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Family-based Care and Psychological Problems of AIDS Orphans: Does It Matter Who Was the Care-giver?

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Abstract

The purpose of this study is to compare psychological symptoms among double AIDS orphans (i.e., children who lost both of their parents to HIV/AIDS) who were in the care of different family-based caregivers (i.e., surviving parent, grandparents, other relatives, & non-relatives) before they were replaced in orphanages.

The participants include 176 double AIDS orphans from four AIDS orphanages in rural China. Prior to being replaced in AIDS orphanages, these children had received family-based care by different caregivers, which included surviving parent (38%), grandparents (22%), other relatives (19%) and non-relatives (22%). The psychological measures include traumatic symptoms, depression, and loneliness. Both bivariate and multivariate analyses suggested that children who were previously cared for by non-relatives scored significantly higher in traumatic symptoms, depression and loneliness scales than children who were previously cared for by their surviving parent, grandparents, and other relatives. The children in the care of grandparents reported the best scores on all psychological measures among children in the care of non-parent relatives. Multivariate analysis, controlling for children's gender, age, length in orphanages, number of household replacements, and total duration of replacement, revealed that the type of caregivers was significantly associated with psychological problems.

Results in the current study suggest that children under the care of their grandparents reported the best psychological outcomes when their parents were unable to care for them because of AIDS. Appropriate psychological support and counseling services are needed for AIDS orphans who were either currently or previously under non-relative family-based care in China.

Keywords

China; AIDS orphans; psychological symptoms; family-based care

Introduction

The United Nations estimates that by 2010 there will be at least 20 million AIDS orphans worldwide (Akukwe, 2007). There is evidence that relatives and grandparents tend to be the

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primary caretakers of children affected by AIDS (Abebe & Aasa, 2007; Gilborn, Nyonyintono, Kabumbuli, & Jagwe-Wadda, 2001; Ntozi, 1997; Nyambedha & Gregson, 2005). The number of orphans who require care and support from surviving relatives has risen, which might pose enormous stress on the home-based care in a community where many families are already overburdened by HIV/AIDS and their resultant economic deprivation.

Many previous studies indicated that caregivers of AIDS orphans, especially grandparents, usually were at risk of poor health status, increased social isolation, depression, anxiety and poverty (Joslin & Harrison, 1998; Kanya & Poindexter, 2009; Kipp, Tindyebwa, Karamagi, & Rubaale, 2007; Ssengonzi, 2007). However, very little is known about the well-being of AIDS orphans who were under the care of these caregivers. Children who lost their parents to HIV/AIDS might have experienced many traumatic events in their lives. Yet research suggests that living with a relative such as a grandparent rather than with a non-relative may minimize the trauma by providing the child with an increased sense of stability and family support (Dubowitz et al., 1994; Scarcella, Ehrle, & Geen, 2003).

Limited data are available regarding whether living with relatives might be better than with non-relative caregivers for these already traumatized AIDS orphans, especially when their caregivers might suffer from poor physical and mental health or be under substantial stress. Only one qualitative study conducted in Thailand mentioned that the appropriate placement for an AIDS orphan was with a member of the child's extended family, rather than an unrelated person (Safman, 2004). The further lack is the literature that investigates the well-being of AIDS orphans who were under the care of different caregivers in developing countries including China.

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 are living in Henan Province, an agricultural province in central China with a population of 96.66 million (Li et al., 2009). Some commercial blood stations/centers started collecting blood in remote rural areas of Henan Province in the late 1980s. The blood collection centers used unhygienic blood collection procedures, resulting in the rapid spread of the HIV (Cohen, 2004). Many of the infected people have subsequently died, leaving their children behind (He & Ji, 2007; Zhao et al., 2007). Extended family has been the primary care option for AIDS orphans in rural China. Based on a report from the civil affair department of Henan province, about 85% of AIDS orphans were raised by their extended families in Henan province (Xinhuanet, 2007; Zhao et al., 2007).

Since 2004, in response to the increased number of AIDS orphans, the Chinese government has begun construction of AIDS orphanages in areas hardest hit by AIDS and the first of such AIDS orphanages was built in late 2004 in Henan Province. Some children who lost both of their parents to AIDS and were not infected with HIV or other infectious diseases were admitted to the AIDS orphanages (Zhao et al., 2009). While some of these children were placed in orphanages directly after their surviving parent died, most children were selected from other family-based homes where the caregivers were deemed to be incapable or inadequate (either physically or financially) to provide continuous care of these children.

