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Original Article

Current Status and Influencing Factors of Long-Term Care Needs Among Older Adults with Dementia

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SUMMARY

Background: This study aimed to explore the long-term care needs of older adults with dementia and identify whether demographic characteristics and functional impairment level are associated with these needs.

Methods: A questionnaire survey was administered to 1,212 older adults with dementia across five cities in different provinces in China from January to June 2023. Three questionnaires were used to gather data.

Results: Participants with mild functional impairment were the highest in number (56.7%). Older adults with dementia had the greatest access to both basic and specialist care services (mean = 3.54, standard deviation [SD] = 1.06) and life care services (mean = 3.42, SD = 1.04). Furthermore, functional impairment level (B = 7.98, *Beta* = 0.49), age (B = 4.47, *Beta* = 0.21), monthly income (B = 3.85, *Beta* = 0.18), and living status (B = 3.06, *Beta* = 0.07) influenced participants' long-term care needs (all $p < 0.05$).

Conclusions: The long-term care needs of older adults with dementia vary according to the level of functional impairment and are influenced by multiple community-specific factors. These findings provide a scientific basis for tailoring aging reforms to community contexts.

1. Background

Dementia, commonly known as Alzheimer's disease, encompasses a group of syndromes characterized by advanced impairment of brain function caused by chronic or progressive organic damage to brain structures. This condition primarily manifests as persistent and comprehensive intellectual decline along with behavioral abnormalities, which leads to the loss of the ability to live and work independently.[1] With the intensification of population aging, dementia has become a major public health challenge.[2] In 2019, approximately 57.4 million individuals worldwide were living with dementia, and this figure is projected to rise to 152.8 million by 2050.[3] Currently, dementia ranks as the fourth leading cause of death in developed countries, following cardiovascular diseases, malignant tumors, and stroke.[4] In China, approximately 16.99 million people — about 6% of the older adult population — suffer from dementia. This places the country first globally and accounts for 25% of the world's dementia-affected older adults.[5] With continuous population aging, the number of dementia-affected older adults is expected to grow rapidly.

The prolonged course of dementia results in progressively worsening disability as the disease advances. Consequently, the care process becomes lengthy, complex, and challenging for caregivers. Globally, patients with dementia require more than 8 billion hours of care annually, with women providing 71% of this support. Moreover, providing care to patients with dementia is significantly more demanding than providing care to other disabled populations, which imposes substantial physical, mental, temporal, and economic burdens on caregivers. As aging intensifies and the population of older adults with dementia rises, their long-term care needs exhibit a rigid upward trend.

Providing long-term care involves delivering a range of health care, personal care, and social services to incapacitated individuals or those lacking mobility for an extended period.[6] Scholars worldwide have explored the long-term care service needs of older adults with dementia, focusing on three key aspects: the current state of these needs, the factors that influence these needs, and patients' preferences for care methods. For instance, Lauridsen et al.[7] used ethnographic methods to assess the needs of patients with dementia across three Danish institutions: activity centers, physical rehabilitation centers, and specialized dementia care facilities. Their findings revealed that patients with dementia, family caregivers, and professional caregivers encounter ethical dilemmas that conflict with four principles: benevolence (best interest), non-maleficence (not causing harm), respect for autonomy, and justice. These conflicts create uncertainty in decision-making among all parties involved. Meanwhile, a literature review identified nine frequently cited elements linked to the need for long-term care services: Activities of Daily Living (ADL) score, mental health status, spouse status, children's circumstances, family economic status, awareness of long-term care services, service professionalism, fee level, and government support.[6]

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In China, deepening aging has spurred a substantial increase in dementia cases, thereby amplifying the demand for long-term care. Lianbin[8] argued that older adult care services should prioritize the most urgent needs of older adults, with individuals with disabilities and dementia representing critical populations that require immediate attention to address their practical challenges. Employing stratified cluster sampling in Shanghai, Yujie and Ying[9] found varying levels of satisfaction with medical services among older adults with disabilities and dementia. They also noted that the convenience of receiving these services significantly impacts satisfaction levels. Yaqiong et al.[10] found that older adults with disabilities and dementia have distinct care needs compared to their healthier counterparts. They prefer traditional Chinese medicine, rehabilitation programs, and diagnostic testing for medical issues; peaceful care, feeding assistance, and medication support for daily living; and legal aid for spiritual and cultural services. Meanwhile, Xiaoxin et al.[11] conducted a questionnaire survey and found that more than 70% of dementia caregivers prefer professional care institutions, with demand rising as age increases and daily living abilities decline.

