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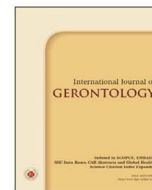
Original Article

The Care Burden and Influencing Factors of Family Caregivers of Older Adults with Dementia

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ARTICLE INFO	SUMMARY
	Background: To analyze the current state of the care burden of dementia caregivers and determine the influencing factors. *Methods:* Using a questionnaire survey, 600 family caregivers of older adults with dementia from five communities in Ningbo were investigated from March to August 2022. *Results:* The average score of care burden of dementia was 52.36 ± 12.08. The total score for social support for older adults with dementia ranged from 19 to 56, with an average score of 34.79 ± 9.54. The total score of social support and the score of each dimension were negatively correlated with the total score of care burden and the score of each dimension, with correlation coefficients between 0.490 and 0.689 ($p < 0.05$). Six factors affecting the burden of care for family caregivers of older adults with dementia were total social support score, dementia level, monthly family income, years of care, educational level, and duration of daily care for older adults with dementia (all $p < 0.001$). *Conclusion:* The care burden of caregivers of older adults with dementia is significant and has many influencing factors. Therefore, it is necessary to relieve the care burden of family caregivers through educational support programs, self-efficacy training of caregivers, breathing care services, and psychological counseling to improve their quality of life and relieve the pressure of caregiving.

1. Introduction

Dementia refers to a common group of advanced brain dysfunctions caused by chronic or progressive organic structural damage in old age.[1] Currently, dementia has become the fourth leading cause of death in developed countries.[2] By the end of 2022, there were approximately 13 million older adults with dementia in China, accounting for approximately 25 percent of the world's total population with dementia.[3] The families of patients with dementia carry a heavy burden, spending 26,000 to 35,000 yuan per person per year.[4] The quality of care plays a pivotal role in the quality of life of older adults with dementia, and the physical and mental health of the caregivers are important factors of the quality of care. Therefore, caring for older adults with dementia has become a prominent social problem regarding China's aging population.

Research on care burden began in the 1970s and entered the stage of rapid development in the early 21st century.[5] The WHO-World Mental Health Alliance survey of 19 participating countries demonstrated that 40% of the countries' caregivers had a different degree of care burden for the caregivers due to care time and economic factors.[6] Zarit et al. first started studying the caregivers of patients with Alzheimer's disease (AD), and then the researchers gradually conducted studies with different populations, focusing on the caregivers of older adults with AD.[7,8] Neuropsychiatric distur-

bances are common manifestations of dementia disorders and are associated with caregiver burden. Studies have investigated caregiver burden as a mediator of the association between the neuropsychiatric symptoms of people with dementia and caregiver mental health, such as depression and anxiety. The results show that it is imperative to improve caregivers' perception of those with dementia to improve caregivers' mental health.[9–12] The influence of stigma is also observed in family caregivers of people with dementia.[13] The stigma indicates that negative behaviors of the public are directed toward those closely associated with family caregivers of people with dementia. The internalization thereof may lead to severe consequences, such as lower self-esteem and self-efficacy, feelings of hopelessness, and poor quality of life, according to the stigma studies with family caregivers of people with dementia.[14] Studies have indicated that family caregivers who perceive stigmatization experience high stress, negative emotions, a high care burden, and social isolation; they engage in less help-seeking behaviors and may be unable to provide high-quality care.[13–15]

Studies have shown that caregiver burden includes physical, psychological, emotional, social, and economic factors. Different types of care burden have different factors related to caregivers' environmental and social factors.[16,17] Caregivers often cooperate with healthcare professionals to provide better treatment. Those with severe burdens may be less capable of working with healthcare professionals, and in extreme cases, this can jeopardize the health of caregivers. Assessing caregiver burden may help healthcare professionals to prevent both caregivers and patients from the worst out-

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comes in this context.[16,17] Studies have shown that care burden is positively associated with factors such as lack of educational support, care skills and coping strategies, time spent to maintain activities of daily living in older adults with dementia, and lack of general support.[18,19]

Studies on the burden focus on cross-sectional studies of small and specific groups in China.[20] Scholars studied family caregivers of older adults with dementia and concluded that the top three care burdens were emotional burden, social activities, and the burden of time dependence.[21] Some studies investigated and analyzed caregivers who care for older adults with dementia and found that the overall care ability of family caregivers was relatively low, and their educational level, physical health, awareness of the disease, and coping methods were all factors affecting the care ability.[22]

Caregivers are sometimes unable to continue working, affecting their family income and quality of life. Therefore, a comprehensive understanding of the current situation of family caregivers' care burden and its influencing factors may allow for effective intervention measures that prevent or reduce caregiver fatigue, prevent physical and mental health conditions, ensure the quality of care for older adults with dementia, and improve the quality of life of older adults with dementia.

