Caregiving Stress Among Family Caregivers of Older Adults Living with Disabilities in China

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Abstract

Objectives This study aimed to describe caregiving stress among family caregivers of Chinese older adults living with disabilities, and explore how care intensity, financial expenses, and care difficulties are associated with caregiving stress.

Methods Data of 220 older adult-caregiver dyads were collected from 6 urban districts and 6 rural counties from Shandong province, China. Descriptive analyses and multivariate ordinal logistic regression analyses were performed.

Results Family caregivers providing nine or more hours of care per day reported higher caregiving stress than those who provided fewer than nine hours. Caregivers who experienced insufficient care abilities, economic hardships, or time conflicts were more likely to report caregiving stress. Financial support provided to older adults was not associated with caregiving stress.

Conclusions Family caregivers of Chinese older adults with disabilities are experiencing excessive caregiving stress. Social support groups and China's long-term care insurance system should be promoted to better assist family caregivers.

Keywords: Care difficulties; Caregiving stress; China; Family caregivers; Older adults living with disabilities

Introduction

China's population is rapidly aging; meanwhile, the number of older adults living with disabilities is also increasing. According to the 2020 China Population Census data, there were more than 42 millions older adults living with disabilities,[1] and this number is projected to reach 77 millions by 2030.[2] Influenced by the Chinese filial piety culture, most family members naturally think they shoulder the responsibilities and obligations to take care of the older adults.[3] Therefore, family caregivers are often the main providers in long-term care, and they make an enormous contribution to the rehabilitation of older people with disabilities. However, impacted by the one-child policy, more than 30 million families only have one child to rely on.[4] As these parents are needing informal care, both the children and the spouses may experience excessive stress. In this study, we interviewed older adults with disabilities and their family caregivers, aiming to identify factors impacting caregiving stress among those informal caregivers and provide reference for the development of intervention measures to relieve caregiving stress of this group.

The stress process model (SPM) proposed by Pearlin and colleagues in 1981 may help explain how providing daily care may lead to caregiving stress. The SPM explains how various social factors cause or relieve stress and the associations between stress and physical and mental health outcomes. According to the SPM,[5] stressful life events (e.g. health deterioration) and continued stress (e.g. providing long-term care) are primary stressors that can cause secondary stressors, such as perceived care difficulties or financial stress. Chronic illness and the provision of care are major stressors for older persons and their caregivers, which can lead to subsequent financial stress, care

difficulties, caregiving stress. Caregiving stress represents a threat to the physical and mental health of caregivers.[6,7] This process is also influenced by the caregiving individual's own socioeconomic conditions, environment, coping skills, and social support.[5] Guided by the SPM, this study explored how primary stressors, such as care intensity, and secondary stressors, such as financial support provided to the older adults living with disabilities and perceived care difficulties, affect family caregivers' caregiving stress.

Among the various factors impacting caregiving stress, the time spent on care has been widely explored. Some studies measured caregiving time by the “duration of care”, such as a few months or several years.[8-10] Other studies measured caregiving time by asking the intensity of daily care, in other words, the average time caregivers spent per day on care. In this study, we focused on care intensity. A majority of previous studies, such as those from Nigeria, Turkey, and Japan, demonstrated that higher care intensity was associated with higher caregiving stress.[11-15] This positive correlation may eventually negatively impact caregivers’ health and well-being.[16] However, one study among caregivers of patients with Alzheimer 's disease in China demonstrated that caregiving stress was positively associated with the duration of care, but not the intensity of daily care.[17] Although a general conclusion regarding how care intensity may impact caregiving stress has been achieved, it is not clear whether the conclusion applies to family caregivers of Chinese older adults with disabilities. In addition, exploring caregiving intensity is conducive to identifying a time threshold, which may be a reference point for defining acceptable care intensity.