While these children were all under the centralized care (i.e., AIDS orphanage) at the time of the data collection in this study, their previous experience with different types of caregivers provided an opportunity to examine the well-being of AIDS orphans in the care of different caregivers. The current study, utilizing the baseline data from a longitudinal assessment of psychosocial needs of children affected by AIDS in China, was designed to compare psychological well-being among AIDS orphans who received care by different family-based caregivers (i.e. surviving parent, grandparents, other relatives, and non-relatives). The ultimate

goal of the study was to provide empirical evidence that can inform the policy development and intervention planning, and eventually the improvement of the quality of care for AIDS orphans.

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 AIDS in China. 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 (Li et al., 2009). Both counties had the highest prevalence of HIV-infection and the community was extreme poor in the area. A total of 244 AIDS orphans were enrolled in four AIDS orphanages in the two counties (2 orphanages in each county) at the time of survey and 176 (72%) participated in the survey. There were other AIDS orphanages built in these two counties, but only these four had enrolled any children at the time of baseline survey. For siblings in the same orphanage, only one child was randomly selected to participate by tossing coins. Children 6 to 18 years of age were eligible to participate in the study.

Consenting Procedure

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; and oral assent was used for children 6 to 12 years. Written or oral permission (in case of illiteracy) were obtained from legal guardians who were available to provide the consents for the children's participation. In case of oral consent, community members accompanying the interviewers served as witnesses for the consenting procedure. 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. Completion of the entire assessment inventory required 60 to 90 minutes. Each child received a gift at completion of the assessment as a token of appreciation.

Measures

Demographic characteristics—These children were asked who was their main caregiver before they were placed in AIDS orphanages, and based on these children's report, four groups of family-based caregivers were identified (i.e., surviving parent, grandparents, other relatives, and non-relatives), in which other relatives included aunts/uncles and a small percentage of elder siblings. Children were also asked to provide a number of individual and family characteristics during the survey. These characteristics included age, sex, total time in orphanages, number of household replacements following the death of their parents, and total duration of replacements.

Depression—Children's depressive symptoms were measured using the Center for Epidemiological Studies Depression Scale for Children (CES-DC) (Fendrich, Weissman, & Warner, 1990). Sample items include "I was bothered by things that usually don't bother me."

The CES-DC is a 20-item self-report depression measure with a 4-point response option (i.e., 0=not at all, 1=a little, 2=some, 3=a lot). A sum score was employed as the CES-DC scale score with higher scores indicating increasing levels of depression. Cronbach alpha of the scale was .85 for the current study sample.

Loneliness—The Chinese version of the Children's Loneliness Scale (CLS, Asher, Hymel, & Renshaw, 1984; Wang, 1993) was administered to the children in the current study. The CLS consists of 16 items assessing children's perceived loneliness and social dissatisfaction. The CLS items have a 5-point response option ranging from "Not at all true" to "Always true". Sample items include "I have nobody to talk to." A mean score was employed as the CLS score with higher scores indicating increasing levels of loneliness. The Cronbach alpha for the 16 loneliness items was .85 for the current study sample.

Trauma Symptom—The children's trauma symptoms were measured using a Chinese version of the Trauma Symptom Checklist for Children (TSCC-CV, Briere, 1996; Li et al., 2009). TSCC-CV is a self-report measure of posttraumatic distress and related psychological symptoms among children 8–16 years of age. The full version TSCC-CV consists of 54 items that produce six 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 four-point scale ranging from 0 ("never") to 3 ("almost all of the time"). In this study sample, internal consistency estimates (Cronbach alphas) for six clinical scales were all in the .80s except the one for DEP which was .79. The TSCC-CV has demonstrated adequate reliability and validity among AIDS orphans and children living with HIV-infected parents in China (Li et al., 2009).

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 different groups of care providers. Oneway ANOVA with post hoc multiple comparisons using the least significant difference criterion was employed to assess the group differences of CES-DC, CLS, and six TSCC-CV scales (ANX, DEP, ANG, PTS, DIS, SC). Finally, general linear model (GLM) analysis controlling for age, sex, total months in orphanage, number of household replacements and duration of replacement was used to assess the psychological differences by different types of caregivers in family-based care setting. All statistical analyses were performed using SPSS for Windows v 11.5.

Results

Sample Characteristics

As shown in Table 1, the mean age for the sample was about 12.42 years (range 6–17), and the children who were cared by their grandparents was significantly younger than children living with other caregivers. There were more boys (61.4%) than girls (38.6%) in the sample. The mean duration for children living in orphanages were 21.17 months. Sixty-six children (37.5%) were replaced in AIDS orphanage following the death of their surviving parent. Among the children (62.6%) who had been replaced to be under the care of other caregivers, the average numbers of household replacement excluding children's own household before they were replaced in orphanages were 1.71 for grandparents, 1.76 for other relatives and 1.51 for non-relatives. The mean duration of total replacements were 58.56 months for grandparents, 38.80 months for other relatives and 37.91 months for non-relatives.

