

# Research Progress on the Care Needs and Community Support for Caregivers of Disabled Older Adults

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## Abstract

With the ongoing intensification of population aging in China, the number of disabled older adults has surged, and home-based care has become the dominant eldercare model. As a result, family caregivers face increasing care burdens and significant skill gaps. Based on domestic and international studies, this article reviews the care needs of caregivers under community support and various forms of interventions, including home visits, psychological support, health education, and “Internet Plus” home care services. It systematically analyzes the effectiveness and limitations of different interventions, providing both theoretical underpinnings and practical references for optimizing community support systems and informing related policy development.

## Keywords

Disabled Older Adults, Family Caregivers, Community Support, Care Needs

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## 1. Introduction

According to the Report on the Development of China’s Aging Undertakings (2024), the number of people aged 60 and above in China has reached 310 million, accounting for approximately 22.2% of the total population [1]. This proportion is expected to exceed 30% by 2050, with those aged over 80 surpassing 100 million. Along with advanced aging, the proportion of disabled older adults suffering from chronic diseases has increased significantly. Data indicate that approximately 51.2% of elderly individuals at the end of life have at least one chronic illness [2]. The functional decline caused by these diseases makes daily care a heavy burden for family caregivers, highlighting deficiencies in community support systems and

revealing the urgent care and support needs for caregivers of disabled older adults. Some components, such as multi-leveled equations, graphics, and tables are not prescribed, although the various table text styles are provided. The formatter will need to create these components, incorporating the applicable criteria that follow.

## **2. Key Concepts**

### **2.1. Disabled Older Adults**

According to the World Health Organization (WHO), “disability” refers to the state in which individuals are unable to independently perform necessary daily activities due to aging, illness, or physical and mental impairments [3]. In Chinese academic discourse, disabled older adults are generally defined as those aged 60 years or above who have partially or completely lost the ability to perform activities of daily living and require long-term assistance. As of 2023, China has recorded approximately 45.63 million disabled and semi-disabled elderly individuals, making it the country with the largest disabled elderly population globally. The corresponding care burden and demand for services are also rising sharply.

### **2.2. Family Caregivers**

Family caregivers are individuals, primarily family members or close acquaintances, who provide unpaid care to disabled persons. Their caregiving roles include daily life assistance, emotional companionship, and disease management. These caregivers may be spouses, children, parents, neighbors, or other relatives and friends of the care recipients. Around 90% of older adults in China prefer aging at home [4]. By 2030, the number of disabled older adults is projected to exceed 60 million [5], posing significant challenges to the sustainability and capacity of the family caregiving system.

### **2.3. Care Needs of Caregivers**

Caregiver needs refer to the professional support requirements related to health and caregiving tasks encountered during the provision of care. Research shows that caregiving burden is a central factor affecting the physical and mental health of caregivers, with a negative correlation between burden levels and caregivers’ well-being [6]. Family caregivers often experience prolonged stress across physical, psychological, and social domains, leading to a pressing demand for internal family support and external community assistance [7]. These caregivers urgently require support in areas such as financial resources, medical knowledge and skills, respite care, and social recognition [8]. Effective coordination between community services and family caregivers can improve the quality of home-based care, reduce caregiver stress, and meet the elderly’s preference to age in place [9].

### 3. Care Needs and Assessment Tools for Disabled Older Adults and Their Caregivers

#### 3.1. Assessment Tools for Caregiver Needs

In China, Liu Lamei and colleagues [10] developed a “Knowledge and Skills Checklist for Caregivers,” which contains 17 items rated on a 5-point Likert scale from “not needed” to “very much needed.” A higher total score indicates stronger caregiver needs. This tool demonstrated excellent internal consistency with a Cronbach’s alpha of 0.97. Wang Yuanrong *et al.* [11] designed a “Care Needs Questionnaire for Family Caregivers of Older Adults,” comprising 13 items also scored using a 5-point Likert scale ranging from “least desired” to “most desired,” with a Cronbach’s alpha of 0.91.

