


BMJ Open Correlations between caregiver competence, burden and health-related quality of life among Chinese family caregivers of elderly adults with disabilities: a cross-sectional study using structural equations analysis

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ABSTRACT

Objective To examine the relationship between caregiver competence and health-related quality of life (HRQoL) among family caregivers of disabled elderly adults, and to evaluate the role of caregiver burden as a potential mediator of that relationship.

Design Cross-sectional study.

Setting Two general hospitals in Shanghai, China.

Participants Study participants were 135 family caregivers of disabled elderly adults listed on a roster for outpatient and emergency services utilisation from January to March 2022.

Data analysis and outcome measures We used stratified linear regression and structural equation model analysis. HRQoL was the main outcome, measured using the Medical Outcomes Study 36-Item Short form Health Survey. Caregiver competence was assessed using the Family Caregiver Task Inventory, and caregiver burden was assessed with the Zarit Burden Interview.

Results Caregivers of moderately and severely disabled elderly adults showed poorer scores in Physical Component Summary ($F=20.463$, $p<0.05$) and Mental Component Summary ($F=17.062$, $p<0.05$) compared with caregivers of older adults with mild disabilities. At the same time, those caregivers showed higher scores on the caregiving burden ($F=19.533$, $p<0.05$) and caregiving difficulties ($F=16.079$, $p<0.05$). A structural equation model was performed and successfully adjusted ($\chi^2/df=1.175$, $p=0.261$, $NFI=0.970$, $RFI=0.949$, $IFI=0.995$, $CFI=0.995$, $GFI=0.963$, $TLI=0.992$, $AGFI=0.920$, $RMSEA=0.036$). The total effect of Family Caregiver Task Inventory scores on HRQoL scores was -0.980 , with a direct effect of -0.645 . The mediating effect on HRQoL scores through the intermediate variable of caregiver burden scores was -0.335 .

Conclusions Family caregivers' HRQoL is closely related to caregiver difficulties and burdens. Early identification and targeted measures are needed to reduce the burden and problems in caregiving.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The critical but underappreciated variable of caregiver burden, which may mediate in caregiver competence and health-related quality of life, was selected and quantified using an assessment tool for analysis according to its value.
- ⇒ A structural equation model was performed to evaluate the role of caregiver burden as a potential mediator of caregiver competence and health-related quality of life.
- ⇒ Due to the cross-sectional and observational nature of the study, causal inferences cannot be made; as such, the findings are presented as correlations.
- ⇒ This study findings were related to disabled elderly and their home caregivers using healthcare resources from two major hospitals in Shanghai; therefore, the results cannot be extrapolated to those who never use healthcare resources or to other regions of China outside of Shanghai.

INTRODUCTION

As the ageing of China's population continues to accelerate, the proportion of older adults also continues to increase.¹ Data from the Chinese Government show that there were 264million people aged over 60 years and 190million people aged over 65 years in 2020. Compared with 2010, the proportion of people aged over 60 years has increased by 5.44% and those aged over 65 years has risen by 4.63%.² It is now well established in numerous studies that China is facing the social and economic challenges of a growing elderly population.^{3 4}

A large and growing body of evidence has investigated that ageing in China has led to millions of functionally impaired older people requiring physical care.^{5 6} China is widely considered to have the most significant

number of partially and entirely functionally impaired older adults in the world.⁷ The number of disabled elderly people who have difficulties in activities of daily living (ADL) has increased from 10.23 million to 15.84 million from 2003 to 2016, among which the fastest rate of increase has been for those with mild disability, from 6.77 million in 2003 to 0.48 million in 2016.⁸ According to statistics from the China Disabled Persons' Federation in 2020, the total number of people with disabilities in China has reached 85 million, with more than 15 million still living below the national poverty line. China's Second National Sample Survey of Persons with Disabilities in 2006 found that more than one-third of people with disabilities developed disabilities after they were reaching old age over 65 years old.⁹ In terms of disability categories, more than half of people with visual and hearing disabilities, one-third of the those with physical disabilities and about 10% of people with other disability categories developed these disabilities at older ages.⁹ Increasing age,¹⁰ weakening body functions and multiple chronic diseases, such as hypertension, diabetes and cerebrovascular disease, are all contributing factors to disability in older adults.¹¹

In the context of traditional Chinese culture and medical resources, the home environment is the primary location for rehabilitating disabled elderly people. During 2011–2020, China's central government officially proclaimed a new elderly care infrastructure, with elderly home care as the foundation, community elderly care as support and state institutional care as a supplement.⁴ Most of China's older adults are living at home and in the community. Thus, the '9073' pattern of elderly care has been established, in which about 90% of elderly people live at home, 7% rely on community support and 3% live in professional institutions.¹² Therefore, the current focus of providing combined medical and elderly care services in China is still on the home.

