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Burden of caregivers who care for oldest-old parents with disability: A cross-sectional study



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ABSTRACT

Objective: To describe the characteristics of oldest-old Chinese with disability and their adult-child caregivers, and the extent to which these characteristics were associated with caregiver burden.

Methods: The study was based on 168 pairs of disabled oldest-old adults and their adult-child caregivers, derived from the Chinese Longitudinal Healthy Longevity Survey. Descriptive analyses of care recipients' and caregivers' characteristics were conducted respectively, in reference to caregiver burden. Statistically significant characteristics identified in these bivariate analyses were then jointly evaluated in multiple linear regression models with caregiver burden as the outcome.

Results: Care recipients positive emotion status $[(\beta = -0.227 \ (-0.412, -0.042)], multiple chronic disease <math>[(\beta = 0.513 \ (0.081, 0.945)], and caregivers spent more caregiving time <math>[(\beta = 0.225 \ (0.061, 0.389)]]$ were main factors associated with caregiver burden.

Conclusion: Adult-children caregivers perceived heavier burden if care recipients had low positive emotions, had multiple chronic diseases, and caregivers spent more time caregiving.

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Introduction

With rapid aging in China, a large number of the oldest old (80+ years) require assistance in their essential activities of daily living (ADL).¹ Influenced by Confucian values, Chinese older adults mainly rely on their adult children for care support.² According to a national survey across China in 2015, ³ most caregivers of disabled older adults were spouses and children, accounting for 40% and 52%, respectively. The caregivers of disabled older adults face great burdens that negatively affect their and the care recipients' well-being.^{4,5}

Potential factors associated with caregiver burden include characteristics of both care recipients and caregivers. Firstly, the dyadic demographics and health status are reported associated with caregiver

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burden. Heavier burden is associated with care recipients' lower education,⁶ lower functional levels, and worse cognitive status.^{7–9} Previous studies have indicated that care recipients' chronic conditions and psychological status are related to caregivers' quality of life. 10,11 Nevertheless, whether care recipients' chronic and psychological health contribute to adult-child caregiver burden has yet to be fully investigated using dyadic data. As for caregivers, older age, 12 being female, 13 having lower levels of education, ¹³ cohabitations with the care recipient, ¹⁴ and poorer health ¹⁵ are related to heavier burden. Secondly, caregivers' psychosocial factors such as belief system and social support¹⁶ are also important for caregiver burden.¹⁷ Although the evidence regarding the influence of filial piety on adult-child caregiver burden is mixed, most studies have showed that stronger filial cultural identity is associated with a lower burden due to the sense of acceptance of the caregiver role and duty. 18,19 Besides, caregivers' involvement is also vital for caregiver burden. Both longitudinal and cross-sectional studies have demonstrated that caregiver burden is heavier as reported caregiver's time investment in caregiving increased.^{20,21}

Many studies have explored potential contributing factors to caregiver burden, some of which have provided data on the adult-child

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caregiver burden of Chinese disabled parents, ^{9,22} and all found that parents' health status is associated with caregiver burden. However, these studies did not consider the disabled care recipients' characteristics of various ADLs or adult children's perception of filial piety, a core value in traditional Chinese culture, in which adult children are expected to provide care for older parents. Existing studies have rarely focused on a specific group of people with disability: the oldest old. In fact, with the rapid increase in life expectancy, the oldest old has been the fastest-growing segment of the population. In 2009, there were 19 million oldest old Chinese, and the number increases to 29 million in 2020.²³ More and more oldest old suffer from disability with advanced aging and rely on their adult children.

This study targeted the rapidly increasing oldest-old Chinese with disability, with the objective to generate first-hand evidence of the characteristics of both oldest-old disabled care recipients and their primary adult-child caregivers, and to examine the extent to which these dyadic characteristics are associated with caregiver burden. Building upon previous literature, we investigated key factors of caregiver burden using the dyadic data available in the Chinese Longitudinal Healthy Longevity Survey (CLHLS). The following three hypotheses were tested in this study:

Hypothesis 1: Oldest-old care recipients with low socioeconomic status (i.e. being old, illiterate, living in a rural area), and poor health conditions (i.e. lower positive emotion, cognitive impairment, multiple chronic diseases and ADL disability) would be positively associated with caregiver burden.