In summary, resources for older adult care remain limited both domestically and internationally. A more rational distribution of these resources necessitates conducting a scientific assessment of the long-term care needs of older adults with dementia. This evaluation is crucial for determining long-term care service demand and ensuring effective supply. Therefore, this study examined the current state of long-term care needs among older adults with dementia in China and identified the factors that influence these needs. With this objective, we aimed to offer insights into developing a robust long-term care service system.

2. Methods

2.1. Design

A correlational cross-sectional design was adopted using structured questionnaires for data collection from January 2023 to June 2023.

2.2. Setting and sample

Through convenience sampling, we selected 1,500 older adults with dementia from five Chinese cities: Ningbo, Qingdao, Chengdu, Shijiazhuang, and Shanghai. Our research team visited five 5-level professional pension institutions located in the aforementioned cities. A 5-level care institution is one that meets the highest level of care facility standards in China. From each city, we selected 300 participants using convenience sampling. All participants had been clinically diagnosed with dementia.

The inclusion criteria were: (a) being part of a local household and over 60 years of age; (b) meeting the diagnostic criteria for dementia (according to the 4th edition of the *American Diagnostic and Statistical Manual of Mental Disorders*) and having *mild dementia* confirmed by specialists; (c) receiving primarily home-based care; and (d) being able to complete the questionnaire independently. Individuals were excluded if they were: (a) unconscious; (b) diagnosed with severe dementia; or (c) could not communicate effectively.

We calculated the sample size in the following manner. Older adults with dementia aged more than 60 years constitute approximately 12% of the older population (P) in China. With a sampling survey tolerance (d) of 0.15P, $\alpha = 0.05$, $t \approx 2$, and $Q = 1 - P$, the calculation formula, $n = \frac{t_{\alpha}^{2} PQ}{d^2}$, yielded a minimum required sample size of 1,303. Considering a 15% invalid questionnaire rate, the total sample size increased to 1,500. Furthermore, a power sensitivity analysis was conducted ($r \geq 0.07$).

2.3. Data collection

Ten trained investigators conducted face-to-face interviews to collect data. Participants resided either in their own homes or in nursing homes. Managers of nursing homes and community service centers scheduled meetings based on the list of clinical diagnoses. During these meetings, the investigators explained the study's objectives and methods and secured consent from eligible participants and their families. The consenting participants received an envelope containing questionnaires, which were to be completed immediately and returned in the envelope. To ensure anonymity, the investigators assigned code numbers to the questionnaires they received.

2.4. Measures

Three questionnaires were used in this study: one to collect demographic and clinical data, the ADL scale, and another to assess long-term care needs. The research team compiled a questionnaire to collect demographic and clinical data of older adults with dementia. In particular, this self-administered tool solicited data on age, sex, marital status, education level, monthly income, medical expense payment method, living status, illnesses, and medications.

The ADL scale, developed by Lawton in 1969,[12] has been validated in Chinese by Tong and Man.[13] This scale assesses functional impairment levels among older adults with disabilities. It comprises 14 items rated on a 4-point rating scale ranging from "cannot do it yourself" to "can do it yourself". The total score ranges from 14 to 56, with higher scores indicating greater levels of functional impairment. The scale demonstrated a total Cronbach's α of 0.92 and content validity of 0.86.[13]

The research team compiled another questionnaire to collect data on long-term care needs. They created statements using relevant literature and expert suggestions. The final Chinese version was derived after a formal discussion with five experts in the field of older adult care. These experts were selected based on the following criteria: (a) having at least 5 years of experience in providing care to older adults; (b) having a master's degree or higher educational qualifications; and (c) having a professional title of deputy senior or above. The final questionnaire contained 30 statements across four sections: life care services (8 items; e.g., housekeeping and transportation services), basic and specialist care services (12 items; e.g., regular physical examinations and safe medication guidance), mental comfort psychological services (4 items; e.g., psychological counseling services and cultural and recreational activities), and home care support services (6 items; e.g., legal advice and training for home caregivers). Each statement was scored on a five-point scale ranging from 1 ("none") to 5 ("a lot"). Higher scores indicated higher demand. The Content Validity Ratio values ranged from 0.8 to 1.0. The questionnaire exhibited a content validity of 0.96 and a Cronbach's α of 0.98.

