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Depression symptoms among caregivers of children in HIV affected families in rural China

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Abstract

The objectives of this study were to examine symptoms of depression among caregivers of rural AIDS orphans (i.e., children who had lost one or both of their parents to HIV/AIDS) and vulnerable children (i. e., children who were living with HIV-infected alive parents), and to explore factors associated with the presence of symptoms of depression among caregivers.

Cross-sectional data were collected from 160 adult caregivers (parents, relatives or other adults) from a rural area in China where many residents were infected with HIV through unhygienic blood collection. The sample included 120 caregivers from households caring for AIDS orphans and vulnerable children (OVC) and 40 from households without OVC. The Center for Epidemiological Studies Depression Scale (CES-D) was used to assess the symptoms of depression among the caregivers. Multiple regression analysis was performed to assess the associations of depressive symptoms with various individual and family factors among caregivers.

The mean score of CES-D for the entire sample was 19.18 (17.84 for men and20.44 for women). The univariate analysis indicated that the score of CES-D was significantly higher among caregivers with lower education, fewer household items/assets, from families with adult or pediatric HIV infection. Controlling for age, gender, and caregivers' education, multiple regression analysis revealed significant associations between symptoms of depression and reduced family SES, adult or pediatric HIV infection in family.

Our results indicated an elevated level of depression symptoms among caregivers of OVC and underscored the needs for psychological support and intervention for their caregivers, especially for those with lower family SES, from families with an adult or pediatric HIV infection.

Keywords

Depression; Caregiver; AIDS orphan; Vulnerable Children; China; HIV/AIDS

Introduction

By the end of 2007, approximately 700,000 persons were infected with HIV in China (UNAIDS China, 2009). The China Ministry of Health estimated that there were at least 100,000 AIDS

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orphans (children who had lost one or both of their parents to HIV/AIDS) and many more vulnerable children (children who were living with HIV-infected, alive parents) in China (Zhao et al., 2007). Many of the AIDS orphans and vulnerable children (OVC) 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). Based on the report from the Civil Administration Department of Henan Province, about 85% of AIDS orphans in Henan were raised in the extended families (Xinhuanet, 2007), which means that family-based care was still the main care option for OVC in rural China.

In recent years, increased attention has been focused on the children who have been affected by HIV/AIDS in many countries (Safman, 2004). However, only limited data are available concerning the mental health status of the caregivers of those children although the caregivers may have been profoundly affected by the disease. In addition to caring for OVC, there are multiple routes through which caregivers can be affected by HIV/AIDS. These additional routes include economic burdens of child-rearing, physical and health impacts related to caregiving, and emotional impacts related to the strain of living with or caring for persons living with HIV/AIDS (PLWHA) (Freeman & Nkomo, 2006; Ji, Li, Lin, & Sun, 2007; Joslin & Harrison, 2002; Linsk & Mason, 2004; Paige & Johnson, 1997; Safman, 2004; Thampanichawat, 2008).

Previous studies regarding the impact of HIV/AIDS on the caregivers' mental health mainly focused on HIV-infected caregivers or caregivers of HIV-infected adults. Data from several studies indicated that HIV-positive gay and bisexual caregivers reported higher levels of depression than those who were HIV-negative (Land, Hudson, & Stiefel, 2003; Wight, 2000). Some studies have documented that caregivers of PLWHA experienced heightened levels of psychological distress as a result of the increased stress associated with their situations, including financial uncertainty, social discrimination, and lack of adequate medical care for the care-recipients (Hughes & Caliandro, 1996; Kipp, Tindyebwa, Karamagi, & Rubaale, 2007; Stetz & Brown, 2004; Wiener, Vasquez, & Battles, 2001; Wight, Beals, Miller-Martinez, Murphy, & Aneshensel, 2007). Some studies conducted in the United States, Thailand, and Africa have indicated that women were experiencing negative health outcomes such as depression and traumatic stress, because women were mostly the ones who were taking on the primary responsibility to care for PLWHA in families (Flaskerud & Tabora,1998; Lindsey, Hirschfeld, & Tlou, 2003; Songwathana, 2001; Wight et al., 2007). Older caregivers of PLWHA also reported that they felt depressed, exhausted, and got other psychological symptoms, for most of them not only bore additional burdens of care but also faced their own deteriorating health status because of their old age (Joslin & Harrison, 1998; Lindsey et al., 2003; Ssengonzi, 2008).