Further, in the process of caring for older adults living with disabilities, family caregivers are often responsible for providing care recipients with basic daily necessities and necessary medical support, which puts financial burdens on caregivers and possibly aggravates their caregiving stress.[18] According to a survey conducted in 2021, nearly 70% of family caregivers expressed pressure in taking care of older adults living with disabilities. Among them, 45% were under financial burden.[19] These financial burdens are attributable not only to care expenses and financial support for care recipients, but also to lost income among the caregiving family members. Financial burdens have been found to intensify the stress of caregiving.[19] Worse still, researchers found that among low-income caregivers of patients with cancer, financial burdens or the lacking of financial support was significantly associated with higher levels of caregiving stress.[18,20] Currently, financial burden, together with limited time and health problems, are listed as the top sources of caregiving stress among caregivers of older adults with Alzheimer's disease.[21,22]

In addition to intensity of care and financial burdens, family caregivers caring for older people with disabilities often encounter various difficulties in the process of providing care, such as the lack of professional care abilities, the lack of medical equipment at home, time conflicts, and the lack of assistance from nursing staff.[23] Essential care abilities are important in ensuring good quality of family care; however, a lot of family caregivers found their care abilities were insufficient because they had not taken any formal care training, and had little knowledge about rehabilitation of the older adults. [24,25] In addition, the lacking of professional nursing equipment increased the labor intensity and care pressure of caregivers to some extent.[26] Studies also reported that some

caregivers faced significant time conflicts between caregiving and their own work or daily lives, which might put more stress on them.[26] Family caregivers who lacked social support such as family members or nursing staff had low confidence and efficacy in caring for older adults living with disabilities, and their levels of caregiving stress were relatively high.[27] Therefore, in this study, we intended to explore whether these difficulties caregivers usually encounter explain caregiving stress among family caregivers of older adults with disabilities.

Although a lot of the literature in China has focused on caregiving stress among formal caregivers in general, very few studies have specifically focused on family caregivers of older adults living with disabilities. Elucidating factors impacting family caregivers' caregiving stress would provide reference for the development of intervention measures to avoid or relieve caregiving stress among family caregivers, and greatly improve the well-being of both caregivers and older adults living with disabilities.

Methods

Sampling

Samples were selected based on stratified random sampling in Jinan, Shandong. A total of 718 older adults and 275 family caregivers were approached and consented to participate in this study completed the questionnaire. The inclusion criteria for older adults was aged 60 or above. The inclusion criteria for family caregivers were: 1) aged 18 years old or older, 2) have been main caregivers of an older adult with disabilities at home for more than three months, and 3) without obvious cognitive impairment and were able to complete the questionnaire independently. Nannies or other paid workers were not

considered as family caregivers. For the purpose of this study, we only included older adults living with disabilities and their family caregivers. Therefore, our final sample included 220 older adults and caregiver dyads; information of care recipients, such as age, sex, and ADL limitations, was merged into the caregiver survey.

Procedure

Structured interviews were conducted in 2020-2021 with older people and their caregivers. A group of 29 postgraduate and doctoral students majoring in social medicine and health service management and public health were trained to administer the survey questionnaire. The questionnaire covered sociodemographic characteristics, family care situations, caregiving stress, care ability, and more. The time used to complete the questionnaire ranged from 15 to 30 minutes. After the interviews, the interviewers double-checked the questionnaires, and immediately corrected any mistakes or omissions of routine problems. A series of quality control measures, such as monitor the survey process and inspect data entry, were implemented.[28]

Ethical consideration

This study was approved by the medical ethics committee of Shandong University. The IRB number was ECSHCMSDU20200901. Informed consent was obtained from all participants in written and verbal forms.

Measures

Caregiving stress. Caregiving stress is defined as a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual.[29]In this study, we used the 12-item Zarit Stress Inventory Short Form (ZBI-12) to measure caregiving stress. It is a validated and shortened version of the Zarit Stress Inventory

(ZBI) used to measure stress experienced by family caregivers of older adults living with disabilities.[30] Caregivers were asked to report the frequency of a range of psychological outcomes (e.g., “Did you feel angry around your relative,” “did you feel that your health has suffered because of your involvement with your relative” , “did you think you should be doing more for your relative,” “did you think that you could do a better job in caring for your relative?”). Items on the scale were scored from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = frequently, and 4 = nearly always).[31] The final score ranges from 0-48, higher scores indicate higher levels of caregiving stress. Based on the grouping criteria of ZBI scale, caregiving stress was divided into three groups: (1) mild stress (0 to 10 points), (2) moderate stress (11 to 20 points), and (3) high stress (21 or above points).

