

Factors associated with health-related quality of life among family caregivers of disabled older adults: a cross-sectional study from Beijing

Juan Du, PhD^{a,*}, Shuang Shao, PhD^a, Guang-Hui Jin, MS^a, Chen-Guang Qian, MS^b, Wei Xu, MS^c, Xiao-Qin Lu, MS^a

Abstract

Because of the aging population and the shortage of standardized institutional solutions for long-term care (LTC) in China, family caregivers in Beijing are increasingly called upon to provide home care for disabled older adults. Caregivers face a heavy care burden, and decreased physical and mental health (MH). This study aims to describe health-related quality of life (HRQoL) and to identify its predictors for Chinese family caregivers of disabled older adults.

A total of 766 caregivers were recruited from 5 communities in the Dongcheng District of Beijing. Measures included the 36-item Short-Form Health Survey (SF-36), the Zarit Caregiver Burden Interview (ZBI) scales, and the Chinese Social Support Rating Scale (SSRS). Hierarchical multiple regression (HMR) analysis was used to identify the predictors.

HMR analysis showed that each block of independent variables (demographic characteristics of disabled older adults, demographic characteristics of caregivers, caregiving context, and subjective caregiver burden) had contributed significantly to caregivers' physical and mental quality of life. Subjective caregiver burden explained the greatest amount of total variance in all MH subscales and the 2nd greatest amount of variance in most physical subscales. Therefore, subjective caregiver burden was the strongest predictor of HRQoL.

Our findings suggest that a decrease in caregiver burden can improve caregivers' HRQoL, and additional social support is important in decreasing the impact of caregiving on HRQoL. Importantly, an LTC system should be established in China as soon as possible.

Abbreviations: BP = bodily pain, GH = general health, HMR = hierarchical multiple regression, HRQoL = health-related quality of life, LTC = long-term care, MCS = mental component scores, MH = mental health, PCS = physical component scores, PF = physical functioning, QOL = quality-of-life, RE = role limitations-emotional, RP = role limitations-physical, SF = social functioning, SF-36 = 36-item Short-Form Health Survey, SSRS = Chinese Social Support Rating Scale, VT = vitality, ZBI = Zarit Caregiver Burden Interview.

Keywords: Beijing, disabled older adult, HRQoL, social support, subjective caregiver burden

1. Introduction

The older population is growing rapidly in China. At the end of 2016, 230 million people, or 16.7% of the population, were aged 60 years or older, and the proportion is estimated to increase to

25% by 2050.^[1] Along with this increase, there is a growing number of older individuals within the community who are functionally or cognitively disabled. A national survey showed that approximately 33 million Chinese over the age of 60 years could not take care of themselves, and almost one-third of them were entirely dependent on others for assistance.^[2] In China, family members tend to view caring for disabled older adults as their obligation. This is influenced by the Chinese cultural tradition of filial piety, combined with the shortage of institutionalized long-term care (LTC). However, there are not enough resources – such as home care services – to support these families. In most Western countries, LTC services can be provided at home, in the communities or institutional settings. During 1980s and 1990s, the LTC funding schemes based on general taxation or social insurance were set up and covered institutional care and home health care. Meanwhile, public and private programmes provided a number of supports (eg, information and training, respite care, tax benefits, and payments) for family caregivers.^[3] Most studies conducted in Western populations have shown that increased caregiving burden was related to decreased mental and physical health and premature mortality among the family caregivers.^[4–7]

In recent years, the impact of caregiving on health-related quality of life (HRQoL) among family caregivers of disabled older adults has also been reported in Asian areas such as Japan and Taiwan.^[8,9] However, data on HRQoL in Beijing or

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^a School of General Practice and Continuing Education, Capital Medical University, ^b Andelu Community Health Service Station, ^c Hepingli Community Health Service Station, Dongcheng District, Beijing, China.

* Correspondence: Juan Du, School of General Practice and Continuing Education, Capital Medical University, No. 10, You An Men Wai Xi Tou Tiao, Beijing 100069, China (e-mail: cuckoo@ccmu.edu.cn).

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mainland China are limited. Thus, this population-based study had 2 objectives: to investigate HRQoL among Chinese caregivers of disabled older adults in Beijing; and to explore the predictors of caregivers' HRQoL.

2. Methods

2.1. Ethics

This study was approved by the Medical Ethics Committee of Capital Medical University, Beijing, China. Written informed consent was obtained from each participant involved in this study. All participants' information was kept confidential and tracked anonymously with identification number only.

