

# Caregiver Burden Among Informal Caregivers of Persons Living with HIV/AIDS in Liangshan Prefecture, China

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**Purpose:** Previous studies revealed that informal caregivers for persons living with HIV/AIDS (PLWHA) experience perceived caregiver burden. Although Liangshan prefecture is one of the areas with the fastest growing HIV/AIDS epidemics in China, little is known about burden of informal caregivers for PLWHA. This study aimed to evaluate caregiver burden and these predictors among informal caregivers of PLWHA in Liangshan prefecture, China.

**Methods:** This was a cross-sectional study conducted from August to December 2017. We used convenience sampling to recruit informal caregivers of PLWHA. A total of 222 participants completed questionnaires including demographic information, caregiving-related information, and caregiver burden (measured by Zarit Burden Interview, ZBI). SPSS software was used to analyze the data. Independent student's *t*-test, one-way analysis of variance (one-way ANOVA), Spearman rank correlation, and multiple linear regression analysis were performed.

**Results:** The mean ZBI score was 40.61 (SD = 14.47), and 199 (89.6%) informal caregivers had a mild or above caregiver burden. Multiple linear regression analysis revealed that older age ( $P=0.003$ ), caregivers with poor health ( $P=0.002$ ), parent-caregivers ( $P=0.001$ ), poorer ability in 'balancing caregiving needs and their own needs' ( $P<0.001$ ), and 'managing emotional needs' ( $P=0.014$ ) were significantly associated with higher level of caregiver burden.

**Conclusion:** The majority of informal caregivers had perceived caregiver burden in Liangshan prefecture of China. Findings emphasize that health-care providers, medical institutions and government should develop educational programs and policy to improve caregiver's ability to cope with caregiving for PLWHA, and take more attention to caregivers with health problem, at older age, parent-caregivers. These may contribute to reducing caregiver burden among informal caregivers of PLWHA.

**Keywords:** caregiver burden, family caregiver, informal caregiver, persons living with HIV/AIDS

## Introduction

The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) is a great public health challenge worldwide.<sup>1</sup> World Health Organization (WHO) reported that there were an estimated 37.7 million [30.2–45.1 million] persons living with HIV/AIDS (PLWHA) at the end of 2020.<sup>2</sup> In China, more than 850,000 people are infected by HIV/AIDS virus.<sup>3</sup> Sichuan Province, especially Liangshan prefecture, reported the highest HIV/AIDS prevalence rate in China.<sup>4</sup> Antiretroviral treatment (ARV) has decreased mortality and morbidity among PLWHA, and has transformed AIDS from an inevitably fatal condition to a chronic, manageable disease like hypertension and diabetes.<sup>5,6</sup> Thus, PLWHA undergoing antiviral therapy may

require long-term care from themselves, health-care professionals, and informal caregivers. In many countries, the health-care services offer limited care and support to PLWHA, leaving substantial work to their families and other informal caregivers.<sup>7</sup>

Informal care includes services that are not conducted by health professionals but are provided by family members and friends who are not paid for their support.<sup>8</sup> Unpaid family or informal caregivers provide as much as 90% of in-home long-term care needed by adults.<sup>9</sup> Chinese culture is deeply rooted in Confucian values with an emphasis on the importance of family harmony and the care of impaired relatives.<sup>10</sup> In China, informal caregivers, particularly family caregivers, take considerable responsibilities for providing care to PLWHA.<sup>11</sup> They provide health-related, psychosocial and physical care for PLWHA, such as accompanying relatives to hospitals, administering medication, encouraging and spending time with PLWHA, cooking, bathing, and washing.<sup>12</sup> Most family caregivers are untrained and often feel ill to take on caregiving tasks.<sup>9</sup> Caregiving tasks also put burden and stress on caregivers.<sup>13,14</sup>