Hypothesis 2: Adult-child caregivers who had low socioeconomic status, few supportive family networks, poor health and heavy caregiving involvement would perceive heavier caregiver burden.

Hypothesis 3: Adult-child caregiver burden would be associated with the characteristics of the oldest-old care recipients and adult-child caregivers simultaneously.

Methods

Study population

Initiated in 1998, CLHLS was designed to investigate determinants of healthy longevity in Chinese older adults. The survey began with interviews with the oldest old (aged 80+) in half of the counties and cities selected in 22 provinces in China. The collected information included demographics, life satisfaction, cognitive conditions, ADL, and chronic diseases. The 2002 and 2005 CLHLS waves included an extra module, the Family Dynamic Survey (FDS), conducted in nine provinces: Beijing, Liaoning, Shanghai, Jiangsu, Zhejiang, Fujian, Shandong, Guangdong, and Guangxi. Eligible adult children lived in the same county or city as their parents. All information of caregivers was self-reported, including demographics, family network, and intergenerational interaction. Because the 2002 FDS wave did not collect information on caregiver burden, we used data from the 2005 wave only.

The sample for this study consisted of 168 dyads of adult-child caregivers and their parents, the disabled care recipients. Fig. 1 shows the sample selection process. We excluded 4072 of 4240 dyads from FDS for the following reasons: the parents or the adult children were lost to follow-up, the parents were independent in six ADLs (i.e., bathing, dressing, toileting, mobility, continence, feeding), the parents lived in an institution, the parents were not primarily cared for by their children, or the adult children reported not providing

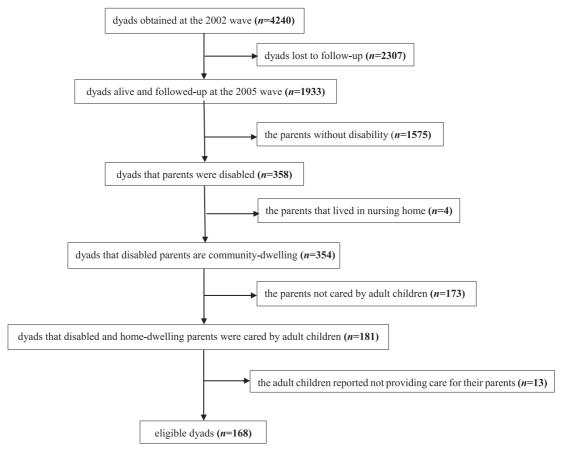


Fig. 1. Flowchart of sample selection.

care for their parents. More details about the CLHLS and FDS were reported elsewhere. $^{\rm 24}$

Measurements

Caregiver burden

Caregiver burden was measured using a modified version of the original Zarit Burden Interview (ZBI). The scale was developed by Zarit in the 1980s to evaluate caregiver burden of dementia patients, composed of 22 items, with a total score range 0 to 88 (higher scores indicating heavier caregiver burden). The ZBI was translated into Chinese in 2006 (Cronbach's $\alpha = 0.87$) and is widely used for caregiver burden assessments in the Chinese population. 28,29

Characteristics of care recipients and caregivers

Characteristics of care recipients and caregivers in this study included sociodemographic and health variables, as well as caregivers' psychosocial factors and caregiving involvement.