Care intensity. Care intensity was measured by asking family caregivers how much time they spent per day, excluding sleeping time, on providing care for older adults living with disabilities. Caregiving intensity was divided into three groups: fewer than 9 hours, 9 to 12 hours, and 13 to 16 hours.

Financial support. Financial support was measured by asking family caregivers how much money they spent on caring for older adults living with disabilities per month. Financial support was divided into three groups: 500 CNY or less, 501 CNY to 1500 CNY, and more than 1500 CNY.

Care difficulties. For this question, we listed frequently reported difficulties in caregiving, including insufficient care abilities, economic hardship, time conflicts, and inadequate nursing equipment. Participants reported “yes” or “no” to these difficulties, and they were allowed to select multiple answers based on their experiences. By care

abilities, we meant special knowledge of certain diseases that the care recipients were suffering, relevant nursing skills, and the ability to seek social support.[32] Economic hardship referred to the difficulties caregivers were facing in paying for medical bills and daily living. For time conflicts, we asked caregivers whether taking care of the older adults conflicted with their work, family lives, or leisure time.[33]

ADL level. The Barthel Index (BI) was used to measure the disability level of the older adults, which was widely used to assess abilities of daily life (ADLs). The BI included 10 items, including bowel function, bladder function, grooming, toileting, feeding, transferring (bed to chair and back), walking, bathing, ascending and descending stairs, and dressing.[34] Each item was scored 0, 5, 10 or 15 according to the degree of need for help. The score ranges from 0 to 100. Lower scores indicate lower ADLs and higher levels of disability. Older adults who scored 100 were excluded from this study because they had no functional impairment. Based on the grouping criteria of the BI scale, older adults were divided into three groups: high disabilities (0 to 40 points), moderate disabilities (41 to 60 points), and mild disabilities (61 to 99 points).[35]

Covariates. Covariates included family caregivers' gender (1=male, 2=female), age (60 or younger, 61 to 70, 71 or older), areas of residence (1=urban community, 2=rural village), the caregiver's relationship to the older adult with disabilities (1=spouse, 2= child or others), and their educational level (1= elementary or lower, 2=junior high school, 3=technical secondary school or above), self-reported physical health (1=good, 2=general, 3=poor), and whether there is an additional person to help with caregiving

(1=yes, 2=no). We also included gender of the older adults living with disabilities (1=male, 2=female) and their age groups (60 to 70, 71 to 80, 81 or older).

Statistical analysis

First, descriptive statistics of sociodemographic variables were conducted. Second, Chi-squared tests were conducted to estimate correlations between variables of interest and caregiving stress experienced by family caregivers for older adults living with disabilities. Third, multivariate ordinal logistic regression was used to explore variables that could predict family caregiver's caregiving stress. In all analyses, a p-value less than 0.05 was considered statistically significant. All analyses were performed using SPSS 22.0.

Results

Socio-demographic characteristics of study samples

The demographic characteristics of the 220 caregivers and the older care recipients are shown in Table 1. Among the caregivers, nearly 60 percent were female (58.6%). About 32% of them were 60 or younger, and 29% were older than 70. Over half had elementary or lower education (50.9%). Less than half of the family caregivers were spouses (48.6%) of the care recipients, and 51.4% were children (i.e., son, daughter, son-in-law, and daughter-in-law) or other relatives. Their residential areas were evenly distributed (47.3% in urban, 52.7% in rural areas). More than half of the family caregivers reported poor physical health (51.4%), and most reported having an additional person to help them care for the older adults (72.3%). With respect to the older adults

receiving family care, more than half of the older adults living with disabilities were female (55.5%), 44.1% of them were over 80 years old, and 53.6% of them were with severe disabilities.