Caregivers have physical, psychological and social problems associated with providing care to PLWHA.<sup>15–17</sup> Caregivers often fear that they could be infected by HIV through their caregiving activities because of inadequate knowledge of ways of transmission.<sup>18</sup> HIV infection is widespread within families.<sup>19</sup> In these families with multiple members infected by HIV, it is more difficult for the caregivers to provide care. The fear of HIV infection and the risk of high exposure put psychological and physical burden on caregivers.<sup>13</sup> The adverse effects of caregiver burden would not only affect the quality of life of caregivers, but also have an impact on patients' health.<sup>20</sup>

For public, HIV/AIDS is associated with evil and dirty behaviors, so discrimination and stigma are almost inevitable among PLWHA.<sup>21</sup> Caregivers of PLWHA also experience social discrimination, stigma, isolation, psychological distress associated to their caregiving.<sup>7,14</sup> Social discrimination brings great stigma on both PLWHA and their family caregivers.<sup>22</sup> Singh et al<sup>23</sup> found that about 47% of the caregivers for PLWHA perceived stigma, which impeded both patients and family members to participate in social activities. Besides, it was reported that 46% of PLWHA's caregivers were depressed, and 27% were anxious, and most of them were stressed caregivers.<sup>24</sup> Consequently, informal caregivers experience a high level of caregiver burden related to providing care for PLWHA.<sup>11,13</sup>

Caregiver burden has been defined as the extent to which caregivers perceived that caregiving had the adverse effect on their physical or emotional health, social life, financial status.<sup>25</sup> Previous studies reported that a majority of caregivers for PLWHA had caregiver burden.<sup>13,26–28</sup> However, little published research has been conducted to investigate caregiver burden in China, especially in underdeveloped areas like Liangshan Yi prefecture. Liangshan Yi prefecture reported high HIV/AIDS prevalence, and most PLWHA lived below poverty line.<sup>29</sup>

Thus, it is necessary to investigate the level of caregiver burden among informal caregivers of PLWHA in Liangshan Yi prefecture, China. The purpose of this study was to evaluate caregiver burden among informal caregivers of PLWHA, and to explore factors associated with caregiver burden. The results should provide the basis for further intervention to reduce the caregiver burden among informal caregivers of PLWHA in underdeveloped area.

## Materials and Methods

### Study Design and Ethical Considerations

This was a cross-sectional study conducted in Liangshan Yi Autonomous Prefecture, China. All procedures of this study were in accordance with the ethical standards of the institutional research committee and the Helsinki Declaration. This study was approved by West China Hospital Medical Ethics Committee. Informed consent was obtained from participants or their legal guardians before data collection.

### Participants and Procedures

The data were collected from August to December 2017. We used a convenience sampling to recruit caregivers of PLWHA from Liangshan Yi Autonomous Prefecture Center for Disease Control and Prevention. The inclusion criteria for caregivers included: (1) an unpaid caregiver of persons affected by HIV/AIDS and undertaking the main caregiving responsibility of the PLWHA; (2) aged 12 years old or older; (3) be able to communicate in Mandarin or Yi language; (4) be willing to participate in this study. We excluded the caregivers who had difficulties in communicating and understanding.

Trained investigators explained the study purpose, procedure, potential risks and benefits, and guaranteed confidentiality and voluntary participation before data collection. Each participant provided informed consent after they agreed to participate in this study. Then, participants completed the questionnaire. The trained investigators assisted the data collection process, and checked the completed questionnaire immediately.

## Measures

### Demographics

Demographic characteristics including gender, age, ethnic groups, educational level, marital status, employment status, and health status. Caregivers' relationship to PLWHA was recorded as spouse, parent, child, sibling and other relationship. Caregivers' willingness to care PLWHA ranked from strongest willingness to weakest willingness. Another single item was used to evaluate the level of caregivers' knowledge to HIV.