Although psychological distress has been documented among HIV-positive caregivers or caregivers of PLWHA, to the best of our knowledge, no previously published studies have investigated the mental health problems among caregivers of OVC as well as the factors that might be associated with their mental health problems. In addition, almost all of the existing studies were conducted in South Africa, Western and Southeast Asian countries, but virtually no data were available in China, where HIV/AIDS epidemic has been on a rapid rising in the recent decade. Therefore, the present study was conducted to examine: (1) the depressive symptoms among caregivers of OVC in rural China; and (2) to explore factors associated with the presence of depressive symptoms among caregivers of OVC, such as characteristics of caregivers, living environment of caregivers, and their relationship with the cared children.

Methods

Study Site

The current study was part of a larger longitudinal assessment of psychosocial needs of children affected by HIV/AIDS that was conducted in 2006-2007 in two rural counties of central China where many residents had been infected with HIV through unhygienic blood collection (Li et al., 2009). Both counties are rural (≥ 94% rural residents) and have similar demographic and economic profiles. Although accurate epidemiological data are lacking, both counties are generally believed to have the highest prevalence of HIV infection in central China (Agence France Presse, 2004; Cohen, 2004). We obtained village-level HIV surveillance data from the anti-epidemic station in each county to identify the villages with the highest number of individuals having died of HIV/AIDS or with confirmed HIV infection.

Participants

The participants in the current study consisted of 120 caregivers from households caring for OVC (OVC caregivers) and 40 caregivers from households without OVC (non-OVC caregivers). The caregivers in this study defined as parents, relatives and other non-family members providing home-based care to at least one child 6 to 18 years of age. To recruit OVC caregivers we asked the village leaders to identify families caring for orphans or with confirmed diagnosis of parental HIV/AIDS. We approached the families and asked them to participate in the study. Only one main caregiver (i.e., adults who spent at least 50% of time with the child) was recruited per family to participate in the assessment. A small number of families refused to participate because of schedule conflict or other reasons (e.g., caregivers were sick or on medication), although the exact number and characteristics of these families were not available. The non-OVC caregivers were recruited from the same areas (e.g., villages) from where OVC caregivers were recruited. An initial convenience sample of 198 caregivers were recruited from the areas and 160 (81%) of them (120 OVC caregivers and 40 non-OVC caregivers) were matched with index children in our larger assessment sample. These 160 caregivers were retained in our final database for further analyses.

Consenting Procedure

After a family was identified and selected from the community, interviewers from the local research team (accompanied by local community members) visited the family. Once the eligibility of a caregiver 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 consent (or oral consent for illiterate caregivers) was obtained. In cases of oral consent, community members accompanying the interviewers served as witnesses for the consenting procedure. The research protocol, including the 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

A confidential assessment inventory including detailed measures of demographic information and a measure of depressive symptoms was self-administered to each participant in the study. During the survey, necessary clarification or instruction was provided promptly when needed. The interviewer read questions to a small number of caregivers who had limited literacy; these caregivers provided oral responses to the interviewers who recorded the responses in the survey instrument. The survey was administered at participant's home or nearby community space (village center, village school). Completion of the entire assessment inventory required 25 to 40 minutes. Each participant received a gift at completion of the assessment as a token of appreciation.

Measures

Demographic characteristics—Participants were asked to report their demographic characteristics including age, sex, and education attainment (no schooling, some primary school, primary school, some middle school, middle school, some high school, high school, ≥junior college). Participants were asked to report both their annual household income (in Chinese Yuan, which has an exchange rate of approximate 0.13 with US dollars at the time of survey) and their households' possession of some valuable assets from a pre-generated list of 25 household items (e.g., TV, cell phone, radio, and tractor). Because of a large number of missing responses on the household income (i.e., n=54 or 34%), we employed the total number of the household items/assets as an estimate of their family SES. The SES score had a range of 0 to 25 with a higher score suggesting a higher family SES. The asset-based family SES estimate was highly associated with the annual household income (r=.612, p<.0001). Participants were also asked whether there was any adult or child in their households who was infected with HIV (yes/no). Participants were also asked whether they cared for any AIDS orphans in their households (yes/no), and were asked about their relationship with the children under their care (parents, grandparents, or other caregivers). For privacy concerns, the caregivers' own HIV status was not asked and no HIV test on adult or child was performed.

Depression—Caregivers' symptoms of depression were measured using the Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D was introduced into China in the early 1990s (Wang, 1993). The CES-D is a 20-item self-report depression measure with a 4-point response option (i.e., 0=rarely or none of the time, 1=some or a little of the time, 2=occasionally or a moderate amount of the time, 3=most or all of the time). Sample items include "I was bothered by things that usually don't bother me." With appropriate reverse coding of some items in different direction, a sum score was employed as the CES-D scale score. The sum score of CES-D ranged from 0 to 60, with higher scores indicating higher frequency of symptoms of depression. The CES-D scores were stratified into two categories (< 16 vs. ≥16), for 16 was considered as a cutoff for possible clinical depression in previous studies among various populations (Radloff, 1977). Cronbach alpha of the scale was .90 for the current study sample.