Internationally, Farahani *et al.* [12] adapted the Marutz and Kreutzer caregiver needs questionnaire to develop the “Family Caregiver Needs Survey for Stroke Patients” in Iran. The tool includes 43 binary-scored items (1 for needed, 0 for not needed), with total scores ranging from 0 to 43. A higher score indicates more extensive needs. This scale achieved a KR-20 coefficient of 0.95, indicating high reliability.

#### 3.2. Current Research in China on Care Needs of Disabled Older Adults and Their Caregivers

Chinese studies consistently show that family caregivers are primarily responsible for daily care and health management but generally lack adequate caregiving skills and training. Many caregivers are unprepared for emergencies and have limited access to professional information [13].

Sun Xiaoning *et al.* [14] identified high caregiver demand for knowledge in chronic disease management, household medication, nutrition, memory enhancement, and rehabilitation training. Caregivers of older adults with hip fractures particularly need extended care support in the areas of community health resources, rehabilitation, and home care services [15].

In their caregiving roles, family caregivers often serve multiple functions—as household managers, healthcare providers, information mediators, communicators, and economic supporters. These overlapping roles create substantial physical and emotional burdens [16]. Tang Lan *et al.* [17] reported that over 60% of disabled elderly need daily care and emotional support, over 80% need medical services, and more than 70% require rehabilitation. As disability severity increases, so does the intensity of service needs across all domains [18].

Positive social support plays a key role in mitigating frailty in both the disabled elderly and their caregivers and promotes the dual health outcomes of both parties. In China, community caregiver needs mainly focus on disease education, psychological support, symptom management, and basic caregiving guidance. However, caregivers often lack structured training and professional instruction.

#### 3.3. Research on Community Support Needs for Caregivers Abroad

International studies have highlighted the psychological burden of caregiving as a

major focus of health services research. Honda *et al.* [19] found that long-term caregiving could lead to heightened psychological distress, deteriorating physical health, social isolation, and increased risk of anxiety, depression, illness, and even mortality.

Riffin *et al.* [20] found that while most caregivers can manage basic tasks such as medication administration, fewer than 25% receive formal support such as training, respite care, or participation in support groups. Their needs are primarily psychosocial, including emotional support and stress relief.

Gardiner *et al.* [21] observed that many caregivers are unaware of how to access available community resources, and complicated service procedures often reduce accessibility. This reflects a widespread issue across countries: the lack of user-friendly, equitable access to community-based professional services.

## **4. Community-Based Support for Caregivers of Disabled Older Adults**

### **4.1. Home Visits as Support for Caregivers**

Home visits, conducted by community healthcare personnel, involve regular, in-home assessments and care guidance for the disabled elderly and their caregivers. This intervention aims to improve health outcomes, provide tailored disease management, and enhance self-care abilities through continued engagement with local health resources [22].

Zhu Yaping *et al.* [23] conducted a randomized controlled study in Jing'an District, Shanghai, involving 84 homebound disabled elderly individuals. The intervention group received structured home visits guided by nursing protocols, covering activities of daily living (ADL) support, while the control group received routine weekly visits. Over a 3-month period, the intervention group showed improved ADL scores and caregiver confidence due to consistent rehabilitation instruction and caregiver training.

Similarly, Yan Zheng's [24] study in Xicheng District, Beijing, applied an enhanced home visit protocol that incorporated individualized care planning and compliance monitoring. Results demonstrated significant improvements in the self-care capabilities of the elderly, confirming the role of structured home visits in promoting rehabilitation outcomes.

In a mixed-methods study by Stijnen *et al.* [25], participants reported high satisfaction regardless of whether direct medical issues were identified during the visit. The value lay in expressing daily concerns and receiving validation. Home visits also fostered caregivers' sense of involvement and capacity to manage caregiving responsibilities. To improve efficacy, future community interventions should develop standardized training for dedicated home visit teams.