### Caregiver Burden

Caregiver burden was evaluated by using the Chinese version of the Zarit Burden Interview (ZBI).<sup>30,31</sup> The ZBI covers areas most frequently mentioned by caregivers as problems, including caregiver's health, psychological well-being, finance, social life and their relationship between the caregiver and impaired person.<sup>25,31</sup> It consists of 22 items relating to 2 dimensions: personal strain and role strain.<sup>30</sup> Each item is scored on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always). The scores of the 22 items were summed to give the overall score of ZBI ranging from 0 to 88, and higher scores indicate heavier perceived caregiver burden. The score of ZBI was categorized as follows: 0–20 = little or no burden, 21–40 = mild to moderate burden, 41–60 = moderate to severe burden, 61–88 = severe burden.<sup>32</sup> This scale has been tested to be a reliable and valid instrument for measuring the emotional, physical and social impact of caregivers caring for their terminally ill family members.<sup>33,34</sup> The Cronbach's  $\alpha$  of Chinese version of ZBI is 0.87.<sup>30</sup>

### Caregiving Ability

Caregiver's ability to carry out caregiving task was measured by the Chinese version of Caregiver Task Inventory (CTI).<sup>35</sup> This scale was originally developed by Clark and Rokowski.<sup>36</sup> Lee and Mok<sup>35</sup> removed the duplicate and ambiguous items from original version and formed the Chinese version, and evaluated its cultural appropriateness. The CTI includes 25 items relating to 5 sub-scales: learning to cope with new role, providing care according to care-receiver's needs, managing own emotional needs, appraising supportive resources, balancing caregiving needs and one's own needs.<sup>35</sup> Each item is scored from 0 (not difficult) to 2 (extremely difficult), and the total, sub-scale scores are calculated by summing the 25 items or each sub-scale items. The overall scores range between 0 and 50, with higher scores indicating the more difficult the caregiving tasks are perceived to be, lower levels of caregiving ability.<sup>35</sup> The Cronbach's  $\alpha$  of Chinese version of CTI was 0.93.<sup>35</sup>

## Data Analysis

All statistics analysis was performed by SPSS 22.0. Descriptive statistics analysis was performed by mean (standard deviation, SD), median [interquartile range, IQR], frequency and percentage. Independent Student's *t*-test, one-way analysis of variance (one-way ANOVA), and spearman rank correlation were used to explore relationships between caregiver burden and other variables. Finally, multiple linear regression analysis was used to explore the predictors of caregiver burden. *P* value <0.05 indicated statistical significance.

## Results

### Participants' Characteristics

We collected 222 valid questionnaires. Caregivers' age ranged from 13 to 78 years, with a mean age of 37.78 (SD = 11.18) years. Around half of the participants were female (112, 50.5%), the spouse/sex partner of care recipients (122, 55.0%) and reported good health (121, 54.5%). Most participants were illiterates (159, 71.6%), cohabited/married (180, 81.1%), employed (204, 91.9%), and Yi population (216, 97.3%). Most participants (171, 77.0%) were willing or adequately willing to take care of the PLWHA. Only 11.3% of the caregivers had a good knowledge of HIV. Sociodemographic characteristics of the participants are shown in [Table 1](#).

