

# *Social support for family caregivers of people with dementia*

Kong Weiwei<sup>1,a</sup>, Qu Lin<sup>1,b,\*</sup>

<sup>1</sup>Harbin University of Commerce, Harbin, Heilongjiang, 150028, China

<sup>a</sup>kk0724@163.com, <sup>b</sup>wangmumu228@163.com

\*Corresponding author

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**Abstract:** According to China's seven universal shows, by 2020 China's population aged 60 and above will be 264 million, accounting for 18.70%, and the population aged 65 and above will be 191 million, accounting for 13.5%. With the deepening of aging in China, the absolute number of dementia patients will be on the rise. Although the number of dementia patients in China is lower than that of other countries in the world so far, the quantity and quality of family caregivers are gaining attention because of the large population base and the increasing proportion of the elderly population in China. There are few theories of social support for family caregivers, so this paper looks at the social support problems faced by family caregivers, explores the shortcomings in the social support currently provided, and proposes solutions to help family caregivers of people with dementia receive strong social support.

## 1. Introduction

At present, the prevalence of dementia in old age is 5.56% among people aged 65 and above in China. Based on the fact that dementia is the main cause of dementia and that dementia also occurs mostly in the elderly population, although the prevalence rate in China is lower than that of other countries in the world, the number and quality of caregivers who provide home care for people with dementia is gaining attention because of the large population base and the increasing proportion of elderly people in China.

Due to the varying degrees of memory loss and aggressive behaviors associated with dementia, people with dementia not only gradually forget their relationships and roles, their general knowledge and skills, and their ability to avoid risks and take care of themselves, but they may also develop unpredictable aggressive behaviors due to their physical and mental health conditions, causing tremendous workload and psychological stress for family caregivers. Caregivers of patients with severe disease cannot leave them alone at home or even take them out for recreational activities. At the same time, family caregivers are essential for people with dementia because their condition is not universal and requires professional attention, and because they may be aggressive and unsuitable for living with the elderly in institutions or community centers, or for long-term care in nursing homes or day care facilities.

However, the number of studies on social support for family caregivers is small and shallow, and

research on the social support provided by family caregivers as a special group of dementia patients is still emerging.

## **2. Current Issues for Family Caregivers of People with Dementia**

### **2.1. Economic and Mental**

The tremendous pressure on family caregivers of people with dementia comes in two main parts. On the one hand, there is the financial pressure. When care is provided by a relative as a caregiver, the caregiver must quit their job and devote themselves to caring for the person with dementia, and therefore have no income from their job. While the family loses part of its financial resources, the fact that dementia is an irreversible and progressive disease that requires long-term medical treatment to slow down the disease and that there is currently no medical insurance coverage for this type of disease increases the financial burden on the family. Another stressor is the psychological one. Caring for a person with dementia requires more energy and physical effort than caring for an infant or child, a person with a disability, or a person who needs a family caregiver to provide care at home.

### **2.2. Low social support for such family caregiver**

#### **2.2.1. Low number of poor results did not form a normalized and standardized support**

Because long-term care is long, stressful, difficult, and demanding, the lack of social support for long-term independent caregivers can easily lead to financial stress, emotional breakdown, and adverse health effects. A number of studies have shown that the quality of life of family caregivers of the elderly with disabilities and dementia is significantly lower. A survey of 150 family caregivers of elderly with dementia in Zhumadian City using the SF-36 Health Survey Scale by Eminent Niu found that the quality of life status of family caregivers was poor and significantly lower than the national normative level. A survey study conducted by Shao Shuang et al. in Beijing showed that the model of long-term home care for the disabled elderly led to a significant reduction in the quality of life of the caregivers. The results of a study by Yanbo et al. on a sample of 20 individuals similarly showed that family caregivers of Alzheimer's patients had problems in quality of life. In the United States, Markowitz et al. used the Quality of Life Short Form SF-12 to measure health-related quality of life in 2477 family caregivers and found that this group scored low on mental and physical health. In a Japanese study comparing 1302 family caregivers of patients with Alzheimer's disease or dementia with 53758 non-family caregivers, the family caregiver group had a low health-related quality of life <sup>[1]</sup>.