2. Materials and methods

2.1. Study design

A correlational cross-sectional design was adopted, and questionnaires were used for data collection.

2.2. Setting and sample

Convenience sampling was used to obtain a list of older adults with dementia provided by clinicians in five communities in Ningbo between April and July 2022. Six hundred older adults with dementia completed the questionnaires with their home caregivers. Participant inclusion criteria were as follows: 1) family caregivers of older adults with dementia who were diagnosed by clinicians; 2) being in a caregiving position for at least one year; 3) living in a community with older adults with dementia; and 4) being over 18 years old, conscious, and able to voluntarily participate in the study. The exclusion criteria were as follows: 1) cognitive impairment and 2) severe heart, liver, lung, or brain dysfunction.

2.3. Sample size calculation

According to the regression models, to justify the required sample size in the study,[23] the sample size is calculated by formula $n = 100 + 50i$ where i refers to number of independent variables in the final model. In this study, $i = 6$ and the required sample size was greater than 400.

2.4. Data collection

Two investigators underwent unified training for data collection. Data were collected through face-to-face interviews after the participants engaged in scheduled meetings arranged by community managers. The investigators explained the research objectives and methods to individuals who met the inclusion criteria and obtained informed consent and cooperation from them. Consenting participants received an envelope containing a packet with the question-naires. Participants completed the questionnaires immediately upon receipt and placed them in an envelope for collection by the investigators. Each completed questionnaire was assigned a specific code to ensure anonymity.

2.5. Instruments

Four structured questionnaires were used for the data collection. The general information questionnaire for family caregivers of older adults with dementia consisted of general information including gender, age, occupation, marital status, educational level, monthly income, medical insurance payment method, number of joint caregivers, relationships with older adults with dementia, years of care, and length of care.

The Mini-Mental State Examination (MMSE) is a clinical tool used to screen AD patients. It is a widely used cognitive function screening scale at home and abroad and is currently the most influential screening tool for dementia.[24] It contains 19 items with a total score of 30 and the subject's MMSE score of 24. Considering that the patients had dementia or other diseases with a cognitive function component, the subject score was closely related to their education level, and the cutoff value for dementia had different educational levels. It has been reported in the literature that the standard cut-off value was set at 24 points: 17 points for the illiterate (uneducated) group, 20 points for the primary school (6 years of education) group, and 24 points for the middle school or above group. The Cronbach's α was 0.83.

The Caregiver Burden Inventory (CBI) was used to investigate home caregiver care load.[25] It contains 5 dimensions (time-dependent, development-limited, physical, social, and emotional load) and 24 items. The scoring method is 0 to 4 with a scoring range of 0 to 96. Higher scores indicate a heavier caregiving load. The content validity index of the questionnaire is 0.95. The Cronbach's α of this questionnaire is 0.90.

The Social Support Rating Scale was used to measure the level of social support provided by a certain group of people.[26] The scale's Cronbach's α coefficient is 0.94, the reliability is high, and the domestic norm is 44.38 ± 8.38 with a score of 34. The scale consists of 10 entries, which can be divided into 3 dimensions. The objective support dimension consists of items 2, 6, and 7; the subjective support dimension consists of items 1, 3, 4, and 5, respectively, and the utilization dimension of 'support' consists of items 8, 9, and 10. The total score ranges from 12 to 66, with a lower score indicating a lower level of social support. Regarding the social support level, 22 indicates a low level, 23 to 44 indicates a middle level, and 45 to 66 indicates a high level.

2.6. Ethical considerations

This study was approved by the Ningbo College of Health Sciences Institutional Review Board (Approval no. NBWY-031). All participants provided written informed consent before participating in this study. Two researchers were responsible for informing the participants, both in writing and orally, about the purpose of the study and data gathering. The participants were informed that participation in the survey was voluntary and that withdrawal from the study was always without any negative consequences.

2.7. Data analysis

The questionnaires were collated, checked, and entered by two people, and SPSS 26 was used for statistical analysis (results were

considered significant at $p < 0.05$). Descriptive statistics were used in the general data, care burden and social support data of older adults with dementia and their caregivers are given. Pearson correlation was used to analyze the correlation between social support and care burden scores for caregivers of older adults with dementia. Multiple linear regression analysis was used with the dependent variable, statistically significant variables and the total score of social support in the univariate analysis as independent variables, and multiple linear gradual regression analysis was conducted to explore the influencing factors of care burden.