The long-term care system in China relies heavily on informal family care. In contrast to Western value systems that are focused on independence, the cultural norms of social obligation, reciprocity, loyalty and duty in China explain the substantial levels of family caregiving.⁵ Family caregivers play a significant role in long-term home care for disabled elderly people, and these are primarily children, spouses and other family members. Caregiving tasks are carried out almost exclusively by family caregivers.¹³ These family caregivers are not paid for their care services and have low levels of education and training.¹⁴ However, family caregivers are progressively occupied with increasing demands and have less time to devote to their own needs, career planning and daily life. Caregivers commonly report a wide variety of physical and psychological symptoms of their own.¹⁵ Data from the Tianjin Municipal Government of China in 2017 showed that the average age among caregivers of disabled elderly adults had reached 59.47 years.¹⁶ Studies have shown that there are many problems regarding family members' caregiving behaviour, such as a lack of professional knowledge, lack

of caregiving skills and lack of social support resources, which may because family members are not professional caregivers.^{17 18} This situation not only seriously affects the physical rehabilitation and quality of life (QOL) of disabled elderly adults, but also affects the caregivers' physical and mental health (MH) status. It is difficult to care for a disabled elderly adult when the caregiver is facing a poorer QOL themselves. Hence, poorer QOL of caregivers can affect the QOL of older adults with disabilities. The saying, 'When a man is disabled, the whole family is out of balance' depicts the real picture of family care for the disabled elderly population in China. Therefore, it is important to focus on the health and QOL among family caregivers of disabled elderly adults, and to investigate the caregiving burden and ability of family caregivers. Also, it is significant to have sustainable pools of family caregivers to care for dependent family members, as future health systems have to match high demands for long-term care with family caregivers.

Caregiver competence and health-related QOL

The term health-related QOL (HRQoL) was first introduced in the literature on health status measurement as the value of 1 year in full health to explain the term 'quality-adjusted life years'. HRQoL implies 'a more direct linkage to health conditions, that is, to denote the HRQoL'.¹⁹ Measures of HRQoL describe health in broader terms (functioning and well-being) than clinical measures with a broad description of health.²⁰ Therefore, it is justified to classify typical HRQoL measures as measures of self-perceived health status.²¹ HRQoL is a widely used indicator to describe the combined psychological and physical condition among family caregivers of disabled elderly adults. Caregiver competence is essential for family members acting as caregivers. Previous studies show that competence affects the physical and MH of the person being cared for and their caregivers.^{22 23}

From the above discussion, we devised the following hypothesis:

Hypothesis 1: Caregiver competence is positively correlated with the HRQoL of family caregivers

Caregiver competence and burden

Early in 1986, Zarit *et al* proposed a helpful definition of care burden: 'The extent to which caregivers perceive that caregiving has hurt their emotional, social, financial, physical and spiritual functioning'.²⁴ Other studies have also considered the care burden as the overall impact of physical, psychological and social demands on caregivers' QOL, including persistent stress, hardship and negative experiences from providing care.²⁵ In general, predictors of caregiver burden concerning to caring for older people with disabilities can be divided into two categories: care receivers' variables, such as ADL and cognitive impairment; and caregivers' variables, including caregiver characteristics, health status, caring capacity and social support.²⁶ Disabled elderly people may have one

or more chronic illnesses, which can leave caregivers with a lack of ability to meet care needs. The complexities of disabled elderly care place higher demands on caregivers, making it more difficult for them to complete caregiving tasks such as implementing rehabilitation exercises. Disabled elderly adults may develop health problems due to caregivers' difficulties. In such cases, the caregiver may face complaints from other family members or the older adult being cared for, which may lead to greater negative feelings and caregiving burden.

Caregiver burden as a potential mediator between caregiver competence and HRQoL

Some caregivers may experience depressive symptoms when exposed to chronic stress and others may have worsening health.²² Previous research has established that sociocultural stress and coping models of caregiving confirm that caregiver burden mediates the effects of stress on caregiving outcomes, including psychological symptoms and physical symptoms.²⁷ Due to the growing list of caregiving tasks and increasing duration of caregiving, caregivers can become frustrated and stressed owing to the burden correlated with caregiving. Research shows that caregiver burden can be the most compelling problem affecting caregivers of chronically ill elderly patients.²⁶ Caregivers' health status and caregiving competence change dynamically with an increased number of caregiving days and may influence each other. The burden of care may reflect the caregiver's feelings during caregiving difficulties, and thus moderate their mental and physical health.

Hence, we hypothesised the following.

Hypothesis 2: Caregiver burden is negatively correlated with the HRQoL of family caregivers.

Hypothesis 3: Caregiver burden mediates the negative correlation between competence and HRQoL among family caregivers.

Figure 1 sets out our model diagrammatically, which assumes that caregiver competence is correlated with HRQoL and that caregiver burden mediates the effects of caregiver competence on HRQoL.