2.2. Study design and sample

We conducted a cross-sectional community-based study of caregivers in the Dongcheng District in Beijing during May and June 2013. There are 205 communities with similar aging levels in Dongcheng District. We plan to direct an intervention with family caregivers in 5 of those communities in the future, so we selected our convenience sample of 800 primary family caregivers of disabled older adults from those same communities in Beijing. Family doctors and community nurses in these 5 communities were invited as investigators and were trained by researchers from this study.

We recruited disabled older adults aged 60 years or older, who had experienced at least 1 difficulty out of the 6 activities of daily living (bathing, dressing, feeding, indoor transferring, incontinence, and going to the toilet) for at least 6 months. Additionally, the disabled older adults were family members, relatives, or friends needing help from a caregiver residing in the same household or a different household. The criteria for family caregivers included the following: aged 18 years or older; a primary caregiver who had provided a minimum of 2 hours of daily care for at least the past 6 months for disabled older adults. Family physicians from the community health service centers who participated in the project used electronic health records to identify the individuals who fulfilled the inclusion criteria, then explained the study to them and their primary family caregivers. After attaining the written informed consent from each participant, we interviewed family caregivers face to face in the home of the disabled older adults.

A total of 800 caregivers were identified; 21 declined to participate. The response rate was 97.4%. Thirteen caregivers did not complete the interview and were excluded from the study. Thus, 766 caregivers were included in the final analysis. The valid response rate was 95.8%. The characteristics (sex, race, and caregiving context) of the 766 caregivers were similar to those of the 13 excluded caregivers.

2.3. Measures

Based on both conceptual models and empirical evidence regarding factors associated with caregiver HRQoL, potential predictors included: care recipients' characteristics, caregivers' sociodemographics, caregivers' psychosocial resources, and caregivers' perceptions of caregiving burden.^[5,10–12] Therefore, we adopted a closed-ended questionnaire to investigate the sociodemographic characteristics of: the caregivers and their care recipients; the caregiving context (eg, objective caregiving loads and social supports); the subjective caregiving burden; and the HRQoL of caregivers.

2.3.1. Sociodemographic characteristics of caregivers. This part of the questionnaire included questions addressing age, sex, education, marital status, current employment, household income, living situation, and relationship to the disabled older adult. We also asked family caregivers what was the status of any chronic diseases they had. Common chronic diseases that had been diagnosed (eg, hypertension, cardiovascular disease, diabetes, and stroke) were defined as "chronic disease" in this study.

2.3.2. Sociodemographic characteristics of care recipients. We obtained information about care recipients' age, sex, education, marital status, and number of chronic diseases from their caregivers. Functional status was measured by the number of activities of daily living limitations (ranging from 1 to 6), with higher scores reflecting higher levels of dependency. We also inquired of caregivers whether their care recipients had dementia. Dementia included Alzheimer disease, as well as other forms of dementia.

2.3.3. Caregiving context. This section of the questionnaire included information regarding family caregivers' objective caregiving loads and levels of social support. Objective caregiving loads were measured using parameters such as time per day spent providing care and overall duration of caregiving.

We used the Chinese Social Support Rating Scale (SSRS) to evaluate individual social support level.^[13] It has 10 items, which measure 3 subscales of social support: 3 items on objective support, 4 items on subjective support, and 3 items on social support availability. The total score (12–66) was dichotomized into "high-level social support" (>33) and "low-level social support" (≤33).^[13]

2.3.4. Subjective caregiver burden. The Zarit Caregiver Burden Interview (ZBI) was performed to estimate a caregiver's subjective burden.^[14] The ZBI encompasses 22 items, each of which has 5 responses ranging from 0 (never) to 4 (nearly always). The total score was between 0 and 88. Scores between 61 and 88 indicated the burden was severe; scores between 41 and 60 indicated a moderate to severe burden; scores between 21 and 40 indicated a mild to moderate burden; and scores below 21 indicated little or no burden.^[15] Previous studies have suggested that the Chinese version of ZBI has stronger reliability and validity.^[16]

2.3.5. Caregivers' quality of life. The 36-item Short-Form Health Survey (SF-36),^[17] which is the most commonly used HRQoL measure worldwide, was used to evaluate caregivers' HRQoL. A Chinese (China mainland) version of the SF-36 has been developed elsewhere, and normative values of the SF-36 for Chinese adults have been established.^[18] The SF-36 consists of 36 items, one of which measures health transition. The remaining 35 items cover 8 quality-of-life (QOL) dimensions: physical functioning (PF) (10 items), mental health (MH) (5), general health (GH) (5), role limitations-physical (RP) (4), vitality (VT) (4), role limitations-emotional (RE) (3), bodily pain (BP) (2), and social functioning (SF) (2). Four health profiles (PF, RP, BP, and GH) cover physical component scores (PCS), while the other 4 profiles (VT, SF, RE, and MH) cover mental component scores (MCS). Scores for all scales are expressed on a scale of 0 to 100, with higher scores indicating better QOL.