#### **2.2.2. Less specialized and less targeted to give effective support**

The definition of quality of life in studies related to interventions to improve the social quality of family caregivers is mostly reflected in the chosen quality of life measurement instruments, which include the Brief Health Survey Scale (SF-36) and the World Health Organization Quality of Life Short Form (WHOQOL-BREF). Physical health and mental health are the two main concerns in measuring the quality of life of family caregivers. Four types of social support interventions are available abroad: (1) friend and peer support, (2) family support and social network interventions, (3) support groups, and (4) remote interventions using the Internet and telephone, with multiple combinations of social support interventions being the most effective, and inconsistent results for remote interventions. The main domestic interventions for family caregivers are (1) comprehensive health education interventions, (2) behavioral interventions including three components of disease

knowledge dissemination, emergency response methods, and caregiving skills training, (3) health education guided by empowerment theory, (4) supportive psychological interventions aimed at improving anxiety and depression in guardians of hospitalized Alzheimer's patients, and (5) knowledge dissemination, skills training, psychological guidance, stress coping styles, etc. as the main content of nursing interventions, micro-extended care; and (6) cognitive training and caregiver support parallel interventions for Alzheimer patients [2].

Shortcomings of existing domestic interventions. First, the interventions are mostly small-scale, short-term practice in nature, or interventions conducted for the purpose of conducting academic research, and the intervention methods are not effectively promoted or continued to reach more family caregivers. Intervention content needs to be enriched. The existing interventions are mainly knowledge dissemination and skills training, and there are fewer interventions at the family and community levels and less full exploitation of social resources. There are fewer forms of interventions based on online platforms. In practice, the network platform can be fully utilized for the purpose of resource sharing, instant consultation and information finding to meet the diverse needs of caregivers. In terms of policy, the Social Aging Service System Construction Plan (2011-2015) has paid attention to the group of elderly people with disabilities, but domestic regulations and policies for the group of caregivers of people with disabilities and dementia are in a blank state. The policy of long-term care service provision in China does not involve the provision within the family, and a large amount of financial subsidies go to institutional care services and community day care centers, however, the proportion of services provided outside the family such as elderly care institutions, community and home care services is less than 5%. Family caregivers, the mainstay of long-term care, receive insufficient formal support. In addition, direct respite services for family caregivers are concentrated in large urban areas such as Hangzhou, Shanghai, and Beijing, and are rarely available in smaller cities or even rural areas. At the same time, the development of respite services is faced with barrier factors at the formal and informal levels of social support [3].

### **3. Social support for family caregivers of people with dementia.**

With the development of modern science and medical knowledge, there has been more research on some difficult diseases and it is possible to prevent and cure some of them. Although brain disorders such as dementia are still a blind spot for medical treatment, it is possible to apply different levels of intervention and treatment to patients before and during the onset of the disease, thus reducing the chance of the onset of the disease in the elderly and slowing down its severity when it occurs.

#### **3.1. Scientific prevention and treatment of dementia**

As the core link of graded treatment, family doctors provide or start to provide more targeted health management services for dementia patients according to their physical functions, chronic diseases and family care ability, and provide health service management for dementia patients in a reasonable and accessible way that combines medical care and health care in a community radius, so that they do not have to go around the big circle and run to big hospitals for minor illnesses, and change from seeking medical treatment to sending medical treatment to their homes and promote the intensive use of resources.

#### **3.2. Development of Internet Healthcare**

Use Internet medical care as the driving engine to make stronger online contacts. Internet

medical care is the Internet as a carrier and information technology as a means of medical information query, online disease consultation, electronic health records, electronic medical records prescription, remote video consultation and other forms of online medical services. In response to the characteristics of dementia patients who have limited mobility and limited escorts but need more professional medical and nursing care, the full use of the Internet can promote the expansion of high-quality medical resources, improve the efficiency and quality of medical services available to dementia patients, and at the same time reduce the trouble of dementia patients going out.