METHODS

Study design, setting and participants

This was a cross-sectional study. Participants in this study consisted of 135 caregivers of disabled elderly people

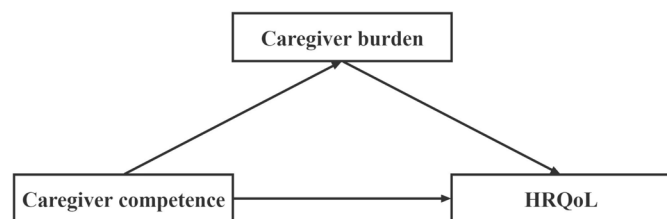


Figure 1 Theoretical model between caregiver competence, burden and HRQoL. HRQoL, health-related quality of life.

listed on a roster for utilisation of outpatient and emergency services from January to March 2022 from two tertiary general hospitals in Shanghai, China. The criteria for study inclusion were as follows: (1) disabled adults older than 60 years old,²⁸ who spent more than 95% of their time at home and less than 5% in a hospital or rehabilitation or care facilities in the previous 6 months; (2) disabled elderly adults with varying degrees of functional deficit due to age, disease or accidents, illness, or physical or mental impairment are all considered disabled unable to take care of themselves or to need to rely on others for care; (3) coresident family members (identified as family caregivers) who assisted with most daily care needs of a disabled elderly adults; (4) caregivers living in the same house with the older adult and caring for the older adult more than 60% of the total time of the older adult's disability and (5) both disabled elderly adults and their family caregivers being able to communicate normally and clearly. Disabled elderly people were classified into three major categories according to ADL criteria: mild disability, moderate disability and severe disability.

Measures

We administered basic information questionnaires including the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36),²⁹ Zarit Caregiver Burden Interview (ZBI)³⁰ and Family Caregiver Task Inventory (FCTI) to the family caregivers of disabled elderly adults. We interviewed caretakers who had cared for a disabled elderly adults for at least 20 hours per week within the past 3 months and who could give reliable information about the disabled older adult they had cared for.

Basic information registration

Demographic information of disabled elderly adults and their family caregivers was recorded by the investigator in face-to-face interviews. The registration form was designed by the research team and included three sections: (1) disabled elderly person duration of disability, cause of disability, Katz Index (KI), chronic disease prevalence and cost of treatment, (2) family caregiver relationship with the disabled elderly adults, occupational status, income and chronic disease prevalence, and (3) care-related content duration of care, perception of caregiving responsibilities, impact of caregiving on daily life, sources of caregiving stress and available assistance caregiving resources.

Disability severity

The KI was developed as a standardised quantitative measure for use in the evaluation, treatment, prognosis and functional change assessment of older people.³¹ The KI is the most appropriate scale to assess patients' ability to perform ADL independently.³² The KI evaluates the ability to perform six ADL.³³ Using a Likert scale,³³ scores on the items range from 0 to 3, where 0 reflects total independence; (1) indicates the need for non-human assistance; (2) indicates the need for human help; (3)

indicates total dependence. Item scores are summed, for a total score ranging from 0 to 18. Higher scores indicate higher levels of dependence in performing ADL.³⁴

Health-related quality of life

The SF-36 is a brief health survey questionnaire developed by the Institute of Health Research, New England Medical Center, Boston, USA. The Department of Social Medicine, School of Medicine, Zhejiang University translated the SF-36 into Chinese, and is widely used in the measurement of quality of survival in the general population, evaluation of the effectiveness of clinical trials and health policy assessment. The SF-36 contains eight dimensions, Physiological Functioning (PF), Role-Physical (RP), Bodily Pain (BP), General Health (GH), Vitality (VT), Social Functioning (SF), Role-Emotional (RE) and MH. The first four dimensions are used for physical health evaluation and the last four dimensions are for MH evaluation. Entry scores of each dimension are summed to obtain the raw score, which is then converted to standard scores according to the formula. The range of standard scores is 0–100. The higher the standard score, the better the health status.

Caregiver burden

The ZBI is a validated instrument for assessing the caregiving burden among caregivers of patients in home rehabilitation. The ZBI is a self-assessment scale with 22 entries divided into two dimensions: personal burden (PB) and burden of responsibility (RB). The total ZBI score (TB) is the sum of all entry scores and ranges from 0 to 88. A score of 0–20 indicates little or no burden; 21–40 mild to moderate burden; 41–60 moderate to severe burden and 61–88 severe burden. Higher scores imply a higher level of perceived burden.

Caregiver competence

The FCTI was translated into Chinese by Li Li-Tong of the Hong Kong Polytechnic University. The FCTI contains five dimensions: adapting to the caregiver role, responding to needs and providing assistance, dealing with personal emotions, assessing family and community resources, and adjusting life to meet care needs. There are 25 items in total, and each item is scored on three levels: no difficulty (0 point), difficulty (1 point) and extreme difficulty (2 points), with a total score ranging from 0 to 50 points. The scale measures the caregiver's perception of difficulty in performing caregiving tasks. The higher the score, the more difficult it is for the caregiver to perform caregiving and the lower the level of caregiving ability.