Child psychosocial well-being by caregiver group

Table 2 depicts the group differences of children's psychological well-being by caregiver group. The bivariate comparison showed that there were significant differences among the four groups (i.e., surviving parent, grandparents, other relatives, and non-relatives) in six items of child psychological measures (i.e. CES-DC, CLS, ANX, DEP, ANG, and SC). The children who were in the care of non-relatives reported the highest scores in all measures of psychology. The children in the care of other relatives scored higher than children in the care of surviving parent and grandparents in all measures except for SC. The post hoc pair-wise comparison confirmed that children living with non-relatives reported significantly higher scores than children living with their own surviving parent and grandparents in depression, loneliness, and four of the trauma symptoms (i.e., ANX, DEP, ANG, and SC).

The general linear model (GLM) analysis (Table 3) revealed both multivariate significance ($F=1.64, p<.05$) and univariate significance with regard to the effect of caregivers (i.e., surviving parent, grandparents, other relatives, and non-relatives) on the measures of DEP ($F=2.73, p<.05$) and SC ($F=4.73, p<.01$) while controlling for age, sex, duration in orphanage, number of household replacement and total duration of replacement. There were no significant effects with all other factors (i.e., age, sex, duration in orphanage, number of household replacement and duration of replacement) in either multivariate test or univariate test. In addition, none of the interaction terms among factor variables was significant.

Discussion

The data in the current study demonstrate that AIDS orphans who were under the care of a surviving parent and grandparents reported better scores in child psychological measure than children in the care of other relatives and non-relatives. Children who were under the care of non-relatives reported the worse psychological outcomes than those under the care of other type of caregivers (i.e., surviving parent, grandparents, and other relatives). The finding is consistent with results of several previous studies that a child living with relatives was better than living with non-relatives when their parents were not able to take care of the children (Dubowitz et al. 1994; Safman, 2004; Scarcella et al., 2003).

The current study showed that children under the care of grandparents reported the better scores than children living with other relatives in all measures of child psychological well-being, and such scores were almost the same as that of children in the care of their own surviving parent. The result suggested that grandparents should be the first-choice family-based caregivers for double AIDS orphans, especially in poor communities in rural China. The possible reasons that grandparents were better than other relatives (i.e., aunts/uncles and elder siblings) on the care for children were not only because grandparents had more experiences in raising children, but also because they were believed to equally share the parents' affection for the children (Cattell, 1993; Safman, 2004; Young & Ansell, 2003). Other caregivers, especially aunts or uncles, might favor their own children over the fostered child, particularly in poor communities where sources are too scarce to meet the needs of the whole family (Ansell & Young, 2004; Safman, 2004; Van der Waal, 1996). Furthermore, in China, there exists a historical tradition of extended family and a strong norm guiding intergenerational relationship, and the involvement of grandparents in childcare particularly is one expression of this intergenerational tie (Chen, Short, & Entwisle, 2000; Cornwell, Casper, & Chou, 1990; Hermalin, Roan, & Perez, 1998). So in China, the grandparents are always considered as the first choice for childcare if the parents were unavailable or unable to care for their children.

AIDS orphans and HIV-affected children were mainly cared for by their grandparents in most countries, especially in developing countries (Caliandro & Hughes, 1998; Joslin & Brouard, 1995; Masmas et al., 2004; Safman, 2004; Ssengonzi, 2007). Global literatures indicated that

many grandparents who provided care for AIDS orphans experienced higher risk of emotional and behavioral difficulties concerning the numerous challenges such as financial strain, age-related health problems, isolation, social stigma, and inadequate support (Glass, 2002; Whitley, Kelley, & Sipe, 2001; Kipp et al., 2007; Kanya & Poindexter, 2009; Ssengonzi, 2007). Such grandparents typically show elevated rates of depression, anxiety, anger and irritability, which in turn, might negatively affect children's psychological well-being (Elgar, McGrath, Waschbusch, Stewart, & Curtis, 2004; Lindsey, Hirschfeld & Tlou, 2003; Ssengonzi, 2007; Whitley et al., 2001). Our study suggests some advantages of grandparent care compared with other family-based caregivers. However, these grandparents in rural China might have faced many similar burdens related to caring for AIDS orphans. Therefore, it is important for local government and community to provide necessary support to empower and enable grandparents to take care of these children.