2.4. Statistical analysis

First, the variance component model was used to verify whether the data had a hierarchical structure resulting from sample

selecting based on the community. Wald test was performed to examine the residual variance of community level of 10 dependent variables (PF, RP, BP, GH, PCS, VT, SF, RE, MH, and MCS) in the null model. The result showed the variations of these 10 dependent variables had no aggregation at the community level. Second, hierarchical multiple regression (HMR) analysis was used to assess the impact of different sets of independent variables on the 8 QOL subscales. In the 1st step, characteristics of the disabled older adults were entered; in the 2nd step, demographic characteristics of the caregivers were entered; and in the 3rd and 4th step, caregiving context and subjective caregiver burden were added successively to the predictive model. Each variable was considered to be independent of the others. The change in predictability associated with variables entered in later steps over and above that contributed by variables entered earlier is the focus of HMR analysis. Change in R^2 (ΔR^2) statistics are computed by entering predictor variables into the analysis in successive steps. Thus, in HMR analysis, ΔR^2 and ensuing changes in F (ΔF) and P values are the most significant statistics.^[19] Statistical analysis was performed using SAS, version 8.01 (SAS Institute Inc., Cary, NC). A 2-tailed probability value of <.05 indicates statistical significance.

Table 1
Demographic characteristics of caregivers (n=766).

Variables	N	%
Gender		
Male	284	37.1
Female	482	62.9
Age, y old		
≤40	24	3.1
41–59	370	48.3
≥60	372	48.6
Marital status		
Married	704	91.9
Others	64	8.1
Educational level		
<Senior middle school	271	35.4
≥Senior middle school	495	64.6
Monthly household income of caregivers, yuan		
<2000	28	3.7
2000–3999	262	34.2
4000–5999	279	36.4
≥6000	197	25.7
Number of chronic diseases		
0	22	2.9
1	430	56.1
2	159	20.8
≥3	155	20.2
Relationship to the patient		
Spouse	245	32.0
Children	486	63.4
Others	35	4.6
Currently employed		
No	576	75.2
Yes	189	24.7
Missing	1	0.1
Religion		
Yes	23	3.0
No	739	96.5
Missing	4	0.5
Living with older adults		
Yes	586	76.5
No	180	23.5

3. Results

3.1. Sample characteristics

Caregivers' average age was 60.5 ± 11.7 years, ranging from 26 to 89 years. The other basic characteristics of the participants are described in Table 1. Table 2 shows the characteristics of the disabled older adults. The average age of the disabled older adult was 80.9 ± 7.8 years, ranging from 60 to 99 years. The top 5 categories of chronic disease in the disabled older participants were: hypertension (72.7%; 557 participants out of 766); stroke (49.7%; 381/766); coronary heart disease (47.9%; 367/766); diabetes (41.0%; 314/766); and osteoarthritis (30.7%; 235/766).

3.2. Description of the caregivers' caregiving context, subjective caregiver burden, and HRQoL

The median number of years of care provided for the disabled older adult was 5, ranging from 1 to 35. The median number of

Table 2
Demographic characteristics of disabled older adults (n=766).

Variables	N	%
Gender		
Male	335	43.7
Female	431	56.3
Age, y old		
60–69	77	10.1
70–79	223	29.1
≥80	466	60.8
Marital status		
Married	416	54.3
Others	350	45.7
Educational level		
<Junior middle school	378	49.3
≥Junior middle school	388	50.7
Personal out-of-pocket payment per month, yuan		
<100	129	16.8
100–299	237	30.9
300–499	197	25.7
≥500	201	26.3
Missing	2	0.3
Insurance coverage		
Basic medical insurance of urban employees	595	77.7
Basic medical insurance of urban residents	77	10.1
Publicly funded free medical care	70	9.1
New rural cooperative medical scheme	16	2.1
No medical insurance	7	0.9
Missing	1	0.1
Number of chronic diseases		
1	102	13.3
2	160	20.9
3	214	27.9
≥4	290	37.9
ADL limitations		
6	592	77.3
5	130	17.0
4	36	4.7
3	5	0.7
2	2	0.2
1	1	0.1
Dementia*		
Yes	113	14.8
No	653	85.2

ADL=activity of daily living.