Data analysis

A total of 138 questionnaires were distributed and all were returned. Three questionnaires were incomplete with missing data. The final 135 completed questionnaires had a valid return rate of 97.83%. EpiData V.3.0 was used for data entry, and two researchers entered the data individually to ensure accuracy. IBM SPSS V.22.0 for Windows was used to perform basic descriptive

analyses. Descriptive statistics are shown as mean±SD for normally distributed variables and median (IQR) for variables with a non-normal distribution. Differences in SF-36, ZBI and FTCI scores among caregivers caring for elderly adults with three different levels of disability were analysed using a one-way analysis of variance. Stratified linear regression analysis was used to create the regression equations. Quantitative variables such as caregiving burden and ability were taken to their original values and brought into the equation. Basic information about the participants was placed in the first level of the regression equation, dimensions of caregiving burden were placed in the second level and dimensions of caregiving capacity were placed in the third level. A $p<0.05$ was accepted as statistically significant. The IBM AMOS V.23 program was used to analyse the relationships between the constructs involved in the structural model. We set the bootstrap self-sampling count to 5000 for validation. Once the theoretical model had been developed, a path analysis was performed based on the relationships of the matrix from a structural equation analysis.

Patient and public involvement

None.

RESULTS

Characteristics of caregivers and disabled elderly adults

The personal and demographic characteristics of older adults with disabilities and their primary caregivers in this study are shown in [table 1](#). A total of 135 disabled elderly adults were included in this study, 93 (68.89%) men and 42 (31.11%) women. According to the KI, the degree of disability among elderly people was classified as follows: 63 (46.67%) were mildly disabled, 42 (31.11%) were moderately disabled and 30 (22.22%) were severely disabled. The average score on the KI was 26.97 (SD=6.13). Those with mild, moderate and severe disabilities scored an average of 23.88 (SD=2.69), 32.04 (SD=1.45) and 38.76 (SD=4.41), respectively. No disabled elderly adults were involved in any position or employed within the past 6 months. There were 38 (28.15%) men and 97 (71.85%) women among family caregivers. As for the relationship of caregivers with disabled elderly adults, 78 (57.78%) were the spouse, 33 (24.44%) were children, 15 (11.11%) were nursing workers and 9 (6.67%) for others (eg, siblings).

Caregiver burden, caregiver competence and HRQoL

[Tables 2 and 3](#) present the results of scores for caregiver competence, caregiver burden and HRQoL stratified by different disability levels. The Kruskal-Wallis H test was used to compare the ages of elderly caregivers in the three groups with different disability levels. The results showed that the ages were comparable ($\chi^2=0.942$, $p=0.624$). When comparing paid caregivers with unpaid caregivers, there was no difference between the two groups in the scores on all dimensions of caregiving burden and

Table 1 Sociodemographic characteristics of the participants (N=135)

Characteristic	Mild disability (n=63)		Moderate disability (n=42)		Severe disability (n=30)	
	Elderly adult	Caregiver	Elderly adult	Caregiver	Elderly adult	Caregiver
Age (years, M (IQR))	73 (6)	65 (6)	74 (8)	63.5 (8)	75 (8)	62 (17)
Sex (n, %)						
Male	51 (80.95)	11 (17.46)	22 (52.38)	15 (23.81)	20 (66.67)	12 (40)
Female	12 (19.05)	52 (82.54)	20 (47.62)	27 (64.29)	10 (33.33)	18 (60)
Duration of disability (years), M (IQR)	2 (2)	—	2.5 (2.5)	—	3.5 (4.5)	—
Relationship (n, %)						
Spouse	—	36 (57.13)	—	24 (57.15)	—	18(60)
Child	—	15 (23.81)	—	12 (28.57)	—	6 (20)
Nursing worker	—	6 (9.53)	—	5 (11.91)	—	4 (13.33)
Other (siblings, etc)	—	6 (9.53)	—	1 (2.38)	—	2 (6.67)
Bone and joint diseases (n, %)	6 (9.52)	15 (23.81)	4 (9.52)	17 (40.48)	3 (10)	24(80)
Duration of care (years), n (%)						
<1	—	18 (28.57)	—	8 (19.05)	—	3 (10)
1–2	—	28 (44.44)	—	13 (30.95)	—	7 (23.33)
3–5	—	17 (26.99)	—	17 (40.48)	—	13 (43.33)
6–10	—	0 (0)	—	4 (9.52)	—	7 (23.33)
Daily time together (hours), n (%)						
<4	—	3 (4.76)	—	1 (2.38)	—	0 (0)
4–8	—	21 (33.33)	—	2 (4.76)	—	0 (0)
8–12	—	25 (39.69)	—	19 (45.24)	—	8 (26.67)
>12	—	14 (22.22)	—	20 (47.62)	—	22 (73.33)
Medical expenses (RMB/month), n (%)						
≤1000	25 (39.68)		12 (28.57)		7 (23.33)	
1001–3000	23 (36.51)		19 (44.07)		14 (46.67)	
>3000	15 (23.81)		11 (8.16)		9 (30)	
Average family income (RMB/month), n (%)						
≤2000	—	6 (9.52)	—	3 (7.14)	—	2 (6.67)
2001–5000	—	15 (23.81)	—	16 (38.09)	—	9 (30)
5001–8000	—	24 (38.10)	—	17 (40.48)	—	11 (36.67)
>8000	—	18 (28.57)	—	6 (14.29)	—	8 (26.67)

