub-sample of participants (n = 958) who reported a traumatic or life threatening event(s), 12 % (n = 116) reported this event was still bothering them. In this aspect, our findings are similar to other South African studies, which show high numbers of individuals reporting traumatic events [48]. However, our study provides important details for South African sub-populations by comparing caregivers of orphaned and non-orphaned children.

Of the sub-sample of participants who reported a traumatic or life event was still bothering them (n = 116), a fifth reported PSTD symptoms (19 %, n = 22). Notable here, was that the unexpected death of a loved one was the primary type of traumatic event for those reporting symptoms of PTSD, likely related to high rates of AIDS-related mortality in the study community. This finding confirms our hypothesis that familial death would be the primary traumatic event linked to PTSD symptoms in this population.

Our findings also show that regardless of whether they were caring for AIDS-orphaned or other-orphaned children, a high percentage of caregivers of orphaned children (28 %) reported PTSD symptoms, supporting our hypothesis that adults caring for orphaned children would report PTSD symptoms at higher rates than adults caring for non-orphaned



Table 3 Multivariate logistic regressions testing factors associated with posttraumatic stress disorder (PTSD) symptoms (n = 116)

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	Model 1 OR [95 % CI]	Model 2 OR [95 % CI]	Model 3 OR [95 % CI]	Model 4 OR [95 % CI]	Model 5 OR [95 % CI]
Caregiver type (orphan vs. non-orphan caregivers)	3.47* [1.24–9.67]	2.97* [1.03–8.57]	2.98* [1.03–8.66]	3.12* [1.02–9.56]	3.01*,a [0.96–9.47]
Care provision variables					
Social support ^b		0.65 [0.23–1.83]	0.64 [0.23–1.82]	0.77 [0.26–2.28]	0.77 [0.26–2.35]
Number of children		1.85 [0.47–7.34]	1.92 [0.47–7.74]	2.19 [0.50-9.60]	2.33 [0.51–10.57]
Household variables					
Source of income ^c			1.26 [0.39-4.08]	1.20 [0.36-4.04]	0.88 [0.24-3.20]
Dwelling type ^d			1.01 [0.34–3.05]	1.16 [0.37–3.60]	1.54 [0.45–5.25]
Policy variables					
Old age pension ^e				0.16 [0.21–1.42]	0.11*,a [0.01-1.05]
Disability grant ^e				2.20 [0.59-8.27]	1.84 [0.48–7.12]
Child support grant ^e				0.55 [0.16–1.84]	0.80 [0.22-2.95]
Foster care grant ^e				1.70 [0.123–12.76]	1.78 [0.22–14.45]
Socio-demographic cofactors					
Age^f					1.41 [0.14–13.83]
Gender ^g					3.57 [0.85–15.11]
Education ^h					1.15 [0.33–3.94]

^{*} Denotes significance at p < .05 level

children. This is not unlike the mental health literature on caregivers of orphaned children which indicates elevated risk for poor mental health including stress and depression [49–53]. However, it was surprising caregivers of otherorphaned children were most likely to report PTSD symptoms compared to AIDS-orphaned caregivers. We expected findings to follow patterns in South African studies that showed AIDS-orphaned children were more likely to report poor mental health compared to other-orphaned children [5, 54]. Our findings may be explained by descriptive data that showed caregivers of other-orphaned child most often care for children who have been orphaned through potentially traumatic means, most commonly a violent and/or unexpected parental deaths such as shootings, car accidents, and stabbings. Overall, our findings highlight that regardless of the cause of orphanhood, caregivers of orphaned children are at elevated risk for PTSD symptoms. These data thus emphasize the importance of understanding the mental health of adults caring for AIDS-orphaned and other vulnerable children within the context of the broader challenges they face, rather than simply through an HIV-centric lens.

This study identified household receipt of an old age pension as a possible protective factor for PTSD symptoms among caregivers of orphaned children. This grant is needsbased, with receipt based on a low income threshold, and targets adults 60 years or older [55]. Other studies document the far-reaching social impact of old age pension grants in the developing world [56, 57] but our findings highlight that the grant might serve as a protective factor for reducing PTSD symptoms among caregivers. While this finding should be taken with caution given the old age pension showed a pattern that was a trend towards significance (p < 0.055), it certainly indicates more research needs to be done on grants as protective factors for mental health among adults caring for orphaned children in HIV affected communities. It may be that grants alleviate poverty, which in turn affects mental health; a recent review was conducted showing a strong association between poverty and risk for common mental disorders in low- and middle-income countries [58].



^a Denotes trend towards significance

^b Measured on an 84-point scale; higher values reflect more social support

^c Dichotomous variable calculated based on mean value; higher values reflect more household assets; 1 = high, 0 = low

^d 1 = formal dwelling, 0 = informal dwelling

 $^{^{}e}$ 1 = yes, 0 = no

f Dichotomous variable calculated based on mean value; higher values reflect higher age

g 1 = female, 0 = male

^h Dichotomous variable calculated based on mean value; higher values reflect more education

This study is limited by the cross-sectional nature of the data, which does not allow for the disaggregation of how trauma(s) effects the onset and severity of PTSD symptoms [59]. In addition, our focus on PTSD provides only a partial view of psychological distress, and the traumatic events checklist was not able to provide detail on whether the unexpected death of someone close to the respondent was due to AIDS. Moreover, even with this sample size, gender differences could not be fully explored due to the majority of caregivers being female.

Despite these limitations, our study uniquely contributes to the literature on the health of this understudied population. Previous studies have largely been driven by convenience samples or anecdotal qualitative data. In contrast, our finding are derived from a large representative household study on caregivers of children in HIV-endemic South Africa and to our knowledge, the first representative study to examine prevalence of PTSD symptoms in this population and to compare outcomes among caregivers of AIDS-orphaned and other-orphaned children. Our sample is further strengthened by a high response rate, possibly due to unemployed participants who had time to participate or due to participant interest in health, which previous exploratory qualitative work indicated was a priority for the target population [60].

Conclusions

Together, our findings contribute to a growing understanding of the intergenerational effects of orphanhood in South African families. For example, studies indicate children orphaned by AIDS are at risk for emotional and physical abuse, transactional sexual exploitation [61] and poor educational outcomes [62]; families who take on care for orphans face a range of financial challenges [63-65]; and food insecurity [66]. However, to date we have little understanding of mental health outcomes among caregivers in these families. Our findings contribute insight into the intergenerational effects of HIV and violence on the mental health of families in South Africa, adding to the literature on the burden of mental health in low- and middle-income countries [67, 68]. We still need to better understand how caregiver mental health may affect child outcomes through mechanisms such as parenting, family communication, and caregiver and child relationships. Additional studies also need to be conducted to replicate these findings in South Africa and in other countries affected by the HIV epidemic and/or high rates of orphanhood.

Our study identifies a strong need for interventions that can address PTSD symptoms among caregivers in HIVendemic South Africa. Combined with other literature on mental health vulnerabilities among orphaned children, this study highlights the need for family- and community-based approaches to address mental health in settings with endemic HIV and violence in South Africa. Interventions might try to reduce violence and AIDS-related deaths, which relate to the development of PTSD symptoms in this population. Interventions may also include broader social interventions that are economic in nature, targeting, for example, access and uptake of social grants. It may be particularly important to provide interventions for caregivers of orphaned children. Culturally and contextually relevant development and adaptation of interventions is needed, particularly given the scarcity of mental health practitioners in this setting [69] and other global mental health challenges [70].

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