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Knowing Kids Dying of HIV: A Traumatic Event for AIDS Orphans

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Abstract

Data from 755 AIDS orphans living in a rural area of China with high rates of HIV infection were used to examine the association between a child's trauma symptoms and knowing a peer with HIV infection or one who had died of HIV. Trauma symptoms were measured by the Traumatic Symptoms Checklist for Children-Chinese Version (TSCC-CV). About 47% of participants reported they knew a child with HIV or one who had died of HIV. More orphans living in family-based care reported such knowledge, and trauma symptoms were significantly higher in children who reported such knowledge. Multivariate analysis revealed that such knowledge was significantly associated with traumatic symptoms, controlling for gender, age, family socioeconomic status, orphan status (double vs. single), and care arrangement (family-based vs. institutional care). The findings underscored the importance of psychosocial support and counseling to orphans in communities with high levels of HIV-related mortality.

Keywords

AIDS; China; HIV; orphans; traumatic symptoms

In 2007, approximately 18 million children worldwide had been orphaned by AIDS (Platt-McDonald, 2007). Children who lost their parents to HIV might have experienced additional

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traumatic events in their lives (Li, Fang et al., in press), and one such event may be the personal knowledge of other children who were infected with HIV or had died from HIV.

Previous studies on personal knowledge of HIV infection or HIV-related death have mainly focused on its relationship with changes in personal sexual behaviors such as increased condom use, delayed sexual initiation, and reduced number of sexual partners (Camlin & Chimbwete, 2003; Gray, Morgan, & Shirer, 2001; Gregson, Zhuwaiui, Anderson, & Chandiwana, 1997; Ijumba, Gamieldien, Myer, & Morroni, 2004; Macintyre, Brown, & Sosler, 2001; Mitchell, Severtson, & Latimer, 2007; Palekar, Pettifor, Behets, & Macphail, 2008). Several studies of adolescents found that social anxiety about interacting with persons with HIV infection was lower among teenagers who had known someone with HIV (Zimet**,** 1992; Zimet et al., 1991). However, to our knowledge, no studies have been conducted in China to examine the association between personal knowledge of children dying of HIV/AIDS and traumatic symptoms among AIDS orphans. The present study, using data from China, attempted to investigate whether personal knowledge of other children who were infected with or had died of HIV constituted an additional traumatic event for AIDS orphans.

The China Ministry of Health estimated that there were at least 100,000 AIDS orphans in China in 2004 (Zhao et al., 2007). Many of the AIDS orphans in China known to the public live in Henan Province, an agricultural area in central China with a population of 96.66 million (Li, Fang et al., in press). Some commercial blood stations/centers started collecting cheap blood in remote rural areas of Henan Province between the late 1980s and the middle 1990s. Because of poverty, many farmers sold their blood for quick cash. The blood collection centers used unhygienic blood collection procedures, resulting in a rapid spread of HIV (Cohen, 2004). Many of the infected people have subsequently died, leaving their children behind (He & Ji, 2007; Zhao et al., 2007).

Previous studies have documented that childhood traumatic events are associated with a variety of negative physical and mental health outcomes (Flannery, Singer, & Wester, 2001; Ford, 2002; Friedrich et al., 2001; Guterman, Cameron, & Hahm, 2003; Johnson et al., 2002), and may cause chronic deficits in the behavioral repertoires of affected children and thus shape personality development, such as the increasing risk of psychotic experiences, panic attacks, suicide, and substance use disorder (Flannery, 2003; Kelleher et al., 2008; Spates, Waller, Samaraweera, & Plaisier, 2003). Therefore, it is important for health care providers and researchers, including nurse practitioners and nursing researchers, to identify possible traumatic events and also to assess the effect of these events on traumatic symptoms among children, so that health care providers and policy-makers can be informed and then make arrangements for psychiatric or psychological services if needed. The current study was designed to assess the level of personal knowledge of peer HIV infection or HIV-related death and its association with traumatic symptoms among AIDS orphans in China.