* Includes Alzheimer disease and other forms of diagnosed dementia.

Table 3
Caregivers' caregiving context and subjective caregiver burden (n = 766).

Variables	n	%
Care duration, y		
<5	298	38.9
≥5	468	61.1
Time spent in caregiving everyday, h		
<8	222	29.0
≥8	544	71.0
SSRS score		
≤33	456	59.5
>33	310	40.5
ZBI score		
<21	89	11.6
21–40	289	37.7
41–60	326	42.6
61–88	62	8.1

SSRS=Chinese Social Support Rating Scale, ZBI=Zarit Caregiver Burden Interview.

caregiving hours per day for the disabled older adult was 12, ranging from 1 to 24. The mean SSRS score was 31.3 (SD 6.9), indicating that caregivers experienced low levels of social support. The score of 3 dimensions of the SSRS scale was 17.2±4.6 (subjective social support), 7.4±2.2 (objective social support), and 6.7±1.9 (social support availability). The mean ZBI score was 39.9 (SD 15.3), indicating that caregivers experienced a moderate amount of burden. Table 3 shows the other description of the caregivers' caregiving context and subjective caregiver burden.

As shown in Fig. 1, caregivers rated slightly higher in MCS than in PCS. Among the 8 QOL dimensions, GH was rated lowest while PF was rated highest.

3.3. Predictors of caregivers' HRQoL

Table 4 shows the results of each block of independent variables in the final HMR model of caregivers' HRQoL. In general, each block made a significant contribution to all subscales of QOL; however, the disabled older adults' characteristics only contributed to the subscale of RE. The final model explained 37.5% and 42.3% of the variance in PCS and MCS, respectively.

Compared with the other 3 blocks, the older adults' characteristics explained the smallest amount of variance in the final model in RP, BP, GH, VT, SF, RE, PCS, and MCS.

Among the characteristics of care recipients, personal monthly out-of-pocket payment was a negative predictor in PF, GH, VT, MH, PCS, and MCS.

With respect to physical health subscales and PCS, caregivers' characteristics contributed to the greatest amount of variance (R²) among the 4 blocks of predictors. However, in MH subscales and MCS, caregivers' characteristics only explained 6.2% (VT), 11.1% (SF), 6.2% (RE), 4.5% (MH), and 9.1% (MCS) of the total variance. Among the characteristics of caregivers, caregiver age was negatively related to caregivers' PF, BP, GH, PCS, SF, and MCS, whereas caregiver income was positively related to PF, RP, PCS, VT, RE, and MCS. The number of chronic diseases of the caregiver was negatively associated with all subscales of caregivers' HRQoL.

Caregiving context was the 2nd highest contributor to the variance in most MH subscales and in MCS. In most physical health subscales and in PCS, caregiving context explained the 3rd greatest amount of variance. Among the characteristics of caregiving context, subjective social support was positively associated with RP, SF, RE, MH, PCS, and MCS. Social support availability was a positive predictor in PF, BP, GH, VT, MH, PCS, and MCS. Objective social support was positively related to PF and VT. Time spent in daily caregiving was a negative predictor in GH and MH.

Finally, subjective caregiver burden explained the greatest amount of total variance in MH subscales and in MCS. In most physical health subscales and in PCS, subjective caregiver burden explained the 2nd greatest amount of variance. Subjective caregiver burden was negatively related to all subscales of caregiver HRQoL and was therefore the strongest predictor of HRQoL.

4. Discussion

In this research, we aimed to describe the caregiving burden and HRQoL among Chinese caregivers of disabled older adults, and to examine the predictors of caregivers' HRQoL. Similar to previous studies of caregivers,^[20,21] our findings showed that among Chinese caregivers, the subscales of PF and SF were ranked highest, while GH and RP scores were lowest. Based on aggregated MCS and PCS, the mean PCS score was lower than that of MCS. Moreover, PCS and MCS mean scores were lower than those of a study conducted with mainland Chinese caregivers of older adults.^[15] One possible reason is age related: the participants in this study tended to be older than their counterparts.

