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### Authors

Hsieh, Julie

Li, Li

Lin, Chunging

et al.

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## Spousal role and caregiver burden in HIV affected families in Anhui Province, China

Julie Hsieh<sup>a</sup>, Li Li<sup>a</sup>, Chunqing Lin<sup>a</sup>, Sitong Luo<sup>a</sup> and Guoping Ji<sup>b</sup>

<sup>a</sup>Semel Institute for Neuroscience and Human Behavior, Center for Community Health, University of California, Los Angeles, USA; <sup>b</sup>Anhui Provincial Center for Woman and Child Health, Hefei, China

### ABSTRACT

This study examined the burden experienced by various roles of family caregivers of people living with HIV (PLH), in particular spouses vs. non-spouses. A total of 475 family members of PLH were recruited from Anhui Province, China. Participants responded to a survey using the Computer Assisted Personal Interview method. The assessment collected data on demographic characteristics and their perceived caregiver burden, which was compared between spouses and non-spouses. Multiple regression models were built to identify factors associated with caregiver burden. About 64.4% of our study participants were female and the mean age was 42.1 years. Among various relationships to PLH, almost half reported being a spouse. Spouses reported significantly higher caregiver burden than non-spouses. In addition, older age and lower family income were significantly associated with higher level of caregiver burden. Among the subsample of spouses, significantly higher level of caregiver burden was identified among wives. Future studies should give special consideration to address the needs of female spouses in order to reduce their caregiver burden.

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HIV; caregiver burden;  
spouse; gender; China

### Introduction

Facing HIV as a family is a complex issue. Many studies have documented that HIV affects not only people living with HIV (PLH) but also their family members (Ji, Li, & Sun, 2007; Rotheram-Borus, Flannery, Rice, & Lester, 2005). Previous studies have examined issues related to caregiver burden as reported by informal/family caregivers of PLH. Pirraglia et al. (2005) found that depression is strongly associated with high caregiver burden among informal caregivers of PLH. These informal caregivers may be in need of both mental health services and assistance in caregiving. In a study done in the Democratic Republic of Congo, Nkosi, Kipp, Laing, and Mill (2006) documented experiences of isolation, social stigma, psychological distress and lack of basic training related to their caregiving among family caregivers. In Tanzania, family caregivers who were women and young girls reported having poor overall health (Kipp, Tindyebwa, Rubaale, Karamagi, & Bajenja, 2007). Pallangyo and Mayers (2009) revealed that HIV-related stigma and discrimination as well as caregiver burden were widely experienced by informal female caregivers in Tanzania. In India, moderate to very severe levels of caregiver burden were observed in approximately one third of adults caring for PLH, and the

caregiver burden has negatively impacted the caregivers' quality of life (Chandran et al., 2016). In Thailand, Lee, Li, Jiraphongsa, and Rotheram-Borus (2010) examined how depression negatively affected the levels of caregiver burden and social support positively impacted caregiver's quality of life. A study in Vietnam reported similar findings as previous studies that family caregivers lack education and provision of care and mostly kept a secret about family member's HIV status to avoid stigma (Lundberg, Doan, Dinh, Oach, & Le, 2016).

To date, limited extent of research has focused on the implications of caregiver-care recipient relationships within a family, the role of gender, age, or other social structural factors that influence caregiver burden among people affected by HIV (Miller, Bishop, Herman, & Stein, 2007). Spousal caregiver burden is well documented in other chronic conditions such as heart disease (Park, Yates, Meza, Kosloski, & Pullen, 2015), dementia (Kahn, Wishart, Randolph, & Santulli, 2016), and Alzheimer's disease (Monin, Schulz, & Feeney, 2015). Nonetheless, spouses were rarely studied as caregivers of PLH. A Vietnamese study briefly examined gender and found no difference in regards to total caregiver burden; however, it documented several differences between older and younger caregivers in some categories of measured caregiver burden (Lundberg et al., 2016).