Methods

Study Site and Participants

The participants in the current study were a subsample of the baseline cohort of a longitudinal assessment of psychosocial needs of children affected by HIV in China (Li, Fang et al., in press). The larger study was conducted in 2006–2007 in two rural counties in central China where many residents were infected with HIV through unhygienic blood collection methods. These counties had the highest prevalence of HIV infection in the area. The participants in the current study included 296 double orphans (i.e., children who lost both of their parents to HIV) and 459 single orphans (i.e., children who lost one of their parents to HIV). Children 6 to 18 years of age were eligible to participate in the study. Age eligibility was verified through the local community leaders, school records, or caregivers.

The double orphans included 176 orphans living in the government-funded orphanages (i.e., institutional-care orphans) and 30 orphans living in government-supported group homes. The remaining double orphans ($n = 90$) and all single orphans were in family or kinship care. Group homes were managed by pairs of local residents serving as “house parents” for a small number (4–6) of AIDS orphans in a family style, and the orphans would call house parents “father” and “mother” and call each other bothers or sisters (Zhao, Li, Fang et al., in press). One of the main reasons for establishing small group homes was to let orphans live in an atmosphere of a “simulated family.” Orphans living in the small group homes and orphans living in other family-care settings (e.g., surviving parent or kinship) all received financial assistance from the local government (Zhao, Li, Fang et al., in press). Therefore, for the purpose of data analysis in the current study, we combined orphans living in the small group homes and orphans living with other family-based care settings into a single group (orphans in family-based care). The orphans in family-based care included 30 double orphans living in group homes and all other double and single orphans living with a surviving parent or relatives (i.e., kinship care).

Sampling Procedure

The sampling and recruitment processes of the larger study have been described in detail elsewhere (Li, Fang et al., in press). Briefly, the institution-care orphans were recruited from four government-funded orphanages in the two counties. A total of 244 AIDS orphans were enrolled in the four AIDS orphanages at the time of the survey and 176 (72%) participated in the survey. A total of 43 orphans were living in the eight group homes and 30 (70%) participated in the survey. The remaining orphans (including 90 double orphans and 459 single orphans) were recruited from the family or kinship care settings. To recruit orphans from the family or kinship care settings, we worked with the village leaders to generate a list of families caring for AIDS orphans. We approached the families on the list and recruited one orphan per family to participate in the assessment. If no orphan in a selected family was available to participate, the next family on the list was selected. When there was more than one eligible child in a household, a single child was randomly selected. This process was repeated until all available orphans in the selected villages were approached. Once the eligibility of a child was confirmed, the interviewers provided him/her with a detailed description of the study design and potential benefits and risks (including confidentiality issues) and invited him/her to participate. Written assent was used for children between 13 and 18 years of age; and oral assent was used for children 6 to 12 years of age. Written or oral permissions (in case of illiteracy) were obtained from caregivers/legal guardians who were available to provide the consents for their children’s participation. In case of oral consent, community members accompanying the interviewers served as witnesses for the consenting procedure. In situations where no parents or legal guardians were available to provide parental permission/consent, a “resource person” was identified for each of these children as a means of protection. The resource persons included legal representatives of the orphanages, community leaders, older siblings (16 years of age or older), or school teachers. Each resource person received an information sheet with a detailed description of the study design and potential benefits and risks (including confidentiality issues) in order to help the child make the decision to participate or not in the research. The research protocol, including consenting procedure, was approved by the institutional review boards at both Wayne State University in the United States and Beijing Normal University in China.

Survey Procedure

Each child was administered an assessment inventory. For children who were too young or had limited literacy, interviewers read each question to them, and the children gave oral responses to the interviewers who recorded the responses in the survey instrument. During the survey, necessary clarification or instruction was provided promptly when needed. The interviewers were psychology and education graduate students and faculty members from local universities. All interviewers received a 3-day training on research methodology, psychological assessment, and research ethics prior to the field data collection. The entire assessment inventory typically took 75 to 90 minutes, depending on the age of the child. Younger children (e.g., those ≤ 8 years of age) were offered a 10–15 minute break after every 30 minutes of assessment. Each child received a gift at completion of the assessment as a token of appreciation.