caregiving ability, and the difference was not statistically significant ($p < 0.05$). The data analysis results are shown in online supplemental table 1. Subgroup analyses have been conducted according to the gender of the caregiver under different disability groups. The data analysis results are shown in online supplemental table 2. Gender distinction did not significantly affect the caregiving burden and capacity in each disability-level group. The scores on the eight dimensions of the SF-36 for caregivers with the general norms are reported in table 2. The caregivers of disabled elderly adults had significantly lower scores in all eight SF-36 domains ($p < 0.001$) than the Chinese national norms, which were calculated among 17 754 participants randomly selected from six cities in China.³⁵ In the SF 36, PF, RP, BP and GH dimensions are categorised as the Physical Component Summary (PCS). VT, SF, RE and MH are categorised as the Mental Component Summary

(MCS).³⁶ Caregivers of moderately and severely disabled elderly adults showed poorer scores in almost all SF-36 dimensions (except BP) compared with caregivers of older adults who had mild disabilities ($p < 0.05$), and they had higher scores for caregiving burden and caregiving difficulties measures ($p < 0.05$). These results indicate that caregivers of older people with higher levels of disability face more caregiving difficulties, higher caregiving burdens and poorer HRQoL.

Effects of caregiver competence and burden on HRQoL for caregivers

Stratified linear regression analysis was conducted to examine the correlation and effect size of caregiver competence, burden to HRQoL. In this study, the dependent variable HRQoL was a continuous variable with a linear relationship between all 12 independent variables.

Table 2 Scores on dimensions of the SF-36 for family caregivers of elderly adults with different disability levels ($\bar{x} \pm s$)

Items	Caregiver of elderly adults with			General population	F value	P value
	Mild disability	Moderate disability	Severe disability			
SF-36						
PF	83.73±14.37	70.83±23.40	63.50±20.18	87.92±16.98	13.314	***
RP	74.47±23.03	68.45±24.73	33.46±30.43	77.50±34.86	27.768	***
BP	75.83±16.33	74.19±17.61	70.27±11.85	82.22±16.98	1.246	0.291
GH	49.43±17.16	41.48±25.67	36.3±21.86	62.51±17.88	4.356	*
VT	59.21±16.78	51.31±18.68	41.33±19.82	68.17±17.63	10.134	***
SF	70.83±20.45	65.77±20.85	44.17±19.07	80.67±19.98	17.998	***
RE	74.60±21.37	68.15±28.47	56.67±23.41	67.86±39.44	5.579	*
MH	65.59±15.13	58.11±15.79	54.93±12.47	68.47±16.90	6.348	*
PCS	70.85±12.55	63.73±15.83	50.88±14.60	–	20.463	***
MCS	67.55±15.07	60.83±14.90	49.28±10.47	–	17.062	***

*Correlation is significant at the 0.05 level (two tailed). ***Correlation is significant at the 0.001 level (two tailed).

BP, bodily pain; GH, general health; MCS, Mental Component Summary; MH, mental health; PCS, Physical Component Summary; RE, role-emotional; RP, role physical; SF-36, 36-item Short-Form Health Survey; SF, social functioning; VT, vitality.

All variables had relatively independent observations, and no multicollinearity or significant outliers existed. The dependent variable for models 1–3 was PCS, and the dependent variable for models 4–6 was MCS (table 4).

Model 1 included PCS and characteristics of disabled people and caregivers. Based on the model 1 variables, PB and responsibility burden were added to model 2. In this study, model 2 differed from model 1 only in the care burden variable, suggesting that the inclusion of PB and RB in the regression increased the explanatory power of the independent variables for the PCS variance

by 6.9%. Based on model 2, caregiving capacity-related variables were added to model 3. Model 3 showed a 14.4% increase in the explanatory power of the independent variables for the variance in PCS after including the five dimensions of caregiving capacity variables in the regression.

In the same way, model 4 included MCS and characteristics of disabled people and caregivers. Model 5 added the caregiving burden variable and model 6 included the caregiving capacity variable. The explanatory power of the independent variables for MCS variation increased

Table 3 Scores on dimensions of ZBI and FCTI for family caregivers of elderly adults with different disability levels ($\bar{x} \pm s$)

Items	Caregivers of elderly adults with			F value	P value
	Mild disability	Moderate disability	Severe disability		
ZBI					
PB	21.27±5.386	23.57±4.855	26.57±3.559	12.241	***
RB	10.87±3.220	12.10±2.739	13.40±1.812	8.524	***
TB	37.75±3.689	41.43±4.949	42.90±3.595	19.533	***
FCTI					
X1	3.48±1.865	3.81±2.178	4.80±1.883	4.590	*
X2	2.35±1.667	2.88±1.851	3.67±1.213	6.634	*
X3	2.76±1.521	3.38±1.481	4.30±1.264	11.477	***
X4	2.49±1.722	3.05±2.095	4.47±1.937	11.151	***
X5	3.95±1.971	4.95±2.083	6.43±1.942	15.765	***
Total	15.03±7.166	18.07±7.614	23.67±7.602	16.079	***

X1: Adapt to care roles; X2: respond and provide assistance;

X3: Deal with personal emotional needs; X4: evaluate family and community resources.