There are several limitations in the current study. First, the sample size was relatively small which might limit the statistical power of the data analysis. However, even with this limited statistical power, the data have revealed significant differences in psychological outcomes among different caregiver groups, which suggests a potentially stronger effect of caregiver on the psychological well-being of AIDS orphans. Second, all the data were self-reported and some were retrospective with no objective data available to further validate the findings. Finally, the finding of the current study may be confounded by other factors for which data were not available in the current study. For example, the economy status and living condition of different care settings and the health status of caregivers may be related to the psychological well-being of these children. Future research is needed to examine potential effects of these factors on the well-being of AIDS-affected children.

Despite these limitations, the current study is one of the first efforts to compare the psychological well-being of AIDS orphans under the care of different family-based caregivers (i.e., surviving parent, grandparents, other relatives, and non-relatives) in developing countries. The research indicates that grandparents are the best family-based caregivers next to surviving parents who provided care for their children before they passed away, in terms of child self-report of psychological well-being. Therefore it is important for government and community to make efforts to support grandparents on the health, economy and other living situations so as to improve the ability and quality of grandparents' child care. The findings also underscore that psychological support and counseling services are specially needed for AIDS orphans who were either currently or previously under the care of non-relative families in China and other developing countries.

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Table 1

Demographic characteristics of study sample

Variables	Overall	Parents	Grandparents	Other relatives	Non-family caregivers
N (%)	176(100%)	66(37.5%)	38(21.6%)	33(18.8%)	39(22.2%)
Gender					
Boy	108(61.4%)	43(65.2%)	20(52.6%)	20(60.6%)	25(64.1%)
Girl	68(38.6%)	23(34.8%)	18(47.4%)	13(39.4%)	14(35.9%)
Mean age (SD)	12.42(2.56)	12.79(2.64)	12.03(2.83)	13.52(2.28)	11.23(1.83)***
Months in orphanage (Mean/SD)	21.17(17.38)	23.76(15.25)	19.71(19.17)	22.26(19.65)	17.22(16.86)
Number of household replacements (Mean/SD)	1.65(0.92)	N/A	1.71(1.04)	1.76(1.00)	1.51(0.72)
Duration of displacement in months (Mean/SD)	45.31(55.42)	N/A	58.56(70.60)	38.80(35.26)	37.91(51.40)

 $p < .001$

Table 2

Group differences in child psychological well-being

Variables Mean(SD)	Parents (1)	Grandparents (2)	Other relatives (3)	Non-relatives (4)	Post-hoc comparison
Depression	18.06(7.74)	18.55(8.04)	21.27(9.88)	23.28(10.30)*	4>1**; 4>2*
Loneliness	2.26(0.70)	2.33(0.80)	2.45(0.71)	2.71(0.63)*	4>1**; 4>2*
Trauma symptoms					
ANX	48.79(8.59)	48.47(9.96)	53.41(11.15)	53.78(13.23)*	4>1*, 4>2*
DEP	48.55(7.64)	47.55(8.86)	51.79(9.69)	53.33(11.97)*	4>1*, 4>2**
ANG	48.65(8.09)	50.53(10.99)	50.91(8.63)	57.16(15.09)**	4>1****; 4>2*, 4>3*
PTS	49.76(8.88)	49.46(10.40)	52.26(11.19)	53.98(13.34)	
DIS	49.96(8.84)	49.51(10.60)	52.59(11.74)	54.04(13.03)	
SC	49.14(8.91)	47.82(9.72)	48.75(5.71)	56.41(13.57)****	4>1****; 4>2****; 4>3***

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 child psychological well-being by type of caregiver

	Main effect			Covariates		
	Type of Caregiver ^a	Sex	Age	Time in orphanage	household replacements	Duration of displacement
Multivariate Test	1.64 *	1.75	1.76	<1	<1	<1
Depression	1.95	<1	<1	<1	<1	2.00
Loneliness	2.32	<1	2.70	<1	1.77	<1
Trauma symptoms ^b						
ANX	2.46	1.33	<1	<1	1.04	<1
DEP	2.73 *	1.26	<1	1.08	<1	<1
ANG	2.41	<1	<1	<1	1.25	<1
PTS	1.33	<1	<1	1.57	1.42	<1
DIS	1.59	<1	<1	<1	<1	<1
SC	4.73 **	1.32	1.17	<1	1.99	<1

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

^aType of caregiver: parents, grandparents, other relatives, and non-relatives.

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

* $p < .05$;

** $p < .01$;

*** $p < .001$;

**** $p < .0001$