Measures

Demographic characteristics—Children were asked to provide a number of individual and family characteristics during the survey. These characteristics included age, sex, care arrangement (i.e., family-based care, institutional care), orphanhood status (i.e., double AIDS orphan, single AIDS orphan). Four items were employed to assess the children's family socioeconomic status (SES): paternal and maternal education (no schooling, elementary school, middle school, ≥high school) and the main occupation their father/mother engaged in (farmer, migrant worker, small business vender, or other). Following general recommendations in the global literature on measuring SES in health disparities research (Shavers, 2007), a composite score was created to provide an estimate of the children's family SES by indexing those children whose parents (father and mother) had more than elementary school education and engaged in non-farming occupational activities. The SES composite score had a range of 0 to 4 with a higher score indicating a better family SES. Missing data on any of the four SES items were allowed during the calculation of the composite score.

Personal knowledge of peer HIV—Two dichotomous items (*yes/no*) were used to measure AIDS orphans' personal knowledge of peer HIV infection and death. The first item (knowledge of infection) asked AIDS orphans whether they personally knew any child who had been infected with HIV. The second item (knowledge of death) asked orphans whether they knew any child who had died of HIV. A third dichotomous variable was created by combining the responses to these two items to measure the overall knowledge of peer HIV (i.e., knowledge of peer HIV infection or HIV-related death).

Trauma symptoms—The children's trauma symptoms were measured using a Chinese version of the Trauma Symptoms Checklist for Children (TSCC-CV). TSCC-CV is a self-report measure of posttraumatic distress and related psychological symptoms among children 8–16 years of age (Briere, 1996). The full version TSCC-CV consists of 54 items that produce 6 clinical scales: anxiety (ANX), depression (DEP), anger (ANG), posttraumatic stress (PTS), dissociation (DIS), and sexual concerns (SC). Each TSCC-CV item is rated according to its frequency, using a 4-point scale ranging from 0 (*never*) to 3 (*almost all of the time*). The TSCC-CV has demonstrated adequate reliability and validity among AIDS orphans and children living with HIV-infected parents in China (Li, Fang et al., in press). In this study, internal consistency estimates (Cronbach alpha) for 6 clinical scales were all in the .80s except the one for anxiety (.79).

Statistical Analysis

Chi-square test (for categorical variables) and ANOVA (for continuous variables) were employed to examine the group differences of individual characteristics among AIDS orphans by their personal knowledge of peer HIV-related infection (*yes/no*), peer HIV-related death (*yes/no*), as well as combined score of such knowledge (*yes/no*). ANOVA was employed to compare the group difference in total scores of the 6 TSCC-CV scales (anxiety, depression, anger, posttraumatic stress, dissociation, and sexual concerns). Finally, general linear model (GLM) analysis controlling for age, sex, family SES, care arrangement, and orphanhood status was used to assess the differences by combined knowledge of peer HIV (*yes/no*). All statistical analyses were performed using SPSS for Windows 11.5.

Results

Sample Characteristics

As shown in Table 1, the mean age for the study sample was about 13 years. About 16.6% of boys and 19.9% of girls reported personal knowledge of both peer HIV infection and HIV-related death; 24.6% of boys and 20.8% of girls reported personal knowledge of only HIV infection; and 6.2% of boys and 5.9% of girls reported personal knowledge of only HIV-related death. In total, about 47% of boys and 47% of girls reported personal knowledge of HIV infection or HIV-related death. About 35% of double AIDS orphans and 54% of single AIDS orphans reported that they had such personal knowledge. Compared with institution-care AIDS orphans (orphans who were living in AIDS orphanages), more family-care AIDS orphans (orphans who were living in small group homes or with surviving parent/kinship) reported such personal knowledge (53% vs. 25%). The composite family SES score was lower among AIDS orphans with personal knowledge of peer HIV infection or HIV-related death than AIDS orphans who did not have such knowledge ($F = 4.79$, $p = .029$).

Trauma Symptoms

As shown in Table 2, all 6 subscales of TSCC-CV among AIDS orphans who knew other children being infected with HIV were higher than AIDS orphans who did not have such knowledge, although only the difference with anxiety, depression, posttraumatic stress, and dissociation reached statistical significance. All 6 subscales of TSCC-CV were also higher among AIDS orphans who knew other children who had died of HIV than AIDS orphans who did not have such knowledge and all differences except the one with sexual concerns reached statistical significance. All TSCC-CV subscales were significantly different by the combined knowledge with AIDS orphans who knew of peer infection with or death from HIV scoring higher in traumatic symptoms.