Care recipients' sociodemographic variables were age, gender (female [reference group] vs. male, education level (illiterate [reference group] vs. literate), marital status (widowed [reference group] vs. married), and residence area (rural [reference group] vs. urban/ town). Health variables were positive emotion, cognitive impairment (no [reference group] vs. yes), ADL disability (mild [reference group] vs. moderate vs. severe) and multiple chronic diseases (no [reference group] vs. yes). Positive emotion was assessed via three questions: "Do you usually feel nervous or afraid?" "Do you usually feel lonely?" and "Do you usually feel more and more useless?" The response choices for each question range from never (coded as 5) to always (coded as 1). We created a composite measure by summing the three variables (range 3 to 15), with high scores indicating good emotional condition.³⁰ The older adults' cognitive status was measured with the Mini-Mental State Examination (MMSE; Cronbach's $\alpha = 0.98$).³¹ MMSE scores range from 0 to 30; respondents with a score of 24 or above were considered not to have cognitive impairment.³² We used the Katz index (Cronbach's α = 0.87) to assess the care recipients' functional status.³¹ ADL disability was defined as being incontinent or needing assistance in performing one or more of the five activities (bathing, dressing, toileting, mobility, eating).³³ Disability in one or two activities was considered as mild, three or four activities as moderate, and five or six activities as severe.³⁴ The measure of disability was limited to ADL, excluding instrumental ADL (IADL), given the amount of overlap between these two in the oldest old (the proportion of IADL disability accounted for 98.8% in our sample). Chronic diseases included 13 conditions: hypertension, diabetes, heart disease, stroke or cerebrovascular disease, bronchitis or emphysema or asthma or pneumonia, cataracts, glaucoma, cancer, prostate tumor, gastric or duodenal ulcer, Parkinson's disease, bedsores, arthritis. Multiple chronic diseases were defined as having two or more chronic conditions.

Caregivers' sociodemographic variables were age, gender (male [reference group] vs. female), education (elementary school and below [reference group] vs. junior high school and above), marital status (unmarried/divorced/widowed [reference group] vs. married), working status (unemployed [reference group] vs. employed), average family monthly income, co-residence with the care recipient (no [reference group] vs. yes) and the number of siblings and children. Health variables were caregiver's self-reported health ((very) bad [reference group] vs. fair vs. (very) good). Caregivers' psychosocial factors involved the relationship with care recipients (not very close [reference group] vs. very close), willingness to provide care (without patience/need respite care/unwilling to do [reference group] vs. willing to do so) and filial piety. Filial piety was measured by eight items

on the Filial Piety Scale (Cronbach's α ranged from 0.79 to 0.90).³⁵ Examples of items are "Gratitude for parents' fosterage" and "Respect to parents, no matter how parents did with you." Response choices ranged from *not important* (coded as 0) to *very important* (coded as 4). We created a composite measure by summing the eight variables (range from 0 to 32), with higher scores indicating greater filial piety. Caregivers' involvement was measured by the number of days and money spent in caregiving during the past 12 months.

Data analyses

We used descriptive analyses to evaluate the characteristics of care recipients and caregivers. Bivariate analyses were conducted to measure the association between ZBI score and characteristics, with t tests, analyses of variance (ANOVA), and Kruskal-Wallis tests for categorical variables and Spearman's rank correlations for continuous variables. Multiple linear regression was performed to identify potential factors associated with caregiver burden, using caregiving dyads' age, gender, and significant variables in the bivariate analysis as independent variables, and all continuous variables were standardized by z-score. The proportion of missing data for a single variable ranged 2.4% to 28.0%. Multiple imputation (m = 50, method = bayesian linear regression³⁶) was used for and sensitivity analysis was conducted with complete data (n = 94, 56.0%). The significance level was set at p < .05. Analyses were conducted using R (Version 3.6.2) software.

Ethics approval and informed consent

The use of CLHLS data was approved by the Biomedical Ethics Committee of Peking University and informed consent by participants was obtained.

Results

The average ZBI score of 168 caregivers in this study was 25.3 (SD = 14.4, range 0 to 73).