X5: Adjusting life to meet care needs.

*Correlation significant at the 0.05 level (two tailed). ***Correlation significant at the 0.001 level (two tailed).

FCTI, Family Caregiver Task Inventory; PB, personal burden; RB, responsibility burden; TB, Total ZBI score; ZBI, Zarit Caregiver Burden Interview.

Table 4 Regression coefficients of caregiver competence, burden to HRQoL in family caregivers

Variables	Model 1‡		Model 2‡		Model 3‡		Model 4§		Model 5§		Model 6§	
	β	SE	β	SE	β	SE	β	SE	β	SE	β	SE
Constant	437.03†	72.80	473.20†	68.79	401.45†	58.85	397.57†	80.99	500.78†	58.81	422.20†	47.42
DEA	-0.29	0.82	0.53	0.79	0.36	0.67	-1.663	0.91	0.12	0.67	0.21	0.54
FCA	-1.68†	0.54	-1.76†	0.50	-1.25†	0.44	0.172	0.60	-0.13	0.43	0.21	0.35
REL	14.54†	4.64	10.79*	4.47	14.73†	3.75	10.54*	5.16	0.16	3.82	4.56	3.02
DD	-5.64*	2.51	-5.391*	2.35	-3.352	1.98	-3.76	2.80	-2.38	2.01	-1.28	1.60
DED	-38.99†	5.78	-29.84†	9.13	-22.94†	5.08	-34.68†	6.43	-13.49†	4.99	-14.69*	6.26
PB			-0.90	1.01	2.58†	0.94			-6.56†	0.86	-3.24†	0.76
RB			-5.56†	1.64	-2.92*	1.45			-4.15†	1.40	-1.72	1.17
X1					-5.07*	2.44					-3.46	1.97
X2					-4.82	2.53					-1.140	2.04
X3					-5.17	2.82					-3.816	2.28
X4					-9.79†	2.67					-4.91*	2.15
X5					-6.00†	2.15					-8.25†	1.73
R2	0.519		0.589		0.733		0.384		0.689		0.821	
Adj R2	0.493		0.559		0.702		0.350		0.666		0.800	
ΔR2	-		0.069		0.144		-		0.305		0.132	
ΔF	19.60†		10.56†		12.98†		11.303†		61.233†		17.627†	

*Correlation is significant at the 0.05 level (two-tailed).
 †Correlation is significant at the 0.01 level (two-tailed).
 ‡Dependent variable = Physical Component Summary.
 §Dependent variable = Mental Component Summary.

DD, duration of disability; DEA, disabled elderly adults; DED, degree of disability; FCA, age of family caregivers; HRQoL, health-related quality of life; PB, personal burden; RB, responsibility burden; REL, relationship of disabled elderly adults and family caregivers; X1, adapt to care roles; X2, respond and provide assistance; X3, deal with personal emotional needs; X4, evaluate family and community resources; X5, adjusting life to meet care needs.

by 30.5% after including PB and RB and by 13.2% after including the five dimensions of caregiving capacity.

Mediation role of caregiver burden between competence and HRQoL

Through a review of the literature and using the above statistical results, structural equation modelling was used to construct a pathway analysis of the interaction between caregiving capacity, caregiving burden and HRQoL among caregivers of disabled elderly adults. We hypothesised that there are two pathways: one is that the caregiving capacity of family caregivers of disabled elderly adults directly affects HRQoL, and the other is that caregiving capacity affects HRQoL by affecting the caregiving burden. The hypothesised pathways are shown in figure 1 and the final model is presented in figure 2. The regression weights for each variable are shown in table 5. The above model was further tested using the bootstrap bias-corrected self-help method; the results are shown in table 6.

The initial model was tested using the maximum likelihood method, and the model fit parameters were as follows: $\chi^2/df=1.175$, $p=0.261$, normed fit index (NFI) =0.970, relative fit index (RFI) =0.949, incremental fit index (IFI) =0.995, comparative fit index (CFI) =0.995,

goodness-of-fit index (GFI) =0.963, tucker-lewis index (TLI) =0.992, adjusted goodness-of-fit index (AGFI) =0.920, and root-mean-square error of approximation (RMSEA) =0.036. The model fit was good. The total effect of FCTI scores on HRQoL scores was -0.980, with a direct effect of -0.645. The mediating effect on HRQoL scores

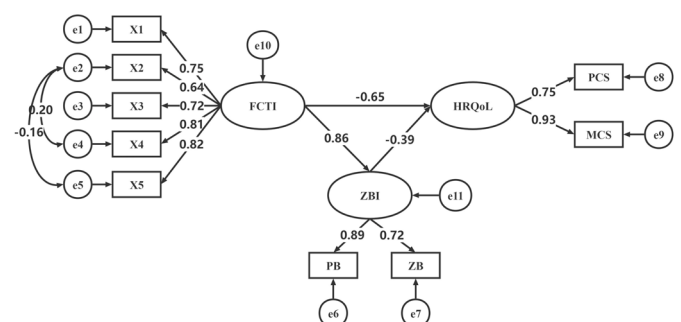


Figure 2 Mediating effects of caregiver burden on the relation between caregiver competence and HRQoL. PB: RB: HRQoL, health-related quality of life; MCS, Mental Component Summary; PB, personal burden; PCS, Physical Component Summary; RB, responsibility burden; X1, adapt to care roles; X2, respond and provide assistance; X3, deal with personal emotional needs; X4, evaluate family and community resources; X5, adjusting life to meet care needs.