Statistical Analysis

First, analysis of variance (for continuous measures) or chi-square test (for categorical measures) was performed to examine the difference of sample characteristics by gender. Second, analysis of variance (ANOVA) was employed to compare mean scores of the CES-D scale by demographic factors. To facilitate group comparison on the depression scale among samples, several demographic variables were dichotomized using the median-split (e.g., <40 vs. ≥40 years for caregivers' age, <2450 vs. ≥2450 Yuan for annual household income, < 7 vs. ≥7 for asset-based family SES indicator). The education of caregivers was divided into two groups (≤primary school vs. ≥middle school), as most of the caregivers had no more than primary school education. Because most of the caregivers were parents or surviving parents of the children (including OVC), the relationship between caregivers and children were also combined into two categories (parent vs. non-parent).

A total sum score of 16 on CES-D has been accepted as cutoff point in North America for identifying individuals with an elevated level of depressive symptoms (Myers & Weissman, 1980; Roberts & Vernon, 1983). Individuals with CES-D score <16 were considered to have low depressive symptoms and individuals with CES-D score ≥ 16 were considered to have high depressive symptoms. Because of the lack of appropriate test norm among Chinese population, we employed the score of 16 as a cutoff point in the current study. Chi-square test was performed to examine the proportion of participants with CES-D scores ≥ 16 between different groups: caregivers' gender, age, education, family SES, relationship with children, caring for orphans, HIV infection among adult family member, and HIV infection among dependent children.

Finally, multiple regression analyses were performed to assess the associations between depressive symptoms and various individual and family factors of caregivers (i.e., gender, age, education level, family SES, relationship with children, caring for orphans, HIV infection among adult family members, HIV infection among dependent children). Annual household income was excluded from the regression analysis because of the large number of missing values. The individual factors (gender, age, education level, family SES) were first entered into the regression model as one block, followed by a block of family factors (relationship with children, caring for orphans, adult HIV infection, pediatric HIV infection). All statistical analyses were performed using SPSS for Windows version 11.5.

Results

Sample Characteristics

As shown in Table 1, the mean age of the participants was 40.01 years (SD=9.00) and 51.9% were female. About 40.0% participants were ≥40 years old, and about 64.1% participants reported no more than primary school education. More female than male participants reported a level of no more than primary school education (76.8% vs. 50.0%). The annual household income ranged from 0 to 30,000 Yuan with an average of 2450 Yuan (SD=3725) which was equivalent to about 306 US dollars at the time of survey. The mean score of the asset-based family SES index was 7.13 (SD=3.31), with 44.7% of the participants scoring lower than 7. More female than male participants reported SES<7 (52.4% vs. 36.4%). The majority (71.9%) of participants were parents or surviving parents of the children under their care (including OVC), about 8.9% were grandparents, and the remaining (19.2%) were other relatives (i.e., aunt, uncle) or non-family members. About 21.9% of the participants were caring for AIDS orphans in their households. About three quarters of the participants reported at least one adult infected with HIV in their households and about 17.3% of the participants reported having children in their households who were infected with HIV or being uncertain about their children’s HIV status.

Group Difference of CES-D Scores

The entire sample had a mean CES-D score of 19.18 (SD=12.08) with 17.84 (SD=10.20) for men and 20.17(SD=13.95) for women. Table 2 (the left part) revealed that the score of CES-D was significantly higher among caregivers with lower education level (p= .008), lower family SES (p= .007), from families with at least one adult infected with HIV (p= .020), and caring for children with HIV or uncertain HIV status (p= .001). The caregivers who were female, older, caring for AIDS orphans, and non-parents also reported higher score of CES-D than their counterparts although the differences didn’t reach statistical significance. The right part of Table 2 showed that more than 50% of the caregivers reported a CES-D score of ≥16. The percentage of caregivers who reported CES-D ≥16 were similar between various groups except annual income and caring with AIDS orphans. More caregivers from families with a below-average annual income (82.8%) than those with a above-average annual household income (17.2%) reported a CES-D score ≥16 (p=.001). More caregivers caring for AIDS orphans reported CES-D scores ≥16 than their counterparts who did not have AIDS orphans in their households (73.5% vs. 48.8%, p= .008).