Descriptive statistics of the main study variables

Table 2 shows that nearly half of the family caregivers felt high caregiving stress (47.3%). A majority of the family caregivers spent 13 to 16 hours per day on caring for the older adults living with disabilities (62.7%), while 21.8% of them had been caring for the older adults living with disabilities for fewer than 9 hours per day. One third of caregivers providing fewer than 9 hours of care per day reported high levels of caregiving stress, among caregivers who provided 9 to12 hours of care per day or 13-16 hours of care per day, more than half reported high stress. With respect to financial support for older adults living with disabilities, 29.5% of the family caregivers provided 500 CNY or less per month in expenditures, 37.7% spent 501 to 1500 CNY, and 32.7% spent more than 1500 CNY. Among those who provided more than 1500 CNY per month, the majority reported high caregiving stress. The Chi-squared tests did not show significant differences on caregiving stress among the caregiving time or financial support groups. In terms of perceived care difficulties, most of the family caregivers felt they lacked sufficient care abilities (49.5%) and faced economic hardship (55.0%). Most family caregivers who faced difficulties in care provision reported a high level of stress. Insufficient care abilities ($p < .001$), economic hardship ($p < .001$) and inadequate nursing equipment ($p = .018$) were significantly associated with heightened caregiving stress.

Multivariate ordinal logistic regression analyses

Results from multivariate ordinal logistic regressions are provided in Table 3. In

Model 1, we examined the association between caregiving time and caregiving stress, controlling for covariates. We found that caregivers who provided 9 to 12 hours of care per day (OR=2.72, p<.05, 95%CI: 1.10-6.90) and those who provided 13 to 16 hours per day (OR=2.12, p<.05, 95%CI:1.07-4.17) were more likely to report high caregiving stress, compared to those who provided fewer than 9 hours of care per day. We conducted other regression models with different caregiving intensities as the reference groups and found no difference in the effects of 9 to 12 hours of care per day versus 13 to 16 hours of care per day on caregiving stress.

Furthermore, we included financial expenses in Model 2 and found that financial expenses were not statistically associated with caregiving stress (500 CNY or less: OR=0.79, p>.05, 95%CI:0.40-1.58; 501 CNY to 1500 CNY: OR=0.81, p>.05, 95%CI:0.42-1.57). After adjusting for financial expenses, caregiving time was still significantly related to caregiving stress (9 to 12 hours: OR=2.74, p<.05, 95%CI: 1.11-6.76; 13 to 16 hours: OR=2.08, p<.05, 95%CI:1.05-4.10).

In the last model (Model 3), we included the four types of perceived caregiving difficulties. The results showed that caregivers who reported insufficient care abilities (OR=2.50, p<.05, 95%CI:1.32-4.74), economic hardship (OR=3.11, p<.01, 95%CI:1.68-5.78), and time conflicts (OR=2.52, p<.05, 95%CI:1.23-5.17) were likely to report higher caregiving stress than those who did not report these difficulties. However, inadequate nursing equipment was not significantly associated with caregiving stress.

Discussion

As the number of older adults living with disabilities continues to grow, their family

caregivers are facing stress from various aspects of care. This study explored caregiving stress among family caregivers of Chinese older adults living with disabilities from three perspectives: care intensity, financial expenses, and perceived difficulties of caregiving. Findings from this study contributed to the understanding of potential factors affecting family caregivers' well-being.

Although the Chi-squared tests did not show significant differences on caregiving stress among the care intensity groups, after control variables were taken into consideration, we found significant difference between care intensity groups. This means that caregiving stress is also shaped by other factors. Results from multivariate ordinal logistic regression were consistent with findings from previous studies,[36,37] showing that higher care intensity was associated with higher caregiving stress. What our findings added to the literature was that 9 hours of care seemed to be an important threshold, as care hours exceeding this point were associated with higher levels of caregiving stress. For family caregivers providing high intensity of care, establishing community-based respite service centers or day care centers may help reduce their care time as well as caregiving stress.

Regarding financial support, although we found that general economic hardship was an important factor contributing to caregiving stress, the amount of money spent specifically on the older adult receiving care was not significantly related to caregiving stress. This seemed to relate primarily to the income gap of each family and the psychological capacity of family caregivers. Some family caregivers who provided more monthly financial support for the older adults felt less economic hardship, likely because their family had a higher monthly income and a higher ability to withstand financial

pressure. Some family caregivers did not have a high monthly income, but when they had to provide considerable financial support, they still reported that they did not feel too burdened financially. This may be because of their close relationship with the older adults living with disabilities and their strong psychological endurance. Moreover, this may also relate to the Chinese filial piety culture and traditional cultural norms about providing support for family members. Family members may perceive financial support more as their family responsibilities or obligations rather than financial burden. The government may increase attention toward the problems existing in the provision of family pensions for older adults living with disabilities, especially vulnerable groups, and provide additional financial assistance to economically-disadvantaged members of this population.