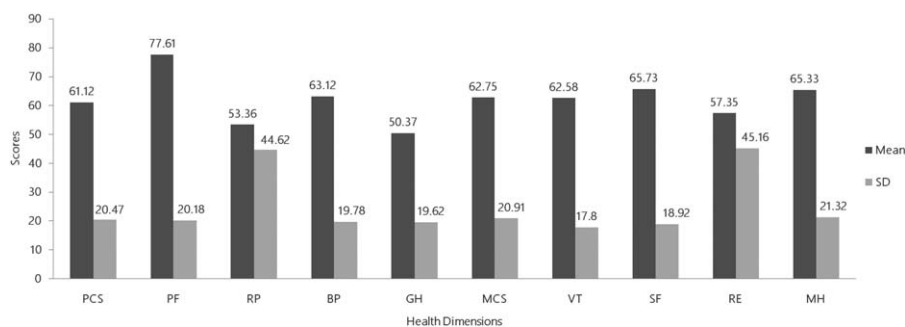


Figure 1. Health-related quality of life scores among caregivers. BP=bodily pain, GH=general health, MCS=mental component scores, MH=mental health, PCS=physical component scores, PF=physical functioning, RE=role limitations-emotional, RP=role limitations-physical, SD=standard deviation, SF=social functioning, VT=vitality.

Table 4
Hierarchical multiple regression predicting caregivers' HRQoL (SF-36) 8 subscales, PCS, and MCS.

Predictors	PF	RP	BP	GH	PCS	VT	SF	RE	MH	MCS
Block 1. Older adults' social-demographic characteristics										
Age, y	NS	NS	-.123**	NS	NS	NS	NS	NS	NS	NS
Gender (male=0; female=1)	NS	NS	NS	NS	NS	NS	-.063*	NS	NS	NS
Personal out-of-pocket payment per month (<100 yuan=0; ≥100 yuan=1)	-.133***	NS	NS	-.124***	-.073*	-.156***	NS	NS	-.113***	-.070*
R ²	.023**	.017*	.021*	.042***	.028*	.047***	.028*	.016	.047***	.034***
Block 2. Caregivers' social-demographic characteristics										
Age, y	-.158*	NS	-.172**	-.155**	-.159**	NS	-.156**	NS	NS	NS
Monthly household income of caregivers (<4000 yuan=0; ≥4000 yuan=1)	.090**	.121***	NS	NS	.100***	.072*	NS	.101**	NS	.088**
Number of chronic diseases	-.146***	-.100**	-.199***	-.208***	-.189***	-.090**	-.154***	-.105**	-.070*	-.128***
Relationship to the patient (others=0; spouse=1)	-.226***	NS	NS	NS	NS	NS	NS	NS	NS	NS
Living with older adults (no=0; yes=1)	NS	NS	NS	NS	NS	NS	NS	NS	-.070*	NS
R ² change	.192***	.090***	.148***	.137***	.190***	.062***	.111***	.062***	.045***	.091***
Block 3. Caregiving context										
Time spent daily in caregiving, h	NS	NS	NS	-.085*	NS	NS	NS	NS	-.085**	NS
Care duration, y	NS	NS	-.095*	NS	NS	NS	NS	NS	NS	NS
Subjective social support	NS	.111*	NS	NS	.096*	NS	.140***	.125***	.081*	.151***
Objective social support	.113**	NS	NS	NS	NS	.088*	NS	NS	NS	NS
Social support availability	.112**	NS	.089*	.138***	.074*	.126***	NS	NS	.208***	.082*
R ² change	.046***	.040***	.059***	.077***	.061***	.100***	.094***	.062***	.166***	.112***
Block 4. Subjective caregiver burden										
ZBI score	-.090*	-.298***	-.347***	-.332***	-.348***	-.391***	-.416***	-.347***	-.498***	-.492***
R ² change	.006*	.068***	.093***	.085***	.093***	.118***	.132***	.092***	.190***	.185***
Overall R ²	.267	.216	.321	.341	.372	.327	.366	.232	.448	.423

Table entries are regression standardized coefficients in the model. *P ≤ .05; **P ≤ .01; and ***P ≤ .001. BP = bodily pain, GH = general health, HRQoL = health-related quality of life, NS = no significance, MCS = mental component scores, MH = mental health, PCS = physical component scores, PF = physical functioning, RE = role limitations-emotional, RP = role limitations-physical, SF = social functioning, SF-36 = 36-item Short-Form Health Survey, VT = vitality, ZBI = Zarit Caregiver Burden Interview.