Multivariate Analysis

The results of multiple regression analysis were presented in Table 3. When only the individual characteristics of caregivers were entered into regression analysis, education and family SES were significant predictors with depression symptoms being associated with lower education

(β=-.210, p<.05) and lower family SES (β=-.188, p<.05). The individual characteristics accounted for 9% of the variances in CES-D scores. When the remaining variables were included in the model, family SES, adult HIV infection and child HIV infection were significantly associated with symptoms of depression among caregivers. Caregivers from households with adult HIV or pediatric HIV showed significantly higher scores of CES-D (β=.261 for adult HIV and β=.236 for pediatric HIV, p<.01 for both). The final model accounted for 22.7% of the variances in depression symptoms among caregivers.

Discussion

This study suggests a higher level of depression symptoms among caregivers who provide home-based care to OVC in rural China. The OVC caregivers in the current study demonstrated an elevated level of depressive symptoms with almost two-thirds of caregivers caring for AIDS orphans reporting a CES-D score ≥16. These findings are consistent with the results of previous studies on the higher presence of depressive symptoms among female and elderly caregivers of PLWHA (Lindsey et al., 2003; Ssengonzi, 2008).

The data indicated that the depression symptoms were significantly higher among caregivers who had adult family members living with HIV in their households and who were caring for HIV-infected children. Similar results have been shown in previous studies. In these studies, family members and sometimes the caregivers themselves were infected with HIV, which might magnify the psychological problems among caregivers, as they would struggle with ongoing HIV infection and face more difficulties related to HIV specific medical demands and problems such as cost of treatment and service shortfalls (Kipp et al., 2007; Meadows, Le Maréchal, & Catalán, 1999; Thampanichawat, 2008; Wiener et al., 2001; Wight, 2000). The strong association between family SES and depression found in this study were consistent with the results of previous studies reporting that many households affected with HIV were experiencing significant financial hardship which might be an important contributor to caregiver anxiety and depression (Flaskerud & Tabora, 1998; Ji at al., 2007; Linsk & Mason, 2004; Songwathana, 2001). Likewise, the negative relationship between depression and education, another important indicator of family SES, was consistent with results of existing studies (Kessler et al., 1994; Mirowsky & Ross, 2003; Scarinci et al., 2002).

The data in the current study suggest that the CES-D score of 16 might not be an appropriate cutoff for this study population. The CES-D score of 16 as a cutoff for clinical depression was established in the United States. Although this cutoff has been used among some Chinese populations (Hong, Li, Fang, & Zhao, 2007), its validity in China has not been established. More than 50% of the participants in the current study, including both OVC caregivers and non-OVC caregivers, reported a CES-D score ≥ 16. The reason for such a high level of depression score among the study sample might be a combined effect of HIV/AIDS and widespread poverty in the area (e.g., both participating counties were designated by the China central government as “national poverty county”). This large proportion of the high CES-D score (i.e., ≥16) may also be the reason for the discrepancy in the number of significant differences between the continuous measures and dichotomous measures shown in Table 2. Our exploratory analysis of the current data revealed that a cutoff score of 20 would yield similar group differences by individual and family factors as the continuous measures. Future studies are needed to further examine and validate the cutoff score of CES-D for possible clinical depression in various socioeconomically disadvantaged populations in China and other developing countries.

There are several limitations in the current study. First, the data were based on caregivers’ self-report of depression symptoms without further diagnostic evaluation to validate the findings. Second, although numerous efforts have been taken to ensure the representativeness of the study sample, the participants were recruited through convenience sampling, which may limit our ability to generalize the findings to other OVC caregivers in China. Third, as with all cross-sectional studies, there was the possibility that some unobserved factors might be responsible for the significant relationship between depression symptoms and various individual and family factors (e.g., caregivers' personal health status, including HIV infection). Fourth, the asset-based composite family SES score used in the current study has not been validated for rural Chinese population, although the development of such a score followed general recommendations in the global literature on measuring socioeconomic status (SES) for farm families in rural communities (Akinbile, 2007). Finally, the sample size was relatively small and limited the statistical power of the data analysis.

Despite these potential limitations, this study has some important implications for future research and clinical practice. First, society should consider deploring resources to alleviate the economic burden shouldered by caregivers of HIV-infected dependents or the communities that were hard hit by HIV/AIDS, especially those that were in rural or other resource-poor areas. Second, a variety of services are needed to help families and communities affected by HIV/AIDS. In addition to wide provision of free Antiretroviral drugs, free prevention of mother-to-child transmission, free voluntary counseling and testing, free schooling for children orphaned by AIDS, and economic assistance to the households of people living with HIV/AIDS (Wang, 2005), services that provide caregivers with practical assistance in issues such as medical care or symptom management of infected individuals (both adults and children) may be useful in reducing the impact of caregiving stress on the caregivers mental health. Finally, the findings in the current study suggest that psychological interventions and social support are necessary for the mental health well-being of members of HIV-affected families including the caregivers of OVC, caregivers of adult or pediatric HIV, especially those with lower family SES.