Further, we found that caregiving stress was related to caregivers' perceived difficulties, including insufficient care abilities, economic hardship, and time conflicts. In our research, many family caregivers described a lack of care abilities or professional care equipment. Medical staff should take the initiative to teach family caregivers certain basic care skills. The government and relevant departments should regularly carry out publicity and education activities on health care knowledge and focus on practical exercises to jointly improve the caring ability of family caregivers from theoretical knowledge and practical aspects. For example, in cases of a shortage of care equipment, home-based care can be introduced.[38]Through the adjustment of the medical insurance settlement policy, part of the cost of nursing equipment used by some families will be included in the scope of reimbursement,[39] and rental services for nursing supplies, rehabilitation training, and other equipment will be made available.[40] In the future,

home-based care and medical insurance can be integrated to reduce the family's economic difficulties and reduce the care pressure faced by family caregivers.

Several limitations of this study should be mentioned. First, its cross-sectional design cannot confirm causal relationships between each variable and outcome. In addition, this research is limited only to family caregivers in Jinan, Shandong Province, and the small sample size may make differences difficult to detect. This suggests that further research using a larger sample size is needed. Finally, during the interview, interviewers did not provide a rigid definition of caregiving to survey participants, therefore, participants who answered the questions based on their own understanding of caregiving may lead to bias. Future data collection should provide a clear definition of what caregiving means.

Acknowledgements

The project was funded by Social Science Foundation of Shandong in China (Grant Number: 20CGLJ30) and Public Bidding Project of the Aging Research Base of Shandong Youth University of Politics Science of the China Association on Aging " Research on Intergenerational Support and Mental Health of Older Adults Couples in China " (2021) (Grant Number: SDYULY01). The authors are grateful to all participants who agreed to participate voluntarily in this study. The author of this article contributed as follows: conceptualization, Lirong Yue, Congxi Jia, Shuangshuang Wang; formal analysis and data curation, Lirong Yue, Congxi Jia, Zhenzhen Zhang; writing—original draft preparation, Lirong Yue, Congxi Jia; writing—review, editing, and supervision, Bo Hu, Meng Bai, Shuangshuang Wang, Nengliang Yao. All authors have read and agreed to the published version of the manuscript.

Disclosure statement

The authors declare no conflict of interest.

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Table 1. Sociodemographic characteristics of family caregivers and older adults living with disabilities（n=220）

Variables	n	%
Family caregivers		
Sex		
Male	91	41.4
Female	129	58.6
Age		
60 or younger	70	31.8
61 to 70	86	39.1
71 or older	64	29.1
Educational attainment		
Elementary or lower	112	50.9
Junior high school	57	25.9
Technical secondary school or above	51	23.2
Region of residence		
Urban community	104	47.3
Rural village	116	52.7
Relationship with the older adult with disability		
Spouse	107	48.6
Child or other	113	51.4
Self-reported physical health		
Good	28	12.7
General	79	35.9
Poor	113	51.4
Whether there is an additional person to help with caregiving		
Yes	159	72.3
None	61	27.7
Older adults living with disabilities		
Sex		
Male	98	44.5
Female	122	55.5
Age		
60 to70	62	28.2
71 to 80	61	27.7
81 or older	97	44.1
ADL level		

Mild disabilities	70	31.8
Moderate disabilities	32	14.5
High disabilities	118	53.6

Table 2. Descriptive statistics of the main study variables.