**Table 1** Demographic Characteristics of Caregivers, and the Univariate Analysis of Caregiver Burden

Characteristics	Frequency (%) / Mean $\pm$ SD	Caregiver Burden (Mean $\pm$ SD)	r/t/F	P
Age	37.78 $\pm$ 11.18	40.61 $\pm$ 14.47	0.208 <sup>a</sup>	0.002
Gender			-0.824 <sup>b</sup>	0.411
Male	110 (49.5)	39.80 $\pm$ 13.98		
Female	112 (50.5)	41.40 $\pm$ 14.95		
Ethnic group			1.069 <sup>b</sup>	0.286
Han	6 (2.7)	46.83 $\pm$ 11.84		
Yi	216 (97.3)	40.44 $\pm$ 14.52		
Educational level			0.517 <sup>c</sup>	0.723
Illiteracy	159 (71.6)	41.14 $\pm$ 15.27		
Primary school	37 (16.7)	40.97 $\pm$ 12.86		
Middle school	15 (6.8)	36.27 $\pm$ 8.84		
High school	7 (3.2)	37.43 $\pm$ 14.82		
College and above	4 (1.8)	37.75 $\pm$ 14.20		
Marital status			4.133 <sup>c</sup>	0.007
Single	18 (8.1)	36.00 $\pm$ 12.46		
Married/cohabited	180 (81.1)	39.89 $\pm$ 14.47		
Divorced/separated	17 (7.7)	47.94 $\pm$ 12.86		
Widowed	7 (3.2)	53.14 $\pm$ 12.93		
Employment status			1.984 <sup>b</sup>	0.049
Employed	204 (91.9)	41.18 $\pm$ 14.57		
Unemployed	18 (8.1)	34.17 $\pm$ 11.74		
Health status			-3.230 <sup>b</sup>	0.001
Good health	121 (54.5)	37.80 $\pm$ 15.33		
Poor health	101 (45.5)	43.97 $\pm$ 12.63		
Relationship to PLWHA			4.870 <sup>c</sup>	0.001
Spouse/sex partner	122 (55.0)	40.61 $\pm$ 13.20		
Child	21 (9.5)	44.24 $\pm$ 15.50		
Parent	22 (9.9)	49.77 $\pm$ 10.18		
Sibling	28 (12.6)	38.14 $\pm$ 16.72		
Others	29 (13.1)	33.38 $\pm$ 15.62		
Care willingness			1.570 <sup>c</sup>	0.183
Adequately willing	83 (37.4)	38.24 $\pm$ 13.69		
Willing	88 (39.6)	41.82 $\pm$ 14.94		

(Continued)

**Table 1** (Continued).

Characteristics	Frequency (%) / Mean $\pm$ SD	Caregiver Burden (Mean $\pm$ SD)	r/t/F	P
So-so	30 (13.5)	40.33 $\pm$ 13.52		
Unwilling	20 (9.0)	46.05 $\pm$ 16.01		
Extremely unwilling	1 (0.5)	30.00		
The level of knowledge to AIDS			4.043 <sup>c</sup>	0.008
Know nothing	125 (56.3)	41.41 $\pm$ 15.21		
Know a few	72 (32.4)	42.42 $\pm$ 11.50		
Know a lot	23 (10.4)	31.30 $\pm$ 14.78		
Totally know	2 (0.9)	32.50 $\pm$ 30.41		

Notes: <sup>a</sup>Spearman rank correlation analysis, <sup>b</sup>Independent sample t-test, <sup>c</sup>One-way ANOVA.

Abbreviations: SD, standard deviation; PLWHA, person living with HIV/AIDS.

## Caregiver Burden

Table 2 shows the results of ZBI scores. The mean ZBI score of the participants was 40.61 $\pm$ 14.47. The mean scores for personal strain and role strain were 20.93 $\pm$ 7.84, 10.08 $\pm$ 6.09, respectively. In our study, 23 (10.4%) participants experienced little or no burden, 85 (38.3%) participants experienced mild to moderate burden, 98 (44.1%) participants experienced moderate to severe burden, and 16 (7.2%) participants experienced severe burden.

## Factors Associated with Caregiver Burden

The independent sample *t* test and one-way ANOVA revealed that caregiver burden differed in regard to marital status ( $F=4.133$ ,  $P=0.007$ ), employment status ( $t=1.984$ ,  $P=0.049$ ), health status ( $t=-3.230$ ,  $P=0.001$ ), relationship to PLWHA ( $F=4.870$ ,  $P=0.001$ ), and the level of knowledge about HIV/AIDS ( $F=4.043$ ,  $P=0.008$ ). But there is no statistically significant relationship between gender, ethnic group, educational level, care willingness and caregiver burden. These results are shown in Table 1. The Spearman rank correlation analysis showed that caregivers' age, CTI total score and all sub-scales except "Learning to cope with new role" were positively correlated with caregiver burden (All  $P<0.05$ , Table 3).