2.5. Data analysis

All statistical analyses were conducted using SPSS (version 26.0), with statistical significance set at $p < 0.05$. We computed means, standard deviations, frequencies, and percentages to summarize demographic and clinical data, functional impairment levels, and long-term care needs. Using multiple linear regression, we de-

termined the effects of demographic and clinical factors and functional impairment levels on long-term care needs. Linear relationships were tested using scatter plots or correlation coefficients. Normality was tested through residual histograms. The homogeneity of variance was tested using the residual scatter plots. The independence of residuals was assessed using the Durbin–Watson statistic.

2.6. Ethical considerations

This study was approved by the Ningbo College of Health Sciences Ethics Review Board (NBWY-011) in January 2023. Managers of nursing homes and community service centers scheduled meetings, in which investigators informed candidates of their right to withdraw at any time. Participants or their authorized representatives provided consent before receiving the questionnaires. All the participants who consented or were authorized to participate received the questionnaire. To ensure confidentiality and anonymity, the participants sealed the completed questionnaires in envelopes, and investigators assigned code numbers to them.

3. Results

Out of the 1500 participants, 206 participants provided incomplete questionnaires, and 82 participants withdrew from participation due to their unwillingness to complete the questionnaire. These 288 responses were excluded from analysis, resulting in a response rate of 80.80% (1212/1500). All participants had dementia, with ages ranging from 60 to 105 years and an average age of 80.77 years. The sample included 519 females (42.8%) and 693 males (57.2%). Most participants held an elementary school education degree (n = 959, 79.1%) and were widowed (n = 663, 54.7%). Their monthly income ranged from CNY 1001 to CNY 3000 (66.6%). Most participants lived alone or with other older adults (75.7%) and relied on Urban and Rural Residents' Medical Insurance to meet their medical expenses (74.9%) (Table 1).

The results of the ADL scale demonstrated that participants with mild functional impairment were the highest in number (56.7%), followed by those with moderate (19.6%), severe (13.6%), and extremely mild (10.1%) functional impairment (Table 2).

Participants demonstrated high awareness of their long-term care needs (mean = 13.50, standard deviation [SD] = 4.01). They generally believed they had the greatest access to both basic and specialist care services (mean = 3.54, SD = 1.06) and life care services (mean = 3.42, SD = 1.04) (Table 3).

We conducted stepwise regression analysis ($p < 0.05$) using demographic data and functional impairment level as independent variables and long-term care needs as dependent variables. Normality, linearity, homoscedasticity, and absence of multicollinearity were tested and met the required assumptions. The results showed that long-term care needs are significantly associated with age, living status, monthly income, and level of functional impairment (Tables 4 and 5).

4. Discussion

The results demonstrated that most participants exhibited mild dementia symptoms. However, the proportion of functional impairment among participants in Ningbo City (56.7%) exceeded that reported in Shanghai City (23.67%) in a separate study.[14] Several factors might explain this disparity. First, the higher annual per capita disposable income for older adults in Shanghai (CNY 69,442), compared to Ningbo (CNY 49,899), likely affords better access to medical institutions, potentially reducing conditions related to functional impairment. Second, cultural literacy influences health-related behaviors and self-care awareness. Individuals with stronger self-care tendencies seek timely medical intervention, mitigating disability rates to some extent.

Table 3 showed that basic and specialist care services, along with life care services, ranked highest in demand among Chinese older adults with dementia. This result aligns with the needs observed in Western nursing homes.[15,16] It suggests that caregivers in China should prioritize enhancing these services for older adults with dementia, in line with findings from Chinese nursing homes.[6] In Western models, long-term care integrates home care, community settlement facilities, and institutional care with distinct roles.[17,18] By contrast, China relies heavily on home care, necessitating the development of community and institutional care to improve the quality of life of older adults with dementia.