### **4.2. Psychological Interventions to Support Caregivers**

Caregivers of disabled older adults often face long-term care challenges compounded by a lack of effective social support, which significantly increases their

risk of developing psychological problems. As Zhang *et al.* [26] pointed out, caregiving stress combined with limited health literacy and low self-efficacy can adversely affect caregivers' quality of life.

In an intervention study by Huang *et al.* [27], a total of 120 caregivers of disabled elderly residents from Daning Subdistrict were randomly divided into an intervention group and a control group, with 60 participants in each. The control group received routine follow-up care, while the intervention group received structured group-based psychological interventions. These were delivered by a team consisting of certified national-level psychological counselors and professionally trained community healthcare workers. The interventions included group psychological counseling, disease education, and rehabilitation guidance. Sessions were held every 8 weeks for a total of eight sessions, after which monthly telephone follow-ups were conducted.

Results indicated that psychological interventions significantly reduced caregivers' negative emotional states, including depression and anxiety, improved their psychological well-being, and enhanced their overall satisfaction with life and caregiving confidence.

International studies have yielded similar findings. Hounsri *et al.* [28] demonstrated that technology-based psychosocial interventions—such as online counseling and telephone guidance—enhanced caregivers' self-efficacy and caregiving competence, while also alleviating symptoms of anxiety and depression.

However, it is worth noting that in many international contexts, psychological interventions targeting caregivers receive limited attention. As reported by Elsheikh *et al.* [29], despite high caregiver burden, psychosocial interventions often fail to significantly reduce caregiver stress. While patient satisfaction with healthcare providers may improve, caregiver outcomes tend to lag behind, suggesting a disconnect between intervention design and caregiver needs.

To enhance the effectiveness of such interventions, future community-based mental health services should adopt an integrated model that links medical, social, and technological resources, forming a collaborative “medical-social-tech” support mechanism.

### 4.3. Health Education as Support for Caregivers

A lack of professional caregiving knowledge and skills among caregivers of disabled older adults often leads to increased caregiving burden [30]. To provide effective care, caregivers require not only foundational knowledge of elderly care, but also disease management strategies, mental health support for the disabled elderly, and guidance on rehabilitation techniques [31]. Health education plays a pivotal role in reducing caregiver stress and improving caregiving competency.

In a randomized controlled trial by İnci and Temel [32], 70 female family caregivers of stroke survivors were randomly assigned to an experimental group ( $n = 34$ ) and a control group ( $n = 36$ ). The experimental group received, in addition to standard home care, a structured support program covering topics such as an

overview of stroke, caregiving methods, stress and coping strategies, and intra-family communication. The control group received only routine home care. Results showed that health education significantly alleviated caregivers' anxiety and depressive symptoms, reduced perceived caregiving burden, and enhanced caregiving satisfaction, quality of life, and psychological resilience.

In Portugal, a quasi-experimental study by Araújo *et al.* [33] demonstrated that training programs for informal caregivers of post-stroke patients substantially improved caregivers' ability to meet stroke-related healthcare needs at home. Caregivers reported a marked reduction in caregiving burden following the intervention, which further validated the effectiveness of structured educational support.

Health education not only alleviates patients' anxiety related to disease uncertainty but also helps relieve caregiver stress, thereby increasing patients' motivation for recovery and allowing caregivers necessary rest and recovery time. In China, such community-based educational initiatives remain in the early development stage. It is recommended to draw on international experience by establishing standardized platforms for caregiver training and promoting a hybrid model that integrates both online and offline learning to meet caregivers' diverse educational needs.

#### **4.4. "Internet Plus" Support for Caregivers**

In China's eldercare system, over 90% of older adults are cared for at home, while only 6% - 7% utilize community-based care and 3% - 4% reside in institutional facilities. Disabled older adults are primarily cared for by family members at home, yet they often experience limited mobility and anxiety about visiting hospitals. With the advancement of internet technologies, increasing attention has been given to the integration of digital platforms in home-based care. The "Internet Plus Home Care Services" model transcends spatial and temporal barriers by providing direct access to online consultations, caregiving guidance, and rehabilitation services for both disabled elderly individuals and their caregivers [34].