The result of stepwise multiple linear regression analysis is shown in Table 4. Categorical variables were transformed into dummy variables. The older caregivers ( $B = 0.205$ ,  $P=0.003$ ), caregivers with poor health ( $B = 4.694$ ,  $P=0.002$ ), parents-caregivers ( $B = 8.348$ ,  $P=0.001$ ), poorer caregiving ability in balancing caregiving needs and one's own needs

**Table 2** Caregiver Burden Experienced by Informal Caregivers

Caregiver Burden (Score Range)	Frequency (%)	Mean (SD)
Little or no burden (0–20)	23(10.4)	
Mild to moderate burden (21–40)	85(38.3)	
Moderate to severe burden (41–60)	98 (44.1)	
Severe burden (61–88)	16 (7.2)	
personal strain		20.93 $\pm$ 7.84
role strain		10.08 $\pm$ 6.09
Total score		40.61 $\pm$ 14.47

Abbreviation: SD, standard deviation.

**Table 3** The Correlation Between Caregiving Ability and Caregiver Burden

	Mean±SD	r	P
CTI score	17.46±7.71	0.513	<0.001
Learning to cope with new role	4.59±2.22	0.097	0.149
Providing care according to care-receiver's needs	3.42±2.09	0.365	<0.001
Managing own emotional needs	2.98±2.43	0.428	<0.001
Appraising supportive resources	3.49±2.17	0.361	<0.001
Balancing caregiving needs and one's own needs	2.99±2.37	0.580	<0.001

**Abbreviations:** SD, standard deviation; CTI, the Caregiver Task Inventory.

**Table 4** Multiple Regression on Caregiver Burden of Informal Caregivers of PLWHA

	B	SEE	Standardized Coefficients ( $\beta$ )	95% CI	t	P
Constant	14.177	3.342		7.590, 20.765	4.242	<0.001
Age	0.205	0.068	0.159	0.071, 0.340	3.007	0.003
Health status (reference: good health)	4.694	1.495	0.162	1.748, 7.641	3.141	0.002
Relationship to PLWHA (reference: spouse)						
Parent	8.348	2.481	0.173	3.458, 13.238	3.365	0.001
Balancing caregiving needs and one's own needs	2.811	0.369	0.460	2.084, 3.538	7.618	<0.001
Managing own emotional needs	0.883	0.356	0.148	0.182, 1.584	2.482	0.014
$R^2=0.435$ ; adjusted $R^2=0.422$						

**Abbreviations:** PLWHA, person living with HIV/AIDS; SEE, standard errors of estimation; CI, confidence interval.

( $B = 2.811$ ,  $P < 0.001$ ) and managing own emotional needs ( $B = 0.883$ ,  $P = 0.014$ ) were predictors of heavier caregiver burden. The  $R^2$  was 0.435, and adjusted  $R^2$  was 0.422.

## Discussion

This study found that 199 (89.6%) informal caregivers experienced burden of caregiving, and most of them experienced mild to moderate, or moderate to severe burden. The findings were in line with studies that almost all caregivers for PLWHA have caregiver burden.<sup>13,26,27</sup> In the current study, a majority of informal caregivers were family caregivers. Family caregivers, as the primary source of patients' care and support, provide care including assistance with activities of daily living, medical care, and emotional and financial support.<sup>9</sup> These caregiving activities are often stressful and associated with physical, social, economic, and emotional consequence.<sup>13</sup> Our results suggested that health-care professionals, health institutions, and government should develop educational interventions and policy to decrease caregiver burden among informal caregivers of PLWHA.

Multiple linear regression analysis revealed that older age was positively related to higher level of caregiver burden. This finding was in line with previous studies.<sup>11,13</sup> Older people have less than optimal physical health and social functioning, and need more physical strength and resource to take care of themselves.<sup>11,37</sup> Older caregivers experienced physical ailments and psychological problems including backache, sleepless night, social isolation due to caregiving activities.<sup>12,13</sup> The insufficient income, overwhelming needs and high expenditure related to caregiving caused financial burden for older caregivers.<sup>12</sup> Thus, the older caregivers perceived heavier caregiver burden. Health-care providers and health institutions should provide the older caregivers with more help and resources to reduce their caregiver burden.