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Table 1

Demographic Characteristics of Study Sample

	Total	*Male*	*Female*
N(%)	160(100%)	77((48.1%)	83(51.9%)
Caregiver age (years)			
<40	91(59.9%)	40(56.3%)	51(63.0%)
≥40	61(40.1%)	31 (43.7%)	30(37.0 %)
Mean (SD)	40.01(9.00)	40.37(9.14)	39.70(8.92)
Family SES			
<7	71(44.7%)	28(36.4%)	43(52.4%)*
≥7	88(55.3%)	49(63.6%)	39(47.6%)
Mean (SD)	7.13(3.31)	7.66(3.35)	6.63(3.21)*
Annual family income (1000 Yuan)			
Mean (SD)	2.45(3.73)	2.61(3.22)	2.31(4.15)
Caregiver education			
≤Primary school	99(64.1%)	36(50.0%)	63(76.8%)****
≥Middle school	55 (35.9%)	36(50.0%)	19(23.2%)
Relationship with child			
Parents	105(71.9%)	51(77.3%)	54(67.5%)
Grandparents	13(8.9%)	4(6.1%)	9(11.3%)
Others	28(19.2%)	11(16.7%)	17(21.3%)
Family with AIDS orphans			
Yes	35(21.9%)	17(22.1%)	18(21.7%)
No	125(78.1%)	60(77.9%)	65(78.3%)
Family with adult HIV			
Yes	120(75.0%)	61(79.2%)	59(71.1%)
No	40(25.0%)	16(20.8%)	24(28.9%)
Family with pediatric HIV			
Yes or uncertain	23(17.3%)	12(18.8%)	11(15.9 %)
No	110(82.7%)	52(81.3%)	58(84.1%)

* $p < .05$;

**** $p < .0001$

Table 2

Caregivers' Score of the Center for Epidemiological Studies Depression Scale (CES-D)

	CES-D Sum Score			CES-D Score≥16		
	Mean	*SD*	*p-value*	*N*	*%*	*p-value*
Gender						
Male	17.84	10.20	0.178	40	51.9%	0.357
Female	20.44	13.56		46	56.1%	
Age group						
<40 years	18.49	11.04	0.417	51	56.7%	0.175
≥40 years	20.17	13.95		29	47.5%	
Family SES						
<7	22.13	13.62	0.007	36	51.4%	0.355
≥7	16.91	10.28		49	55.7%	
Annual Family Income						
<2450 Yuan	20.96	12.12	0.131	48	82.8%	.0001
≥2450 Yuan	16.97	12.59		10	17.2%	
Caregiver education						
≤Primary school	21.14	12.34	0.008	56	57.1%	0.157
≥Middle school	15.72	11.17		26	47.3%	
Relationship with child						
Parents	18.67	11.57	0.583	55	52.4%	0.263
Grandparents or others	19.93	14.27		24	60.0%	
Family with AIDS orphans						
Yes	21.71	13.18	0.161	25	73.5%	0.008
No	18.46	11.71		61	48.8%	
Family with adult HIV						
Yes	20.49	12.14	0.020	68	57.1%	0.125
No	15.38	11.22		18	45.0%	
Family with pediatric HIV						
Yes or uncertain	24.87	11.28	0.001	15	65.2%	0.230
No	16.44	11.02		59	54.1%	

Table 3

Results of the Regression Analysis of Depressive Symptoms among Caregivers in HIV-affected Families in Rural China[1]

Step	Independent Variables	β	t	R^2	$AdjR^2$	ΔR^2	ΔF
1	Gender	-0.031	-0.300	0.090	0.056	0.090	2.683*
	Age	0.037	0.401				
	Education	-0.210	-2.008*				
	Family SES	-0.188	-1.992*				
2	Gender	0.040	0.404	0.227	0.169	0.138	4.684**
	Age	0.082	0.920				
	Education	-0.121	-1.174				
	Family SES	-0.211	-2.337*				
	Relationship with child[2]	-0.007	-0.076				
	Caring for orphans[3]	-0.019	-0.197				
	With adult HIV[3]	0.261	2.644**				
	With pediatric HIV[3]	0.236	2.615**				

Note:

[1] Dependent variable for the regression analysis was the sum score of CES-D.

[2] Response option: 1=parents; 2=other.

[3] Response option: 0=no, 1=yes.

* $p< .05$;

** $p< .01$