In China, family forms the primary social safety net and family members are often primary providers for the daily and psychological support of PLH, and in most cases they are also the primary sources of financial support for PLH (Fredriksen-Goldsen et al., 2011; Yu, Li, Qiao, & Zhou, 2016). The Chinese government has introduced “Four Frees and One Care” policy in 2005 to increase access to HIV testing and provide treatment and clinical services for HIV affected families (Sun et al., 2010). However, the supports were minimal and inadequate in regards to helping with daily life chores and reducing burden of caring the infected within households. Chinese families live in a tight knit, especially in rural areas (Ji et al., 2007). Although caregiving is shared among all family members of PLH, burden and tasks may not necessarily be shared evenly. Levels of perceived caregiver burden may be different among various members in the family. This study aimed to address gaps in knowledge by examining different levels of burden experienced by family caregivers, in particular spouses vs. non-spouses, in HIV-affected families in China.

## Methods

This study utilized the baseline data from a randomized controlled intervention trial for HIV-affected families in Anhui Province, China. The data were collected from late 2011 to early 2013. A total of 475 HIV-affected families were recruited from 32 villages, and all families included at least one PLH and one seronegative family member. After the PLH were recruited, they referred their family members to the study. If the referred participant also happened to be HIV sero-positive, we would recruit him/her as PLH, and invite an additional HIV sero-negative family member to our family members group. Recruitment criteria for family members included: (1) age 18 or over; (2) living with the PLH; (3) having knowledge of the PLH’s HIV sero-status.

Following a standardized script, a trained interviewer explained the study purpose, procedure, potential risks and benefits, and guaranteed confidentiality and voluntary nature of participation. Written informed consent was obtained from each participant before assessment. The overall refusal rate was less than 5%. All participants completed a questionnaire using the Computer Assisted Personal Interview method. Surveys were conducted in a private room of the village clinic that participants normally visited or another venue where the participant preferred such as his or her home. Each assessment took approximately 45–60 min, and all participants were compensated 50 yuan (U.S. \$8) for completion. Approval for this study was obtained from institutional review boards of participating institutions.

Individual characteristics of all participants such as age, gender, level of education, marital status, and relationship to PLH were collected. Based on a typical family structure, caregivers’ relationships to PLH were categorized into spouses, parents, siblings, children and others of whom could be grandparents, aunts or uncles, or cousins. In addition, family characteristics such as annual family income, family size, and having multiple PLH in the family were recorded.

Caregiver burden perceived by family members of PLH was measured using the Perceived Caregiver Burden Scale (Stommel, Given, & Given, 1990), which has been used in our previous study (Lee, Li, Lin, & Tuan, 2015). Caregivers’ perception of having a HIV-positive person in the household and its impact on their finances, health, and feelings of entrapment were assessed using the modified 17-item scale. Impact on finances was measured using statements such as “caring for him/her has put a financial strain on the family”, and impact on health used “my health has gotten worse since I have been caring for him/her” as an example. Feelings of entrapment included statements such as “I feel trapped by my caregiving role”. Responses to each item ranged from 1 (strongly disagree) to 5 (strongly agree) and a higher score reflected a higher level of caregiver burden as perceived by family members (Cronbach’s alpha = 0.88).

All analyses were performed using SAS statistical software version 9.4 (SAS Institute Inc., Cary, NC, USA). Descriptive statistics and frequencies were first calculated to describe caregivers’ individual characteristics including age in years, gender, level of education, and relationship to PLH. We also assessed family characteristics such as annual family income, family size, and having multiple PLH in the family. We then further explored caregivers’ relationship to PLH and their burden by dichotomizing the variable of relationship to PLH into spouses vs. non-spouses. Pearson’s Chi-square tests and analyses of variance were performed to examine different associations of age, gender, and education level between spouses and non-spouses as well as self-reported caregiver burden. Lastly, multiple regression analyses were performed to survey correlates of caregiver burden controlling for caregivers’ age, gender, level of education, relationship to PLH (spouse vs. non-spouse), annual family income, family size, and having multiple PLH in the family for all family members group and spouses only subgroup. Regression coefficients estimates and their significant levels were reported.

## Results

Background characteristics of the caregivers of PLH are summarized in Table 1. Almost all participants were

married (92.0%). A majority of the sample, 64.6%, was female, and the mean age of all participants was 42.1 years. Approximately a quarter of the caregivers in the study had no formal education, and the mean education level was 4.2 years. About half of the participants ( $N = 229$ ; 48.2%) reported being a spouse to PLH and a quarter of them were children of PLH. The average annual family income was 15,919 yuan (about 2527 USD), and the mean family size was approximately seven members. About 10% of all families in the study had reported having multiple PLH in their families. Spouses in this study were older (mean age =  $47.4 \pm 9.3$  vs.  $37.2 \pm 16.2$ ) and received less education (average years of education =  $3.2 \pm 3.1$  vs.  $5.0 \pm 3.6$ ) than non-spouses. There were more females in non-spouse than in spouse group (72.0% vs. 56.8%).