The multivariate analysis (Table 3) revealed a multivariate significance ($F = 2.72$, $p = .013$) and univariate significance for all TSCC-CV subscales with regard to the effect of orphans' combined knowledge of peer HIV infection or HIV-related death while controlling for age, sex, SES, orphanhood status, and care arrangement. The child's sex showed a multivariate significance in GLM analysis. In addition, sex was significant for 2 TSCC-CV scales (anxiety and dissociation). Child age was a significant covariate for scales of anger and sexual concerns. The family SES was a significant covariate for sexual concerns scale. Neither orphanhood status (double vs. single orphans) nor care arrangement (family-based vs. institutional care) was significant in multivariate or univariate tests. None of the interaction terms among factor variables was significant.

Discussion

The data in the current study demonstrated that compared to double AIDS orphans or AIDS orphans in institutional care, single AIDS orphans or AIDS orphans in family-based care reported more personal knowledge of other children who were infected with or had died from HIV. This might be because most of the double AIDS orphans were living at government-supported orphanages, where they were in relative separation from peers from the local community and were deprived of information about HIV/AIDS (Zhao, Li, Kaljee et al., in press).

The results in the current study indicated that the personal knowledge of peer HIV infection or HIV-related death was strongly associated with trauma symptoms after controlling for other potential individual and contextual confounders. Previous studies found that children who experienced traumatic events scored significantly higher on the trauma symptoms (Li, Barnett et al., submitted; Sadowski & Friedrich, 2000; Singer, Anglin, Song, & Lunghofer, 1995). Findings in the current study suggested that knowing about peers' HIV-related infection or death was a traumatic event for these AIDS orphans, despite the fact that the children had suffered the loss of one or both of their parents and other possible daily traumatic events associated with HIV-related parental illness and loss (Li, Barnett et al., submitted). AIDS orphans who knew of peer infection with or death from HIV represented a subgroup of children at a greater risk for elevated psychological problems. Because previous studies suggested that traumatic memories could be stimulated by symbolic reminders, even those traumatic events that happened earlier in their lives (Flannery, 2003), personal knowledge of peer HIV infection or HIV-related death might serve as an additional stressor for these children and such personal knowledge might revive traumatic memories (loss of parents to HIV) and lead to the development of traumatic symptoms among these children.

There are several potential limitations in the current study. First, TSCC-CV scales used in the current study did not have any utility for clinical diagnosis or individual profiling of trauma symptoms among these children because of the lack of norm data for Chinese children. Second, the current study had a small number of children (*n* = 24 or 3.2%) whose ages were outside the age range of the original TSCC (e.g., 8–16). These out-of-age-range children included one 6-year-old, four 7-year-olds, eighteen 17-year-olds, and one 18-year-old. Because the results with and without these out-of-age-range children were very similar, we chose to maintain the entire sample in the current study. However, it needs to be cautioned that these young children might have been too young to provide reliable information regarding their thoughts and feelings in response to traumatic events in their lives. Finally, some important information (e.g., the timing of child's parental loss, the relationship between the AIDS orphans and the infected or deceased peers they knew) was not available for analysis in the current study. Because these factors might influence the traumatic symptoms among AIDS orphans, future study including such additional information may provide a greater insight into the extent of the effect of the personal knowledge of peer HIV-related infection and death on AIDS orphans in China.

Despite these limitations, this study provided preliminary evidence that knowing other children who were infected with or had died from HIV might adversely affect the mental health of AIDS orphans. Implications of these findings may include the need for all health care providers to recognize the traumatic nature of such personal knowledge among AIDS orphans and to provide targeted services, such as developmentally appropriate psychological counseling and interventions (Rotheram-Borus, Murphy, Miller, & Draimin, 1997) to these already-vulnerable children at home, at school and in communities, especially in communities with a high level of HIV-related mortality.