3. Results

3.1. Participant demographics

A total of 600 questionnaires were distributed and 520 valid questionnaires were administered, with an effective response rate of 86.7%. Of the 520 caregivers in this study, 85 were male (16.3%), and 435 (83.7%) were female; the age range was between 24 and 87 years (mean = 58.38 ± 12.18), with most being between 40 and 59 years; 418 (80.4%) had completed primary school, 73 were students (14.0%), 23 (4%) were in high school and technical secondary school, and 6 cases (1.2%) were in junior college and above; most were married (88.8%). Detailed data are presented in Table 1.

3.2. Family caregivers of older adults with dementia

The average burden of family caregivers for older adults with dementia was 52.36 ± 12.08, and the top three burdens were emotional (16.28 ± 5.21), social (14.52 ± 2.96), and time dependence (11.98 ± 3.78), as shown in Table 2.

3.3. Social support for the family caregivers of older adults with dementia

The total score for social support for caregivers of older adults with dementia ranged from 19 to 56, with an average score of 34.79 ± 9.54. The objective support dimension score ranged from 3 to 18, and the average score was 9.67 ± 3.23. The subjective support dimension scores ranged from 10 to 32, with the average score being (18.62 ± 5.12); the support utilization dimension score is between 3 and 12, with the average score being (6.50 ± 2.54).

3.4. Correlation of care burden with social support

The results showed that the total score for social support and the score for each dimension were negatively correlated with the total score for caring burden and the score for each dimension, with a correlation coefficient between 0.490 and 0.689 ($p < 0.05$), as shown in Table 3.

3.5. Factors influencing care burden for caregivers of older adults with dementia

The results of the multiple linear regression analysis showed that six variables were entered into the regression model: total social support score, degree of dementia, monthly family income, years of care, education level, and time spent on daily care for older adults with dementia. The model was tested for significance using Analysis of Variance (ANOVA) and showed F = 53.842, $p < 0.001$, which was statistically significant. See Table 4 for details.

Table 1

Demographic data of family caregivers of older adults with dementia (n = 520).

Demographics	n	Percentage
Age distribution (years)		
< 40	36	6.9
40–	325	62.5
60–	101	19.4
> 80	58	11.2
Gender		
Men	85	16.3
Woman	435	83.7
Marital status		
Married	462	88.8
Unmarried	5	1.0
Divorced or widowed person	53	10.2
Occupation		
Peasant	121	23.3
Worker	28	5.4
Civil servant or clerk	6	1.2
Retirement	328	63.1
Unemployed	30	5.7
Other	7	1.3
Degree of education		
Primary school and below	418	80.4
Junior middle school	73	14.0
High school and technical secondary school	23	4.4
College degree or above	6	1.2
Monthly income		
≤ one thousand yuan	84	16.2
1001 yuan–3000 yuan	318	61.2
3001 yuan–5000 yuan	61	11.7
> five thousand yuan	57	10.9
Payment method of medical expenses		
Socialized medicine	35	6.7
Urban health care	254	48.8
New rural cooperative	206	39.6
Commercial insurance	7	1.3
At one's own expense	18	3.6
Number of co-caregivers		
0	398	76.5
1–2	101	19.4
> 2	21	4.1
Relationship with the old man with dementia		
Spouse	368	70.8
Son	52	10.0
Daughter	81	15.6
Other	19	3.6
Care for years		
< 2	80	15.4
2–	316	60.8
5–	108	20.8
> 10	16	3.0
Daily care time		
< 8 hours/day	20	3.8
From 8 to 16 hours/day	388	74.6
At > 16 hours/day	112	21.6

Table 2

Care load scores of elderly family caregivers with dementia (n = 520).

The questionnaire and its sub-questionnaire	Mean	Standard deviation	Score range	The number of items
Time-dependent	11.98	3.78	0–20	5
Development-limited	7.46	3.52	0–20	5
Physical load	6.49	3.19	0–16	4
Social load	14.52	2.96	0–16	4
Emotional load	16.28	5.21	0–24	6
Total questionnaire	52.36	12.08	0–96	24

Table 3
Correlation of care burden and social support for family caregivers with dementia (n = 520).

Project	Time dependence	Development limited	Physical load	Social load	Emotional load
Objective support	-0.548**	-0.596**	-0.588**	-0.524**	-0.536**
Subjective support	-0.636**	-0.639**	-0.660**	-0.653**	-0.619**
Usage of support	-0.501**	-0.490**	-0.509**	-0.516**	-0.566**
Social support	-0.660**	-0.676**	-0.689**	-0.628**	-0.626**

** $p < 0.01$.

Table 4
Multiple linear regression analysis of care burden among elderly caregivers with dementia (n = 520).