Table 1
Demographic and clinical characteristics of the participants (n = 1212).

Characteristic	Frequency	Percentage
Age		
60–69 years	108	8.9
70–79 years	340	28.1
80–89 years	707	58.3
≥ 90 years	57	4.7
Sex		
Male	693	57.2
Female	519	42.8
Marital status		
Married	481	39.7
Widowed	663	54.7
Divorced	68	5.6
Education level		
Junior high school and below	959	79.1
High school	206	17.0
College	47	3.9
Monthly income		
CNY ≤ 1000	186	15.3
CNY 1001–3000	807	66.6
CNY 3001–5000	201	16.6
CNY > 5000	18	1.5
Payment method used to meet medical expenses		
Urban Employee Medical Insurance	197	16.3
Urban and Rural Residents' Medical Insurance	907	74.8
Business insurance and self-pay	108	8.9
Living status		
Living with family or a caregiver	295	24.3
Living alone or with other older adults	917	75.7

Table 2
Level of functional impairment among the participants (n = 1212).

Level of functional impairment	Score	Frequency	Percentage
Extremely mild	23.49 ± 1.87	122	10.1
Mild	33.49 ± 3.15	687	56.7
Moderate	41.38 ± 2.54	237	19.6
Severe	53.16 ± 1.95	166	13.6

Table 3
Overall and specific long-term care needs of the participants.

Type of services	Mean	Standard deviation	Score range	Number of items
Life care services	3.42	1.04	1–5	8
Basic and specialist care services	3.54	1.06	1–5	12
Mental comfort psychological services	3.20	1.17	1–5	4
Home care support services	3.21	1.12	1–5	6
Overall	13.50	4.01	4–20	30

Table 4
Assigning values to independent variables to identify the determinants of long-term care needs.

Variable	Assignment of values
Age	60–69 years = 1; 70–79 years = 2; 80–89 years = 3; ≥ 90 years = 4
Sex	Female = 0; Male = 1
Marital status	Other marital statuses as reference
Education level	Junior high school or below = 1; High school = 2; College = 3
Monthly income	CNY ≤ 1000 = 1; CNY 1001–3000 = 2; CNY 3001–5000 = 3; CNY > 5000 yuan = 4
Payment method used to meet medical expenses	Urban employee medical insurance = 1; Urban and Rural Residents' Medical Insurance = 2; Business insurance and self-pay = 3
Living status	Living with family or caregiver = 0; Living alone or with other older adults = 1
Level of functional impairment	Extremely mild = 1; Mild = 2; Moderate = 3; Severe = 4

Table 5
Factors influencing participants' long-term care needs.

Variable	*B*	*Beta*	*t*	*p*
Age	4.47	0.21	4.85	.004
Living status	3.06	0.07	2.77	.037
Monthly income	3.85	0.18	4.78	.007
Level of functional impairment	7.98	0.49	7.58	.006
Sex	26.01	23.16	1.12	.298
Marital status	1.87	7.58	0.27	.798
Education level	9.97	15.17	0.68	.517
Payment method used to meet medical expenses	6.56	5.89	1.05	.319

R^2 = 0.598, adjusted R^2 = 0.521, F = 29.645, p < 0.001.

Standardized regression coefficients in Tables 4 and 5 demonstrated that functional impairment level, age, monthly income, and living status (listed in descending order of impact; all $p < 0.05$) influence long-term care needs among older adults with dementia. Table 5 specifically showed that long-term care needs increase with the severity of functional impairment. Older adults with severe disabilities are often unable to perform basic activities of daily living independently, such as eating, dressing, and bathing. The more severe the disability, the greater the need for round-the-clock care and supervision. Severe disability might also involve needs related to physical care, rehabilitation training, and nutritional support, which requires full-time care from professional caregivers or family members.[19]

The results also revealed that older age increases long-term care needs. Participants over 80 years of age exhibited greater demand compared to younger participants, reflecting age-related declines in organ function, physical capacity, and self-care ability, coupled with increased health concerns and expectations for care services. This is consistent with the findings of Jiang et al.,[20] who found a link between aging and rising care needs.