Care-receivers' socio-demographic characteristic were the weakest contributor to predicting caregivers' HRQoL. Only personal out-of-pocket monthly payment of care-receivers could predict caregivers' more physical QOL subscales (PF and GH) and mental QOL subscales (VT and MH). It did, however, also predict the aggregated SF-36 MCS and PCS. Although 99% of the disabled older adults were covered by health insurance with different reimbursement rates, all of them had chronic diseases, and paid much more out-of-pocket for medications than other populations. Importantly, the culture of filial piety in China obligates family caregivers to pay for medical costs, which adds to the caregivers' heavy burden. Thus, in our study, higher personal out-of-pocket monthly payment for disabled older adults was associated with caregivers' poorer physical and mental QOL.

Consistent with other studies,^[12,20,21] caregivers' demographic characteristics was the strongest contributor to aggregated PCS. For example, socio-demographic characteristics, such as the number of chronic diseases the caregiver had, were negatively associated with all subscales of caregivers' HRQoL. The most likely reason for this is that chronic diseases cause the individual to lose physical strength and vigor. Physical diseases also resulted in depressive symptoms^[22,23] and generally contributed to the decline of physical and MH. We found, as have other investigators in previous studies,^[21,24,25] that when caregivers' income increased, their physical and mental QOL also improved. This might be explained by research showing that low-income caregivers often experience significantly more distress than caregivers with a higher income.^[24] Similar to Hughes study,^[21] our results suggested that as caregivers age, more physical (PF, BP, and GH) than mental QOL dimensions (only SF) worsen. The

gradual decline of an aging caregivers' PF is one possible explanation.

Caregiving context was the 2nd strongest predictor of aggregated MCS. Among these factors, subjective support and social support availability were positively – but moderately – associated with both physical and MH. This is consistent with other published studies.^[26–28] One possible reason for this may be that people who enjoy greater subjective support are likely to use more effective coping strategies, compared with those who experience less support. However, objective support was only found to be significant for PF and VT. This situation could be explained by the fact that an LTC system has not yet been established, and so there are few resources – such as homecare services – to support these families. The Chinese government has recognized that providing affordable and accessible LTC services for older adults has become an urgent issue that must be addressed. Ideally, higher priority will be placed on the development of home-based community care services for older adults, for example, homemaking and meal delivery, transportation and escort services, rehabilitation care, and spiritual support.^[29] Unfortunately, there is currently a lack of LTC insurance, and thus medical and nursing services for disabled older adults living at home are severely limited. In reality, Chinese caregivers are eager to find social support, such as medical and nursing services, care knowledge, skills training, and respite services.^[30,31] In the near future, with the establishment of LTC insurance in Beijing, disabled older adults will be able to obtain more medical and nursing services, and their family caregivers will also be able to acquire knowledge and skills to reduce their caregiving burdens. Another aspect of caregiving context was the

number of caregiving hours, which was only associated with 2 subscales of SF-36 (GH and MH); this result was similar to those of a Japanese study.^[20] It is possible that caregiving hours were a subjective assessment of care-receivers' physical and psychological needs.^[32]

In our study, subjective caregiver burden was negatively associated with all 8 subscales of SF-36. Moreover, subjective caregiver burden was the strongest predictor of MCS and the 2nd highest contributor to the PCS. Similar to other international studies of caregivers, increased caregiver burden was significantly associated with a worsening HRQoL, particularly MH.^[20,21,33,34] Subjective caregiver burden is a caregiver's holistic, comprehensive perception that they are experiencing multiple dimensions of stress.^[35] Caring for a disabled individual directly results in a lack of personal time; consequently, caregivers may find it difficult to relax or to participate in social activities. This often puts considerable strain on the caregiver. Recent research has shown that caregivers who reported high levels of stress also had poorer PF, fewer social contacts, and more emotional distress than other caregivers.^[36] Therefore, stress management programs were implemented to control stress and stress-related symptoms in caregivers. In these programs, caregivers were trained to improve coping skills and to regulate their emotions.^[37,38]

This study has a number of limitations. First, owing to the absence of a list of disabled older adults in Beijing, we recruited a (nonrandom) convenience sample which was, therefore, not intentionally representative. Consequently, the results cannot be generalized to other populations in Beijing. Moreover, we did not assess care-receivers' behavior problems, which may have resulted in an underestimation of care-receivers' status in predicting their caregivers' HRQoL.

Based on our findings, we believe that many Chinese caregivers of disabled older adults experience diminished HRQoL. However, HRQoL can be improved by decreasing caregiver burden. Furthermore, additional social support is needed to reduce the impact of caregiving on HRQoL for Chinese caregivers. Importantly, we suggest that a standardized LTC system be established in China as soon as possible.

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