The relationships between caregiver burden and demographic characteristics are presented for both spouses and non-spouses in Table 2. The different levels of caregiver burden were examined among subgroups. For spouses, gender and educational level were significantly associated with caregiver burden ( $P = 0.0056$  and  $P = 0.0069$  respectively). For non-spouses, age and educational level were significantly associated with caregiver burden ( $P < 0.0001$  and  $P = 0.0145$  respectively).

**Table 1.** Demographic characteristics of caregivers of people living with HIV ( $N = 475$ ).

Variables	All Participants	
	<i>N</i>	%
<b>Individual characteristics</b>		
Age (years), Mean $\pm$ SD <sup>a</sup>	42.1 $\pm$ 14.2	
30 or less	121	25.4
31–40	110	23.2
41–50	116	24.4
More than 50	128	27.0
Gender <sup>a</sup>		
Male	168	35.4
Female	307	64.6
Education level (years), Mean $\pm$ SD <sup>a</sup>	4.2 $\pm$ 3.5	
None	132	27.8
1 to 6 years	200	42.1
More than 6 years	143	30.1
<b>Relationship to PLH</b>		
Spouses	229	48.2
Parents	63	13.3
Siblings	42	8.8
Children	123	25.9
Others	18	3.8
<b>Family characteristics</b>		
Annual family income (yuan), Mean $\pm$ SD	15919.15 $\pm$ 12157	
Less than 5000	45	9.5
5000 to < 10,000	89	18.9
10,000 to < 20,000	183	38.9
20,000 or more	154	32.7
Family size, Mean $\pm$ SD	5.5 $\pm$ 1.9	
4 or less	158	33.3
5 to 6	196	41.3
More than 6	121	25.4
<b>Multiple PLH in the family</b>		
Yes	47	9.9
No	428	90.1

<sup>a</sup>Significant level of difference between spouse and non-spouse using  $\chi^2$  test.

Table 3 outlines results from two multiple regression models examining factors associated with caregiver burden. The first model included all family members of PLH and the second only included spouses. In the model of all family members, age (estimate of coefficient = 0.245,  $P < 0.0001$ ) and being a spouse (estimate of coefficient = 4.120,  $P = 0.0002$ ) had statistically significant positive associations with caregiver burden. We also observed that annual family income (estimate of coefficient =  $-0.672$ ,  $P = .0014$ ) was significantly associated with caregiver burden negatively. In the model that included spouses, age (estimate of coefficient = 0.223,  $P = 0.0065$ ) and being a female spouse (estimate of coefficient = 4.990,  $P = 0.0036$ ) were significantly associated with more caregiver burden.

## Discussion

Since the Chinese government rolled out universal anti-retroviral therapy coverage for PLH, life has been prolonged and the management of the disease has changed to a chronic illness model (Li, Ji, Lin, Liang, & Lan, 2016; Wu, Sullivan, Rotheram-Borus, & Detels, 2007). Thus the nature and duration of HIV/AIDS caregiving has changed dramatically. The traditional Chinese societal belief that elderly would be well taken care of by their offspring is being challenged as HIV alters the culturally prescribed role to involve aging parents and/or underage children to care for the ill. This has important implications for providing care as family caregivers may experience a multitude of strains, and the needs of family caregivers have taken greater priority.