**Table 5** Direct effects of variables

Items	Estimate	SE	T value	P value	St Estimate
ZBI<---FCTI	1.008	0.131	7.696	***	0.86
HRQoL<---FCTI	-17.209	3.904	-4.408	***	-0.65
HRQoL<---ZBI	-8.856	3.217	-2.753	*	-0.39
X5<--- FCTI	1.000				0.82
X4<--- FCTI	0.837	0.077	10.872	***	0.81
X3<--- FCTI	0.623	0.067	9.272	***	0.72
X2<--- FCTI	0.606	0.082	7.421	***	0.64
X1<--- FCTI	0.840	0.086	9.792	***	0.75
PCS<--- HRQoL	1.000				0.75
MCS<--- HRQoL	1.210	0.105	11.509	***	0.93
RB<---ZBI	1.000				0.72
PB<---ZBI	2.171	0.232	9.260	***	0.89

*Correlation significant at the 0.05 level (two tailed). ***Correlation significant at the 0.001 level (two tailed).

FCTI, Family Caregiver Task Inventory; HRQoL, health-related quality of life; MCS, Mental Component Summary; PB, personal burden; PCS, Physical Component Summary; RB, responsibility burden; St estimate, standardised estimate; X1, adapt to care roles; X2, respond and provide assistance; X3, deal with personal emotional; X4, evaluate family and community resources; X5, adjusting life to meet care needs; ZBI, scores on ZBI.

through the intermediate variable of caregiver burden scores was -0.335 , accounting for 34.18% of the total effect. There was a negative correlation between FCTI scores and HRQoL scores. High FCTI scores represent poor caregiving ability of caregivers. Therefore, caregiver competence is positively correlated with HRQoL, and the structural equation results are consistent with the hypothesis of this study. The direct effect of the mediating variable caregiver burden on HRQoL, the 95% CI of bootstrap for the indirect effect and the 95% CI of bias correction did not include 0. This suggests that caregiver burden partially mediates the impact between caregiver competence and HRQoL and the difference was statistically significant ($p < 0.05$).

DISCUSSION

To deepen understanding regarding the unique role of Chinese family members as caregivers of older family members with disabilities, we analysed the correlation between caregiver competence and HRQoL among caregivers in China and determined whether the caregiver burden mediated this correlation.

The results of this study indicated that family caregivers of disabled older adults face the challenges of older age and poor health. The average age of family caregivers was 62.69 years. There were 99 caregivers aged over 60 years, accounting for about 73.33%. In this survey, most older adults with disabilities received unpaid care from family members such as spouses, children or other relatives, and only 11.11% paid to hire caregivers to provide care. This situation arises mainly owing to the influence of the traditional Chinese cultural model of family caregiving. Among caregivers in our study, there was a female predominance, with 72% women. In many studies on caregivers, the number of female caregivers accounted for more than 65%,^{37 38} and 73% of the caregivers were women in Macchi's study.³⁹ Similar to other studies, most female caregivers were spouses.^{40 41} When a family member takes on the role of a caregiver of a disabled elderly adult, the focus of their life gradually shifts towards the disabled person and how best to provide care.

Some chronic diseases such as bone and joint disorders can be explained from the point of long-term care. Older adults with disabilities especially severe disabilities

Table 6 Total, direct and mediated effects of HRQoL

Items	β	SE (95% CI)	P value	Variance (%)
Total effect	-0.980	0.016 (-0.999 to 0.940)	**	—
Direct effect	-0.645	0.125 (-0.937 to 0.418)	**	65.82
Indirect effect	-0.335	0.112 (-0.543 to 0.080)	*	34.18

*Correlation significant at the 0.05 level (two- tailed). **Correlation significant at the 0.01 level (two- tailed).

HRQoL, health-related quality of life; Variance, variance explained in the model.

must be assisted by their caregivers or are totally dependent on them for daily activities. As most disabled elderly adults in China live in housing without an elevator and must walk up and down stairs, caregivers must often carry them, which can be very challenging for some caregivers, such as women and elderly caregivers. Heavy caregiving activities seriously impact the caregiver's physical health, and the frequent lifting and moving of patients make the caregiver susceptible to bone and joint diseases and reduced physical function. On the other hand, the occurrence of most chronic diseases in caregivers, such as hypertension and diabetes, is complex and influenced by multiple factors that cannot be explained from a long-term care perspective alone. In addition, some caregivers in this study had more than one chronic disease, which involves long-term limitations on physical or MH and are a substantial cause of a decline in physical functioning, reduced QOL, disability and increased risk of death. We should subsequently investigate the relationship between the development of chronic diseases and caregivers' long-term care process.