Table 5 also indicated that income is associated with long-term care demand. Currently, most Chinese medical insurance policies exclude coverage for home-based professional nursing costs, making income a critical determinant of access to such services. This underscores the need to raise awareness of long-term care benefits among low-income older adults and establish affordable pricing standards through increased investment and economic compensation mechanisms. This would enable more older adults with dementia to enjoy professional care services, thereby improving their quality of life. Min et al.[21] corroborated the idea that higher-income older adults exhibit a stronger willingness to accept long-term care. Stronger willingness to accept long-term care is associated with higher income through enhanced social support structures.

Furthermore, the findings revealed that older adults with dementia living alone or with other older adults have elevated long-term care needs. These individuals often lack immediate family support, increasing their risk during emergencies — such as falls or acute illnesses — due to delayed assistance. Therefore, they require additional external support to satisfy their daily needs. Moreover, limited social interaction may exacerbate emotional loneliness and mental health challenges in older adults, thus heightening their need for external support.[22] Factors that contribute to the development of an adequate cognitive reserve can help delay the onset of senile dementia, whereas a lack of these factors can increase risks.

Sex, marital status, education level, and payment method for medical expenses did not influence participants' long-term care needs (all $p > 0.05$). A growing number of modifiable factors have been found to be related to senile dementia, such as educational attainment, marital status, and social networks;[23,24] however, these factors were not associated with long-term care needs in this study. This finding is consistent with research conducted in China and abroad.[21,22]

4.1. Limitations and further research

This study had some limitations. First, because it was a cross-sectional study, it was difficult to determine the exact role of long-term care needs in delaying cognitive decline in older adults from the perspective of individualization. Second, the study employed convenience sampling in only five Chinese cities from five different provinces. This sampling strategy carries a risk of selection bias, particularly by potentially excluding individuals with severe dementia who cannot participate independently, as well as older adults who lack access to healthcare or community facilities. The results may differ in rural settings or other cultural contexts, potentially limiting generalizability. Third, factors like comorbidities or the availability of a family caregiver might influence care needs, but they were not measured. Fourth, our study did not verify the relationship between long-term care needs and long-term care outcomes, such as quality of life and cognitive status. Future studies with larger, more diverse samples should assess the utility value of the long-term care needs questionnaire, which can strengthen this study's scope and applicability.

5. Conclusions

China's aging population, coupled with the prevalence of only-child families, fast-paced modern life, and increasing workplace demands, has intensified challenges in long-term care for older adults with dementia, exacerbating caregiver burdens and potentially impeding economic development. This study developed a framework for assessing these needs and identified their determinants. By analyzing the reality of the care of China's older adults, this study found that care for older adults with dementia is in high demand — especially in terms of access to basic and specialist care services and life care services. The results also demonstrated that the level of functional impairment, age, monthly income, and living status influence

the long-term care needs of older adults with dementia. The Chinese government is expanding the construction of dedicated dementia care zones to deliver specialized nursing services. Meanwhile, communities are enhancing daily life support by embedding micro-institution respite care, home care, and other methods to improve the quality of life of older adults with dementia. The study is theoretically significant for professionals working directly with older adults with dementia and those in related research fields. It also has the potential to assist in building a more effective care system for individuals with dementia.

Ethics approval and consent to participate

This study was approved by the Ningbo College of Health Sciences Ethics Review Board (NBWY-011). Managers of nursing homes and community service centers scheduled meetings, in which investigators informed candidates of their right to withdraw at any time. Participants or their authorized representatives provided consent before receiving the questionnaires. All the participants who consented or were authorized to participate received the questionnaire. To ensure confidentiality and anonymity, the participants sealed the completed questionnaires in envelopes, and investigators assigned code numbers to them.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available due to ethical restrictions and patient confidentiality but are conditionally available from the corresponding author on request. Aggregated data are provided in this study's tables.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

LYL contributed to the conception, design, analysis and interpretation of data, drafting of the manuscript, revision of the manuscript, and final approval. NS contributed to data acquisition, project administration, manuscript revision, and final approval. SQC and SY contributed to formal analysis, manuscript revision, and final approval. HYL and QRL contributed to the conception, manuscript revision, and final approval. KYZ contributed to the conception, design, funding acquisition, manuscript revision, and final approval. JXY contributed to the conception, design, project administration, manuscript revision, and final approval. All authors have read and approved the final manuscript.

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