Table 1 reports bivariate associations between characteristics of care recipients and caregiver burden. Care recipients' average age was 92.3 years (range 68 to 117, SD = 9.5); 56.6% were female. Most were illiterate (65.5%), most were widowed (89.3%), and 53.0% lived in a city/town. The average score of positive emotion was 10.4 (SD = 2.2). About half had cognitive impairment (51.0%) and the majority (73.6%) reported multiple chronic diseases. The proportions of the care recipients with mild, moderate, severe disability were 52.9%, 18.5%, 28.6%, respectively. Heavier caregiver burden was associated with care recipient's lower positive emotion (p < .001), cognitive impairment (p = .012), having multiple chronic diseases (p = .004), and severe disability (p = .006). Factors examined in bivariate analyses were not associated with burden, including care recipients' age, gender, marital status, educational level, residence area.

The association of caregiver burden with various ADLs is described in Appendix. Most care recipients (88.7%) needed assistance in bathing; nearly one half needed assistance in dressing (49.4%) or toileting (49.4%) or mobility (44.6%); one fifth were incontinent (20.8%), and one third needed assistance in eating (33.3%). Caregiver burden was higher when care recipients needed assistance in dressing (p = .006), toileting (p < .001), mobility (p = .018) or eating (p = .003), while activities of care recipients examined in bivariate analyses that were not associated with burden were bathing or being incontinent.

Table 2 shows the bivariate association between characteristics of caregivers and caregiver burden. Caregivers had a mean age of 56.7 years (range 38 to 68, SD = 7.3). The majority were male (64.3%) and married (89.3%). More than half were educated at junior high school and above (57.7%) and nearly half were employed (46.4%). The

Table 1 Bivariate association between characteristics of care recipients and caregiver burden.

	Overall (N=168)	ZBI* (points) mean (SD)	$r_s/t/F/\chi^2$	P-value
Demographics				
Age (years) mean (SD)	92.3 (9.5)	25.3 (14.4)	-0.04	.65
Gender n (%)	` ,	,	-0.49	.63
Male	73 (43.5)	24.6 (14.0)		
Female	95 (56.6)	25.7 (14.7)		
Current marital status n (%)	` '	,	0.85	.40
Widowed	150 (89.3)	25.6 (14.4)		
Married	18 (10.7)	22.6 (13.7)		
Educational level n (%)	,	,	-0.30	.77
Illiterate	110 (65.5)	25.5 (14.5)		
literate	58 (34.5)	24.8 (14.2)		
Residence area n (%)	,		-0.09	.93
Rural	79 (47.0)	25.4 (14.8)		
City/Town	89 (53.0)	25.2 (14.0)		
Health status	()	()		
Positive emotion mean (SD)	10.4 (2.2)	25.3 (14.4)	-0.37	< 0.001
Cognitive impairment n (%)	(=-=)	()	-1.55	.012
No	75 (49.0)	23.2 (12.0)	1.55	
Yes	78 (51.0)	26.9 (16.7)		
Multiple chronic diseases n (%)	()		2.96	.004
No	33 (26.4)	19.7 (11.9)		
Yes	92 (73.6)	23.8 (14.8)		
ADL disability n (%)	52 (75.6)	25.6 (1.16)	5.24	.006
Mild	89 (52.9)	22.0 (13.8)	5,21	.000
Moderate	31 (18.5)	27.8 (13.7)		
Severe	48 (28.6)	29.7 (14.5)		

P values < 0.05 (statistical significance) are reported in bold; SD, standard deviation.

Table 2 Bivariate association between characteristics of caregivers and caregiver burden.