In the current study, multiple linear regression analysis showed that caregivers with poor health reported higher caregiver burden. Some studies revealed that caregivers with worse health status had higher level of caregiver burden.<sup>7</sup> Those caregivers with poor health suffer from physical and psychological burden due to their disease. The additional caregiving activities might result in their health deterioration, and increase caregiver burden.<sup>28</sup> Caregiver's well-being is critical to the optimal care of the patient.<sup>38</sup> Health-care professionals, health institutions and government should take more attention and assistant to care the PLWHA whose caregivers live in poor health status.

In the current study, multiple linear regression analysis found that parent-caregivers had heavier caregiver burden. People in Liangshan Yi prefecture live in poverty, and most of them lack saving and pension.<sup>29</sup> Illness made the sick adult children with HIV/AIDS unproductivity and unable to work, thus they need financial support.<sup>7</sup> Parent-caregivers must make money to care their sick children and support the entire families.<sup>7</sup> Caregiving activities have negative effects on parent-caregivers' physical health and social life.<sup>7,12</sup> Parents felt extremely worried, painful, sad, and depressed because their children with HIV/AIDS became ill and could die one day.<sup>7,13</sup> In China, people who were influenced by Confucian culture traditionally regard the family as the basic unit of society. Parents will always do their best to care their children, even though their children have grown up as adults. This might be the reason that parent-caregivers had a higher caregiver burden.

In multiple linear regression analysis, caregiving ability in balancing caregiving needs and one's own needs and managing own emotional needs were related to caregiver burden. Balancing caregiving needs and one's own needs involves attaining self-actualization and fulfillment.<sup>35</sup> To adapt to the new role, family caregivers should make adjustment in family, job and social activities.<sup>27</sup> Half of caregivers in this study had poor health, so they should balance their self-care needs and caregiving activity. Besides, taking care of a family member with HIV/AIDS was a hard and long-term task. Most caregivers experienced emotional problems (eg, psychological stress, depression, stigma, and anxiety) related to providing long-term care for the sick family members with HIV/AIDS.<sup>24,39</sup> Previous studies<sup>40,41</sup> reported the association between emotional problems, such as stress, anxiety and depression, and caregiver burden. Caregivers who perceived lower ability in balancing caregiving needs and one's needs and managing own emotional needs, would have higher level of caregiver burden. Thus, health-care professionals and health institution should provide education and interventions to improve caregivers' ability to manage emotional needs and keep balance between caregiving and own needs.

Our study also had some limitations. Firstly, the study was a cross-sectional study, and causal interpretations of the results cannot be established. Further prospective studies are needed to reveal the causal relationships. Secondly, some Yi participants who could not complete the questionnaires independently received assistance from trained investigators, which might exist bias. Although it is important to explore caregivers' experience during caring for PLWHA, we only used quantitative methods to explore caregiver burden due to limited financial support. Future studies should use mixed research methods to explore informal caregivers' burden.

## Conclusion

This study found that a majority of informal caregivers had perceived caregiver burden in Liangshan Yi prefecture of China. Older caregivers, parent-caregivers and caregivers with poor health had higher level of caregiver burden. Caregiving ability in balancing caregiving needs and one's own needs, and managing own emotional needs were negatively related to caregiver burden. Findings emphasize that health-care providers, health institutions and government should develop educational programs and policy to improve caregiver's care ability, and take more attention to the caregiver with higher level of caregiver burden. These may contribute to reducing caregiver burden among informal caregivers of PLWHA.

## Acknowledgments

A part of this study has been published in *Journal of the Association of Nurses in AIDS Care*, 2021, 32(5): 569-577. DOI: 10.1097/JNC.000000000000197. The authors thank all the participants who took part in this study. Yuqing Song and Huan Wang are co-first authors for this study.

## Funding

Sichuan Province provincial financial subsidy major diseases prevention and control project (Sichuan Health Office [2017] No.70; PI: Hong Chen).

## Disclosure

The authors declare no conflicts of interest in this article.

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