HRQoL among all caregivers in this study was impaired to varying degrees, relative to the national norms of the Chinese population,³⁵ Hong Kong⁴² and the USA.⁴³ Compared with the Chinese norms, GH and SF were the two areas with the sharpest decrease. Decreased GH indicates that caregivers feel more negatively about their health and its development, implying that caregivers may have declining health status. Decreased SF indicates that caregivers have poorer engagement in social activities due to physical or psychological problems, which may result from many homecare tasks.

Inclusion of the variables caregiver burden and caregiver competence in the regression analysis increased the explanatory power of the variance in PCS by 6.9% and 14.4% ($p < 0.01$), and the explanatory power of the variance in MCS increased by 30.5% and 13.2% ($p < 0.01$). These three variables are closely related to each other. Caregiver burden was negatively correlated with PCS and MCS, which supports the finding of studies such as those of Spatuzzi⁴⁴ and Ribé *et al*⁴⁵ showing that higher levels of caregiver burden are correlated with lower QOL levels. Caregiver burden is an independent predictor of caregiver life quality.⁴⁶ Lower FTCI scores represent fewer caregiver difficulties and greater caregiver competence. The caregiver competence among family caregivers of disabled elderly adults positively predicts their QOL. In addition, the operational definition of caregiver competence in this study covers caring for the patient, self-regulation and accessing supportive resources. Higher competence levels suggest that caregivers can balance their personal life and caring role, and therefore, have less perceived burden regarding physical, mental, financial and social aspects.

Caregiver burden showed a mediating effect on the relationship between caregiver competence and HRQoL. Family caregivers are the mainstay of current elderly care in China⁴, and their caregiving capacity directly affects the

quality of family care. Previous research has established that the first step in improving the quality of family care is to assess factors that affect the QOL of family caregivers.⁴⁷

The lack of caregiver competence affects the quality of care because family caregivers lack basic knowledge and relevant skills in caregiving. The standard of care does not meet the needs of disabled older adults, whose satisfaction levels are generally low.⁴⁸ Some surveys have shown that caregiving is provided haphazardly, possibly because caregivers have little knowledge of predisposing factors, basic augmentation skills, complication prevention and rehabilitation in elderly adults.⁴⁹

Additionally, caring competence can have an impact on the caregivers themselves. Many caregivers neglect their health while they care for family members. As such, heavy caring work and stress can lead to a weakened immune system and vulnerability to digestive and cardiovascular diseases. Surveys have shown that caregivers' prevalence of depressive symptoms is 37.7%.⁵ The considerable time and effort involved in caring for elderly adults inevitably affect caregivers' income, and the high medical costs of older adults add to the financial burden on caregivers. In addition, the busy daily caregiving routine limits caregivers' social activities. Several lines of evidence suggest that good caregiving skills improve caregiver productivity and quality of care and contribute to the caregiver's own health and stress relief.⁵⁰ The burden of caregiving as a stressor can affect the physical and MH of family caregivers of the disabled elderly adults. Research has shown that mild stress stimulates the body to be in a state of tension, increasing the individual's ability to cope and reduce stress levels. When excessive external stress is excessive and prolonged beyond psychological limits, it can lead to problems such as bodily imbalances that affect MH and QOL.⁵¹

Since 2020, the number of pilot cities covered by long-term care insurance (LTCI) in China has increased to 49. LTCI is a system that focuses on providing care coverage and financial compensation for insured older individuals in the event of loss of daily living capacity, illness or death. However, LTCI has its limitations, focusing only on elderly people with disabilities; gaps remain for their caregivers. Therefore, proactive and individualised interventions for family caregivers of disabled elderly adults should be implemented to assess whether these can reduce the caregiving burden arising from providing long-term care and improve caregivers' HRQoL.

There are some limitations to this study. Due to the cross-sectional and observational nature of the study, causal inferences cannot be made; hence, the findings are presented as correlations and regressions. This study findings were derived from disabled elderly adults and their home caregivers using healthcare resources from two major hospitals in Shanghai. They, thus, cannot be extrapolated to those who never use healthcare resources or to other regions of China outside of Shanghai. The findings may, therefore, be transferable to different similar settings or conditions but are not generalisable to the population

in the positivist sense. Further research among caregivers who are taking care of disabled elderly people who are never use healthcare resources is warranted.

CONCLUSION

HRQoL among caregivers of disabled elderly adults was relatively poor. An essential reason for the low life quality of family caregivers may be extensive and demanding caregiving tasks. Family caregivers' HRQoL of life is closely related to caregiver difficulties and burdens. Early identification and targeted measures are needed to reduce the care problems in the caregiving process. Reducing caregiving burden and increasing caregiving capacity may be an effective way to improve caregivers' HRQoL. Community hospitals and other family members should provide support and assistance to help primary caregivers improve their caregiving capacity and reduce the stress of caregiving. There is an urgent need to implement of effective and accessible family caregiver support programmes for disabled elderly adults.

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