	Overall (<i>N</i> =168)	ZBI* (points) mean (SD)	$r_s/t/F/\chi^2$	P-value
Demographics				
Age (years) mean (SD)	56.7 (7.3)	25.3 (14.4)	-0.06	.45
Gender n (%)			-1.55	.12
Male	108 (64.3)	24.0 (14.1)		
Female	60 (35.7)	27.6 (14.6)		
Education levels n (%)			-0.35	.73
Elementary school & below	71 (42.3)	25.7 (16.3)		
Junior high school & above	97 (57.7)	24.9 (12.8)		
Marital status n (%)			1.55	.14
Unmarried/divorced/widowed	18 (10.7)	32.4 (21.5)		
Married	150 (89.3)	24.4 (13.1)		
Working status n (%)			0.16	.88
Unemployed	90 (53.6)	25.1 (13.9)		
Employed	78 (46.4)	25.5 (14.9)		
Average family monthly income (dollars) mean (SD)	229.9 (182.4)	25.3 (14.4)	-0.08	.29
live with the care recipient n (%)			-2.29	.024
No	67 (39.9)	22.4 (11.7)		
Yes	101 (60.1)	27.2 (15.6)		
Number of siblings mean (SD)	3.0 (2.0)	25.3 (14.4)	-0.18	.019
Number of children mean (SD)	2.4 (1.4)	25.3 (14.4)	-0.12	.13
Health status				
Self-rated health n (%)			5.45	.07
Bad or very bad	12 (7.1)	33.7 (19.0)		
Fair	44 (26.2)	28.1 (15.8)		
Good or very good	112 (66.7)	23.3 (12.8)		
Psychosocial factors				
The relationship with the care recipient n (%)			0.02	.98
Not very close	118 (70.2)	25.3 (15.0)		
Very close	50 (29.8)	25.2 (12.8)		
Willingness to provide care n (%)			-2.19	.030
Willing to do	153 (93.9)	24.7 (13.9)		
Without patience/need respite care/unwilling to do	10 (6.1)	34.7 (16.8)		
Filial piety mean (SD)	21.6 (4.3)	25.3 (14.4)	0.02	.85
Involvement in caregiving				
Days spent during the past 12 months mean (SD)	199.6 (159.8)	25.3 (14.4)	0.18	.021
Money spent during the past 12 months (dollars) mean (SD)	55.9 (90.1)	25.3 (14.4)	0.02	.84

^{*} ZBI, Zarit Caregiver burden Interview (0–88 points). Higher score indicates heavier caregiver burden.

P values < 0.05 (statistical significance) are reported in bold; SD, standard deviation.

* ZBI, Zarit Caregiver burden Interview (0-88 points). Higher score indicates heavier caregiver burden.

average monthly family income was 229.9 dollars (SD = 182.4). Most caregivers lived with the care recipients (60.1%). Caregivers had a mean of 3.0 siblings (SD = 2.0) and 2.4 children (SD = 1.4). Two thirds (66.7%) reported themselves to be in (very) good health. The proportions of caregivers reporting a very close relationship with the care recipient and willing to provide care were 29.8% and 93.9%, respectively. The average score for filial piety was 21.6 (SD = 4.3). Caregivers reported having spent 199.6 days (SD = 159.8) and 55.9 dollars (SD = 90.1) caregiving during the previous 12 months. Adult-child caregivers with heavier burden tended to live with the care recipients (p = .024), had fewer siblings (p = .019), were not willing to provide care (p = .030), and provided more caregiving time (p = .021). Factors examined in bivariate analyses that were not associated with burden were caregivers' age, gender, marital status, level of education, working status, average family monthly income, the number of children, self-rated health, closeness of relationship with the care recipient, filial piety, and money spent in caregiving.

Table 3 reports the linear regressions of adult-child caregiver burden. Results of sensitivity analysis with complete data were robust. Among the care recipients' characteristics that were significantly associated with caregiver burden in bivariate analysis (Model 1), the disabled older adults with lower positive emotion $[(\beta = -0.254 (-0.442, -0.067)]]$ were confirmed to be significantly associated with higher levels of adult-child caregiver burden. Among the caregivers' characteristics that were significantly associated with caregiver burden in bivariate analysis (Model 2), only days spent during the past 12 months retain significance in this model. After accounting for both care recipients' and caregivers' characteristics with significance in bivariate analysis (Model 3), positive emotion $[(\beta = -0.227 (-0.412, -0.042)]]$ retained significance. Multiple chronic diseases $[(\beta = 0.513 (0.081, 0.945)]]$ and days spent during the past 12 months $[(\beta = 0.225 (0.061, 0.389)]]$ were significant in Model 3.