Variables	Caregiving stress			Total	P-value
	Mild stress （n = 54, 24.5%）	Moderate stress (n = 62, 28.2%)	High stress (n = 104, 47.3%)		
Care intensity /day					.124
Fewer than 9 hours	18 (37.5%)	14 (29.2%)	16 (33.3%)	48 (21.8%)	
9 to 12 hours	7 (20.6%)	8 (23.5%)	19 (55.9%)	34 (15.5%)	
13 to 16 hours	29 (21.0%)	40 (29.0%)	69 (50.0%)	138 (62.7%)	
Financial expenses /month					.678
500 CNY or less	19 (29.2%)	19 (29.2%)	27 (41.5%)	65 (29.5%)	
501CNY to 1500 CNY	21 (25.3%)	23 (27.7%)	39 (47.0%)	83 (37.7%)	
More than 1500 CNY	14 (19.4%)	20 (27.8%)	38 (52.8%)	72 (32.7%)	
Care difficulties					
Insufficient care abilities	15 (13.8%)	30 (27.5%)	64 (58.7%)	109 (49.5%)	.000
Economic hardship	18 (14.9%)	30 (24.8%)	73 (60.3%)	121 (55.0%)	.000
Time conflict	6 (12.5%)	13 (27.1%)	29 (60.4%)	48 (21.8%)	.052
Inadequate nursing equipment	6 (15.0%)	7 (17.5%)	27 (67.5%)	40 (18.2%)	.018

Table 3. Results from multivariate ordinal logistic regressions

Variables	Model 1			Model 2			Model 3		
	OR	95%CI		OR	95%CI		OR	95%CI	
		Lower	Upper		Lower	Upper		Lower	Upper
Family caregivers									
Care intensity/day (ref: Fewer than 9 hours)									
9 to 12 hours	2.72*	1.10	6.69	2.74*	1.11	6.76	2.86*	1.11	7.41
13 to 16 hours	2.12*	1.07	4.17	2.08*	1.05	4.10	2.58*	1.24	5.36
Financial expenses /month (ref: More than 1500 CNY)									
500 CNY or less				0.79	0.40	1.58	0.91	0.44	1.88
501CNY to 1500 CNY				0.81	0.42	1.57	0.83	0.41	1.68
Care difficulties									
Insufficient care abilities							2.50*	1.32	4.74
Economic hardship							3.11**	1.68	5.78
Time conflict							2.52*	1.23	5.17
Inadequate nursing equipment							1.79	0.80	4.02
Male (ref: female)	1.01	0.56	1.83	1.03	0.56	1.9	1.02	0.53	1.95
Age (ref: 71 or older)									
60 or younger	0.86	0.36	2.01	0.87	0.37	2.05	0.58	0.23	1.48
61 to 70	1.04	0.50	2.17	1.04	0.50	2.18	0.84	0.38	1.85
Educational attainment (ref: Technical secondary school or above)									
Elementary or lower	1.29	0.58	2.90	1.33	0.59	2.99	1.29	0.54	3.91
Junior high school	0.98	0.46	2.10	1.00	0.46	2.16	1.12	0.50	2.52
Urban community (ref: Rural village)	0.66	0.35	1.25	0.64	0.34	1.23	1.03	0.51	2.10

Relationship with the older adult with disability (ref: Child or other)									
Spouse	1.37	0.58	3.24	1.33	0.56	3.18	1.17	0.46	2.97
Self-reported physical health (ref: Poor)									
Good	0.58	0.24	1.41	0.60	0.24	1.49	0.64	0.25	1.65
General	0.41*	0.22	0.76	0.43*	0.23	0.80	0.29**	0.15	0.57
Whether there is someone to help with caregiving (ref: None)									
Yes	2.38*	1.22	4.64	2.36*	1.21	4.61	2.42*	1.19	4.91
Older adults living with disabilities									
Male (ref: female)	0.8	0.45	1.43	0.80	0.44	1.45	0.66	0.35	1.25
Age (ref: 81 or older)									
60 to70	1.69	0.73	3.92	1.72	0.74	4.04	1.59	0.64	3.95
71 to 80	0.81	0.37	1.78	0.82	0.37	1.81	0.76	0.33	1.76
ADL level (ref: High disabilities)									
Mild disabilities	0.65	0.34	1.27	0.65	0.34	1.27	1.00	0.48	2.06
Moderate disabilities	0.92	0.41	2.09	0.91	0.40	2.07	0.90	0.37	2.14

*P < .05; **P < .01.