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Table 1

Demographic Characteristics of Study Sample by Personal Knowledge of Peer HIV Infection and HIV-related Death

	Peer HIV infection		**Peer HIV related death**		**Combined knowledge of peer HIV infection or death**	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**
N (%)	292(41%)	421(59%)	171(24%)	536(76%)	335(46%)	388(54%)
Mean age (*SD*)	13.33(2.07)	13.14(2.29)	13.54(2.00)	13.11(2.25)*	13.05(2.30)	13.35(2.08)
Gender						
Boys	157(41%)	224(59%)	86(23%)	292(77%)	181(47%)	206(53%)
Girls	135(41%)	197(59%)	85(26%)	244(74%)	154(47%)	182(53%)
Orphanhood status						
Double orphans	79(28%)	206(72%)	53(19%)	228(81%)	99(35%)	188(66%)
Single orphans	213(50%)	215(50%)****	118(28%)	308(72%)**	236(54%)	200(46%)****
Care arrangement						
Institutional care	27(16%)	142(84%)	30(18%)	139(74%)	42(25%)	129(75%)
Family-based care	265(49%)	279(51%)****	141(26%)	397(74%)*	293(53%)	259(47%)****
Family SES	1.80(1.16)	1.97(1.16)	1.75(1.09)	1.96(1.18)*	1.80(1.16)	1.99(1.16)*

$^{*}p < .05$;

$^{**}p < .01$;

$^{****}p < .0001$

Table 2

Group Differences in Trauma Symptoms by Personal Knowledge of Peer HIV Infection and Death

	Peer HIV infection		**Peer HIV-related death**		**Combined knowledge of peer HIV infection or death**	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**
ANX	51.58(9.76)	49.87(9.72) *	52.54(10.69)	49.74(9.26) ***	51.64(10.05)	49.48(9.39) **
DEP	52.45(10.50)	49.87(9.71) ***	53.41(10.90)	49.96(9.54) ****	52.38(10.60)	49.54(9.45) ****
ANG	50.48(9.36)	49.47(9.73)	51.39(10.64)	49.23(8.89) **	50.75(9.90)	49.02(9.16) *
PTS	51.78(9.92)	49.73(9.63) **	52.97(10.63)	49.58(9.13) ****	51.98(10.21)	49.24(9.19) ****
DIS	51.81(9.45)	50.25(10.02) *	53.19(10.43)	49.94(9.31) ****	52.06(9.83)	49.73(9.63) ***
SC	50.27(9.25)	49.30(9.39)	50.48(10.18)	49.28(9.00)	50.45(9.65)	48.93(8.95) *

Note. ANX (anxiety), DEP (depression), ANG (anger), PTS (posttraumatic stress), DIS (dissociation), SC (sexual concerns)

* $p < .05$;

** $p < .01$;

*** $p < .001$;

**** $p < .0001$

Table 3

GLM Analysis of Effect of Personal Knowledge of Peer HIV Infection and Death on Trauma Symptoms

	Main effect				**Covariates**	
	Knowledge[1]	**Sex**	**Orphanhood status**[2]	**Care arrangement**[3]	**Age**	**SES**
Multivariate test	2.72^{*}	6.75^{****}	<1	<1	13.07^{****}	2.68^{*}
ANX	7.12^{**}	8.00^{**}	<1	1.17	1.15	1.7
DEP	8.76^{**}	2.79	<1	<1	<1	2.82
ANG	7.48^{**}	<1	1.38	<1	6.91^{**}	<1
PTS	15.44^{****}	3.11	<1	2.22	<1	3.4
DIS	8.82^{**}	4.26^{*}	<1	1.76	1.22	3.68
SC	5.72^{*}	3.23	<1	<1	25.98^{****}	6.20^{*}

[1] *Note*. AIDS orphans’ personal knowledge of peer HIV infection or death (*yes/no*)

[2] Double AIDS orphans and single AIDS orphans

[3] Institutional care and family-based care

All interaction terms among factor variables were excluded from this table because of absence of statistical significance.

ANX (anxiety), DEP (depression), ANG (anger), PTS (posttraumatic stress), DIS (dissociation), SC (sexual concerns)

* $p < .05$;

** $p < .01$;

**** $p < .0001$