Spouses overall represent the primary source of an individual's support (Reblin et al., 2016). Their various duties include daily house chores, raising children, taking care of parents and elderly, and providing financial support for the entire family. For spousal caregivers, taking care of the ill family member is an add-on duty. We

**Table 2.** Univariate analysis of caregiver burden by spouses vs. non-spouses.

Characteristics	Caregiver burden			
	Spouses ( $N = 229$ )		Non-spouses ( $N = 246$ )	
	Mean (SD)	<i>P</i>	Mean (SD)	<i>P</i>
Age (years)		0.3379		<0.0001
30 or less	49.8 (15.0)		41.8 (9.5)	
31–40	50.6 (9.6)		45.5 (11.7)	
41–50	51.8 (11.4)		48.6 (10.2)	
More than 50	53.8 (9.9)		53.8 (11.5)	
Gender		0.0056		0.1676
Male	50.0 (9.8)		47.3 (11.9)	
Female	53.8 (10.8)		45.0 (11.2)	
Education level (years)		0.0069		0.0145
None	50.0 (13.4)		54.6 (11.1)	
1 to 6 years	44.8 (10.6)		51.6 (10.5)	
More than 6 years	44.2 (10.5)		49.0 (8.6)	

**Table 3.** Multiple regression on caregiver burden of family members of people living with HIV.

Parameters	Caregiver burden					
	All family members (N = 475)			Spouses (N = 229)		
	Coefficient	95% CI	P	Coefficient	95% CI	P
Spouse	4.120	[1.94, 6.31]	0.0002			
Age	0.245	[0.17, 0.33]	<0.0001	0.223	[0.06, 0.38]	0.0065
Female	2.053	[-0.16, 4.26]	0.0685	4.990	[1.65, 8.33]	0.0036
Education	0.065	[-0.26, 0.39]	0.6984	-0.016	[-0.53, 0.50]	0.9527
Family size	0.267	[-0.24, 0.78]	0.3032	0.250	[-0.47, 0.97]	0.4935
Annual family income	-0.672	[-1.08, -0.26]	0.0014	-0.383	[-0.99, 0.22]	0.2141
Multiple PLH in the family	-0.250	[-3.58, 3.08]	0.8828	-2.140	[-22.62, 18.34]	0.8370

found female spouses experienced more caregiver burden than male spouses, which is consistent with previous studies (Kim, Chang, Rose, & Kim, 2012; Penning & Wu, 2015). This may be explained by the fact that women in general tend to do more house chores, take care of dependents, and sometimes be the sole breadwinner for the family (Sharma, Chakrabarti, & Grover, 2016). This is especially true in Chinese culture where women often burden more work and shoulder the duty to support her family (Lai, Luk, & Andruske, 2007). Specific programs tailor to reduce the overall burden experienced by female spouses through redistributing their duties among other members of the family may be effective in reducing their perceived caregiver burden.

We observed caregiver burden was associated with educational level for both spousal and non-spousal caregivers. The finding is consistent with previous studies conducted among caregivers of heart failure patients (Bozkurt Zincir et al., 2014). Higher educational level is correlated with more resources in terms of income, information, and support network, which may influence one's ability to perform problem-solving focused coping; on the contrary, people with less education are more likely to adopt negative coping strategies and more prone to mental distress and burden (Chen et al., 2016; Kotzé, Visser, Makin, Sikkema, & Forsyth, 2012). Future programs should take education level of its audience into consideration in designing simplified intervention and organized tasks to help reduce caregiver burden. Age was also associated with caregiver burden for all family members. Older people have less than optimal physical health and social functioning while younger caregivers engage in more social activities as a relaxation from the stressful caregiving role (Xie et al., 2016). Older caregivers may need more help and resources in order to perform caregiver role within the family. Chinese families are unique culturally on its emphasis of a tight social knit and its dependence on other family members. The degree of caregiver burden may be felt differently based on family size, gender, and age difference. Interestingly, we did not observe a difference between caregiver burden and family size. This may be due to the closeness in

family sizes in our sample. Almost half of all families surveyed reported having six people in the family and there was no significant variation in family size.

Every study has inherent limitations and ours is no exception. Given that this study used cross-sectional data, we must be cautious in interpreting associations as causation. In addition, sampling strategy, geographic location, and self-reporting all may limit our study's generalizability. This study did not include HIV sero-positive family caregivers. However, as reported in literature, HIV sero-positive caregivers might have different characteristics and face different challenges (Marc, Zerden, Ferrando, & Testa, 2011). Future research should take HIV sero-status into account when studying caregiver burden. Moreover, other life events that might contribute to mental health stress were not measured. Findings should be interpreted within the context of the study limitations.

Our study identified female spousal caregivers of PLH had most perceived caregiver burden. Findings underscore the need to emphasize gender- and role-specific programs in developing future interventions for family caregivers in order to improve the overall family well-being.

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No potential conflict of interest was reported by the authors.

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