Research has shown that more than 75% of disabled or semi-disabled patients express a demand for Internet Plus services, reflecting urgent needs in daily care, health management, and psychological support [35]. Huang Chunli *et al.* [36] demonstrated that the application of this model significantly improves daily functioning among mildly disabled elderly patients and enhances caregiver preparedness.

Additionally, this model overcomes the limitations of time and location, enabling timely responses to caregivers' needs, relieving pressure on medical institutions, and helping caregivers fulfill their responsibilities more effectively while improving the quality of care and reducing their own burden.

Internationally, literature on similar digital care models is limited. Unlike China's integrated "Internet Plus" approach with online medical services, many foreign interventions rely more on telephone support and email-based programs. Several studies, such as those by Graf *et al.* and Bakas *et al.* [37]-[41], suggest that frequent, structured telephone support can partially alleviate caregivers' anxiety

and general caregiving burden. These interventions also offer therapeutic guidance and actionable advice, though they lack real-time interactivity.

Although still in its early stages of implementation, the Chinese government is actively promoting the “Internet Plus” nursing initiative. Communities are encouraged to further advance this model, enabling both caregivers and disabled elderly individuals to easily and promptly access health information. Moving forward, a unified smart care ecosystem should be developed by integrating community healthcare systems, remote monitoring technologies, and mobile applications.

#### 4.5. Respite Services for Caregivers

Currently, home-based respite services in China can be categorized into two main models: those centered on the care recipient and those centered on the caregiver. Most existing research focuses on the former. Respite care centered on the care recipient aims to reduce the burden on family caregivers by offering the following types of services:

- **Household support**, such as cooking, grocery shopping, laundry, and cleaning;
- **Personal care**, including assistance with oral hygiene, bathing, dressing, feeding, toileting, physical activity, companionship, and supervision;
- **Professional care**, which includes medication management and is provided by trained, experienced professionals.

Home-based respite services are typically implemented under the leadership of community organizations. These services are delivered by either formal or informal care providers who visit the patient’s home to offer temporary assistance with daily living or specialized care. In a systematic review by Mason *et al.* [42], day care services were found to reduce social and environmental isolation among elderly individuals, enhance their social engagement, and increase caregiver satisfaction across all types of respite care, thereby relieving caregiver stress.

Abrahams and Kleintjes [43] further emphasized that respite care is a crucial support mechanism, especially for caregivers of individuals with intellectual disabilities, as it offers a tangible means of relief and emotional recovery.

### 5. Conclusion and Outlook

Current research demonstrates that family caregivers play a pivotal role in the long-term care of disabled older adults. Their care needs span multiple dimensions, including professional knowledge and skills, psychological support, medical assistance, and respite services. Community-based support interventions—such as home visits, health education, and “Internet Plus” care models—have proven effective in alleviating caregiver burden and enhancing the quality of care.

Based on the findings of this review, we propose that the development of community caregiving systems be advanced through coordinated efforts in policy, technology, and service delivery:

- **Standardizing “Internet Plus Nursing” services** to improve accessibility and

efficiency. This would not only better meet caregivers' healthcare needs in a timely manner but also ease pressure on healthcare resources.

- **Expanding investment in psychological interventions and caregiver education**, with a particular focus on enhancing caregivers' psychological resilience. Given the close relationship between caregivers' well-being and the physical and mental health of disabled elderly individuals, effective community support remains essential.
- **Promoting a collaborative "community + family" care mechanism** to provide comprehensive support across formal and informal systems

Looking ahead, further empirical research is required to evaluate the long-term effectiveness of various intervention models. Building a sustainable care support system is vital for an aging society, and this includes the development of improved community service centers and professional nursing care infrastructure.

### Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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