Variable	B	SE	Beta	t	p-value
Constant	37.589	6.852		5.369	< 0.001
Social support	-6.028	0.895	-0.268	-5.632	< 0.001
Degree of dementia	4.632	0.913	0.198	4.756	< 0.001
Family monthly income	-4.536	0.918	-0.269	-4.014	< 0.001
Care for years	4.798	1.056	0.268	4.326	< 0.001
Degree of education	-4.236	1.269	-0.168	-3.115	0.001
Daily care time	2.168	1.326	0.088	2.089	0.046

B: regression coefficient; Beta: standard regression coefficient; SE: standard error.

4. Discussion

4.1. Family caregivers of older adults with dementia have a high burden of care

In this study, the average burden of family caregivers of older adults with dementia was 52.36 ± 12.08, which is a high burden; the top three being emotional (16.28 ± 5.21), social (14.52 ± 2.96), and time dependence (11.98 ± 3.78) – similar to results of Lamb SE et al.[27] Society should be timely in providing appropriate help and support, care knowledge, and care skills guidance, as well as evaluating caregivers; physical and mental health, finding existing health problems, and offering psychological counseling to reduce the overall burden of care. This could improve the quality of life of caregivers and better equip caregivers to care for older adults with dementia, as demonstrated by various studies.[28,29]

4.2. Association of care burden and social support in dementia

The results of the correlation analysis showed that social support was negatively associated with care burden; that is, caregivers with higher social support experienced lower care burden, which is consistent with the findings of Grano C et al.[30] This may be because good social support relieves pressure. If family caregivers receive all aspects of objective material support or psychological comfort, they can effectively solve life difficulties and relieve negative emotions while providing care.

4.3. Analysis of factors of dementia

The results showed that the more severe the dementia of older adults, the higher the care burden of the caregivers ($p < 0.05$). The correlation coefficient was 0.198, which is consistent with the results of previous studies.[11,30] This may be because older adults with more severe dementia have more needs that must be met. In addition, completely disabled older adults with dementia depend entirely on their caregivers. This increases the burden on caregivers who must provide physical mobility assistance to older adults.

The results demonstrated that caregivers with lower monthly household income had a higher care burden ($p < 0.05$) and a correlation coefficient of -0.269. This is consistent with previous findings.[25] This may be because most older adults with dementia have other diseases that require long-term medication, and the caregiver family must bear this high medical cost. When caring for older adults, caregivers generally suspend work or quit their previous jobs, thus reducing the family's income.

The results showed that the longer the period of care, the higher the care burden ($p < 0.05$), with a correlation coefficient of 0.268, consistent with previous study results.[17] This may be because longer care time leaves caregivers without rest time, which can partly damage their physical health. Additionally, the caregivers have no personal free time nor opportunity to participate in recreational activities.

The results showed that the lower the education level, the higher the care burden ($p < 0.05$), with a correlation coefficient of -0.168, which was similar to the results of the study by Ge XH et al.[29] Caregivers with higher educational levels have greater care knowledge and skills learned through the Internet, TV, mobile phones, and other devices. Additionally, caregivers can skillfully use WeChat, QQ, and other social software to communicate with family and friends, which strengthens communication with the outside world and relieves negative emotions.

Multivariate analysis revealed that the longer the daily care for older adults with dementia, the higher the burden ($p < 0.05$), with a correlation coefficient of 0.088. In the daily care of older adults, caring for dementia requires more time, thus caregivers have no time to rest, aggravating the burden on the body, resulting in the accumulation of negative emotions, and physical and mental health may be damaged.

The results show that social support could negatively predict caregivers' burden, with a correlation coefficient of -0.268, which is similar to some studies.[11,30] This may be because caregivers can relieve the financial stress of care if they receive material support from family, friends, or society. Simultaneously, if the caregiver receives relief and support, the caregiver's psychological state can be relieved, enabling them to share the care task, allowing them time and opportunity to rest.

4.4. Limitations and future research

First, we used convenience samples and self-reports; thus, common method variance could have biased our results. Therefore, we suggest a longitudinal multisource study to test the causal effects of these variables. Second, the data were obtained from one city in China; therefore, the results may not be generalizable to other cities. Therefore, researchers should use a larger sampling range to verify the proposed model.

5. Conclusion

Family caregivers of older adults with dementia experience pressure in various ways. To mitigate this pressure, attention should

be paid to perfecting the social security system, strengthening nursing services, promoting psychological knowledge and skills, increasing economic subsidies, employing social workers, and enhancing social interactions to enhance nursing knowledge. This can improve the quality of care, alleviate the burden on family caregivers, improve their quality of life, and alleviate the pressure on social endowments.

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