Discussion

In this study, we examined records of 168 community-dwelling disabled older adults and their adult-child caregivers from the FDS in the CLHLS. We delineated the characteristics of both care recipients and caregivers and examined factors associated with caregiver burden. Results suggested that more than half of care recipients were female, and the majority were cared for by male adult children. Three hypotheses were partially supported. Care recipients having lower positive emotions, having multiple chronic diseases, and caregivers

spent more caregiving days were significantly associated with heavier caregiver burden.

Most oldest-old care recipients reported mild disability, with the predominant care need in bathing, consistent with findings from previous national surveys. ^{37,38} For adult-child caregivers, males (i.e., sons) accounted for two thirds, different from the result reported by Zhan, that sons only covered 30%. ⁹ It could be explained that our sample source-2005 FDS (n=1933), adult children were overwhelmingly male (70.8%). FDS sampled eligible children living in the same city or county as their parents, and females in China tend not to live at home when they get married, so caregivers in our study were more likely to be males.

Care recipients' lower positive emotion was related to higher caregiver burden. This finding is consistent with a previous study reporting that, with the poorer mental health of female cancer patients in America, daughters who provided primary care showed poorer physical health. ¹⁰ In a meta-analysis, Hodges and colleagues ³⁹ found a significant association between the mental health of cancer patients and their adult-child caregivers, which implies interpersonal emotion transfer, ⁴⁰ with one person's distress spilling over to the other. It was reported that stress-related hormones secreted by adult-child caregivers and their immune function were linked to care recipients' mental health. ⁴¹ In China, family caregiver burden for stroke patients was closely related to anxiety/depression of caregivers themselves, ⁴² so it is reasonable to conclude that caregiving dyads' mental health contributes to caregiver burden.

The present study showed that adult-child caregivers who spent more caregiving time perceived a higher burden, consistent with findings by Shen. ²² The association between caregiving time and burden was not associated with care recipients' severity of disability. More caregiving time caused the feeling of restriction on time, ⁴³ especially when they have responsibility for their own family or employment. According to role theory, the assumption of multiple roles requires energy and time to face many expectations, leading to role overload, role conflict, and psychological burden. ⁴⁴ In the multivariable context, caregivers' cohabitation with care recipients did not retain significance, possibly because caregivers who lived with care recipients were more likely to spend more time in caregiving (t = 3.08, p = .003).

Different from previous findings, the association between filial culture and caregiver burden was not statistically significant in this study. On the one hand, it was argued that the higher the children's identification with filial culture, the more they would view the task

Table 3 Linear regressions analysis of caregiver burden (N = 168).

	Model 1		Model 2		Model 3	
	β	95% CI	β	95% CI	β	95% CI
Care recipients						
Age	-0.096	(-0.269, 0.076)			-0.088	(-0.287, 0.112)
Male	0.202	(-0.145, 0.549)			0.191	(-0.149, 0.531)
Positive emotion	-0.254	(-0.442, -0.067)			-0.227	(-0.412, -0.042)
Cognitive impairment	0.241	(-0.112, 0.593)			0.111	(-0.236, 0.457)
Multiple chronic diseases	0.427	(-0.025, 0.879)			0.513	(0.081, 0.945)
ADL disability*						
Moderate	0.226	(-0.177, 0.628)			0.233	(-0.157, 0.623)
Severe	0.247	(-0.122, 0.615)			0.245	(-0.114, 0.604)
Caregivers						
Age			-0.088	(-0.243, 0.067)	-0.083	(-0.267, 0.101)
Male			-0.317	(-0.652, 0.017)	-0.209	(-0.536, 0.119)
live with care recipient			0.198	(-0.182, 0.578)	0.174	(-0.196, 0.544)
Number of siblings			-0.117	(-0.277, 0.042)	-0.082	(-0.237, 0.074)
Willing to provide care			0.472	(-0.173, 1.117)	0.202	(-0.436, 0.839)
Days spent during the past 12 months			0.174	(0.003, 0.345)	0.225	(0.061, 0.389)

P values < 0.05 (statistical significance) are reported in bold; Standardized regression coefficients are reported.