### **3.3. Cultivate professional and vocational conservation staff**

There is a significant contradiction between the supply and demand of nursing service personnel, with most caregivers going straight to work without professional knowledge and skills training and lacking relevant expertise and experience after only simple training. Caregivers who provide home care for people with dementia need to have professional knowledge and strong psychological literacy. The goal of "increasing capacity", "increasing quantity" and "increasing efficiency" is to face the difficulties of insufficient development and unbalanced contradictions, and to explore the potential to stimulate the health services for the elderly with dementia. We should continue to strengthen the quality management of the elderly service team, expand the scale of the elderly service practitioners, and improve the career development space of the elderly service professionals, as well as their salaries and benefits. Let professionals do professional work, so as to reduce the pressure and burden of family caregivers of dementia patients.

## **4. Enhancing social support for family caregivers**

To provide social support to family caregivers of people with dementia, their ability and confidence in providing care services should be improved, and internal stress should be relieved. In this way, their quality of life will be improved, and the physical and mental health of family caregivers will also be guaranteed.

### **4.1. Training caregivers on care giving knowledge and skills**

Regular professional training is provided to family caregivers of dementia patients to reduce the difficulties of caregivers in the process of home care, to make care more scientific and effective, and to reduce mood swings and violent episodes of dementia patients. We should also provide scientific information to healthy seniors and their families to increase people's understanding of dementia, so that they can detect, intervene and treat it early compared to their own conditions; at the same time, we should promote science to the public to remove the stigma of "dementia" and eliminate the sense of shame among caregivers and families. This will encourage family caregivers of dementia patients to actively seek social support and help them to actively participate in research and policy development to improve and enhance social support for them.

### **4.2. Establishing mutual support groups and communication platforms in the community**

Support groups and communication groups can be set up under the leadership of hospitals and communities. Family caregivers who are also dementia patients can understand each other's pain and stress better than others, so they can easily find a sense of belonging and be understood in the face of their peers. Family caregivers can share their experiences, exchange ideas, talk about their suffering, and receive encouragement and comfort on this platform.

### 4.3. Psychological guidance and soothing, professional psychological services

Family caregivers of dementia patients should be provided with regular psychological counseling and soothing comfort at different levels, which can be provided by the community, professional institutions, and hospitals separately or jointly. Through regular psychological counseling, the negative emotions and psychological stress of family caregivers can be reduced, and elder abuse can be avoided, while the quality of life of family caregivers can be improved. The provision of different levels of psychological services is aimed at people of different levels and needs to fully meet people's needs in old age.

### 4.4. Vigorously develop long-term care insurance to expand coverage targets and protection items

China has been piloting the long-term care insurance system in 14 cities since 2020, and more and more cities are joining the pilot scope of long-term care insurance. However, long-term care insurance focuses on protecting and subsidizing people with disabilities and their related caregivers and care institutions, while people with dementia and caregivers of people with dementia are not covered by this insurance. It is hoped that with the development of our economy and social progress, LTC insurance will include dementia and its caregivers in the coverage system, provide more social support to family caregivers of dementia patients, and encourage institutions to care for dementia patients to improve the quality and efficiency of dementia care.

## 5. Conclusion

Currently, family caregivers, mainly children and spouses, are still the main caregivers of the elderly with dementia. Among male elderly with dementia, 22.4% are cared for by their spouses and 65.2% by their children; among female elderly with dementia, 4.2% are cared for by their spouses and 84.5% by their children<sup>[4]</sup>. However, with the social structural changes of fewer children, aging, and smaller family structures, the demand for care for dementia patients is bound to grow and the quality requirements increase. As women's education level increases and their economic ability grows, more and more women are joining the workforce, and dementia patients who could originally be cared for at home are bound to move into the community and into institutions. In addition to providing perfect social support for family caregivers of dementia patients, it is crucial to construct a perfect care system for home - community - institutionalized dementia patients.

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