^{*} The reference group was composed of the older adults with mild disability.

of caring for parents as rewarding, increasing positive feelings about caregiving and thus easing burden. ¹⁹ On the other hand, a qualitative study found that adult-child caregivers perceived greater caregiver burden when the filial culture was viewed as a social expectation and pressure rather than a personal value. ⁴⁵ Therefore, it is recommended that future research distinguish differences between external and internal dynamics of filial piety and their contribution to caregiver burden. Although we did not find a direct association between caregiver burden and filial piety, there was a positive correlation between filial culture and positive emotion in care recipients ($r_s = 0.211$, p = .020), indicating that filial culture may indirectly influence caregiver burden by improving parents' positive emotion.

The availability of high-quality data from the largest nationally representative cohort of the oldest-old in the world provided a unique opportunity to examine caregiver burden for caregivers of Chinese oldest-old. Another strength of the study is that we selected dyads of disabled parents and primary adult-child caregivers through matching and analyzed care recipients' disability, involving various ADLs, as well as adult-child caregiver burden, factors that most previous work investigations of parent-child dyads have not included simultaneously, so we present a fuller picture of the characteristics of these caregiving dyads.

However, there are several limitations in this study. First, since the FDS does not have updated data for subsequent years, we used data collected 15 years ago. China continues to undergo rapid social and economic changes that can be expected to affect caregiving. Second, we found the association between the mental health of care recipients and caregiver burden, and there is also evidence that poor mental health in informal caregivers in China is related to greater caregiver burden,⁴² but our study lacks measures widely used tool such as Center for Epidemiologic Studies Depression Scale (CESD) to assess depressive symptoms of caregiving dyads; future research could further evaluate the mental health of them. Another limitation is that the measure of caregivers' willingness to provide care was collected from care recipients, so it might be influenced by the mutuality between them. To obtain more accurate measures, future research should directly assess the willingness from caregivers. Besides, a significant association was found between multiple chronic diseases and caregiver burden, but the types of chronic diseases were not differentiated due to the small sample size in this study, so it is recommended to explore the different impacts of the type of chronic diseases on the burden.

Conclusions

Our study provided first-hand evidence on the characteristics of oldest-old disabled Chinese and their adult-children caregivers. Adult-child caregivers perceived heavier burden if the care recipient had low positive emotion, had multiple chronic diseases, and caregivers spent more time in caregiving, indicating that to improve the well-being of caregivers and their parents in fast-aging China, interventions may be applied to promote positive emotion of disabled older adults, prevent them from multiple chronic diseases, and support adult children that spent much time caregiving particularly.

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Declaration of Competing Interest

None.

Availability of data

All data used in this study was stored at http://opendata.pku.edu. cn and available upon request.

Appendix Bivariate association between care recipients' activities of daily life and caregiver burden

	Overall (N=168)	ZBI* (points) mean (SD)	t	P-value
Bathing n (%)			-0.32	.75
Fully independent	19 (11.3)	26.3 (16.9)		
Need assistance	149 (88.7)	25.1 (14.1)		
Dressing n (%)			2.78	.006
Fully independent	85 (50.6)	22.3 (14.1)		
Need assistance	83 (49.4)	28.3 (14.0)		
Toileting n (%)			3.64	< 0.001
Fully independent	85 (50.6)	21.4 (13.0)		
Need assistance	83 (49.4)	29.2 (14.6)		
Mobility n (%)			2.38	.018
Fully independent	93 (55.4)	22.9 (14.2)		
Need assistance	75 (44.6)	28.2 (14.1)		
Incontinence n (%)			0.22	.83
No	133 (79.2)	25.1 (14.5)		
Yes	35 (20.8)	25.7 (13.9)		
Eating n (%)			3.01	.003
Fully independent	112 (66.7)	23.0 (13.2)		
Need assistance	56 (33.3)	29.9 (15.6)		

P values < 0.05 (statistical significance) are reported in bold; SD, standard deviation. *ZBI, Zarit Caregiver burden Interview (0–88 points). Higher score indicates heavier caregiver burden.

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