Learning from the UK Community Care Intervention Experience in Dealing with the Risk of Dementia

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Abstract. This paper uses a comparative research method to examine the example of the UK community care interventions to address the dementia risk. Based on the ideas of “de-institutionalization movement” and “welfare pluralism”, this paper analyzes the barriers to the care of dementia in China's community elderly care service from three perspectives: policy design, role orientation of community residents committee and civil organization intervention. Suggestions were made to give play to the leading role of the government, to clarify the orientation of community care responsibilities, and to create a community environment for dementia-friendly communities.

1. Introduction

Dementia is a kind of serious and persistent cognitive disorder characterized by a slow-onset mental decline [1]. Due to the increase in the elderly population and the extension of life expectancy in China, China is expected to have 14.1 million people with dementia by 2020. The risk challenge for dementia should not be ignored. This paper introduces summarizes the experience of the UK in solving the risk of dementia by introducing the policy changes for the care of dementia in the UK, the construction of the dementia community care management system, the intervention content and the Dementia Friendly Communities, and proposes corresponding countermeasures and suggestions based on the existing problems in China.

2. Proposal of problem

According to estimates, the economic cost of global response to dementia in 2018 reached one billion US dollars, of which about 40% are social care costs such as family care [2]. With the development of the trend of miniaturization of modern families in China, this has also led to a significant reduction in the family pension resources available to the demented, and it is difficult to effectively cope with the high cost of care for dementia. At the same time, huge care costs and psychological pressure may lead to collapse of family care mode of dementia, which will have a negative impact on the life quality and social integration of the demented, and even lead to family ethical risks and social security systems and unstable factors in social governance. It is
particularly urgent and necessary to learn from the UK experience based on a complete community care system and actively develop community care models to effectively prevent and resolve the social risks of dementia.

3. UK community experience of intervention care services for elderly dementia

The UK government used to provide free inpatient care for disabled people such as the demented elderly and placed them in a large national established welfare home which is separated from their living communities. Affected by the ideas of “de-institutionalization movement” and “welfare pluralism”, it now encourages people who need long-term care to live in familiar communities. Services are provided directly by for-profit organizations, non-profit organizations, volunteers, relatives and neighbors. The government purchases and supervises such services [3]. Diversified community care providers can provide more personalized services for people with different needs, effectively reducing the cost of care. This paper mainly focuses on the following aspects:

3.1 Government-led and policy-driven

As of 2018, there are about 850,000 dementia patients in the UK, and by 2022, this number will increase to 1 million. The UK’s Department of Health and Social Care has published more than 20 government documents or institutional research reports focusing on dementia. Table 1 reflects several key points and main contents of the UK government's policy changes in dealing with dementia.

<table>
<thead>
<tr>
<th>Year</th>
<th>Policy Change</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>Living well with dementia: A National Dementia Strategy</td>
<td>Dementia is one of the biggest challenges facing the UK society today. It provides a strategic framework for preventing the social risks of dementia.</td>
</tr>
<tr>
<td>2012</td>
<td>Prime Minister’s challenge on dementia: Delivering major improvements in dementia care and research by 2015</td>
<td>Based on the existing national strategic achievements, to make significant progress in dementia care by 2015, create a Dementia Friendly Communities and launch a national campaign to address the challenge of dementia.</td>
</tr>
<tr>
<td>2015</td>
<td>Prime Minister’s challenge on dementia 2020</td>
<td>To make the UK the best country for dementia care and social support (including patients and their families) and neurological disease research by 2020. It includes 18 Prime Minister commitments.</td>
</tr>
<tr>
<td>2016</td>
<td>Prime Minister’s Challenge on Dementia 2020: Implementation Plan</td>
<td>It includes 50 commitments and timetable for implementation.</td>
</tr>
</tbody>
</table>

Organized from the official website of the UK Ministry of Health:

https://www.gov.uk/health-and-social-care/dementia
3.2 Complete system and accurate intervention

The UK has established a multi-level system of physical and mental health services for the elderly from the community level. Under the two support systems of medical services and social services, the elderly dementia patients in the UK have received the overall care of daily life care and material assistance in the community. Medical services are handled by the Ministry of Health's NHS system; social care services, including elderly dementia patients, are provided by local social service departments (SSDs).

In the medical services of the demented elderly, the general practitioners (GPs) in the community played a leading role in ensuring the continuity and coordination of dementia elderly care. When a GP preliminarily judges that the elderly has a related physical and mental health risk, the elderly will be referred to the upper-level medical and health institutions for initial medical treatment from the professional medical institution. The UK has also included 40-74-year-old residents in the NHS Health Checks Program to increase the rate of diagnosis of dementia in the country.

A series of policy measures have been taken by the UK government to promote the community of long-term care. The social service system in the community is mainly composed of managers, staff members and caregivers. The managers are responsible for the allocation of government funds, appointment of key personnel, employment of caregivers, and supervision and guidance; staff members are responsible for the care and management of the elderly in certain community, mainly responsible for the placement of pensions, understanding and collecting needs, and helping to solve daily life problems; caregivers, mostly are relatives or neighbors of the elderly, take care of the demented elderly, and the government gives them a certain service subsidy [4] [5]. This kind of government-community integrated management system embedded in the community provides flexible and personalized services for the demented elderly. It is shown in Figure 1:

![Figure 1. the UK Dementia Community Care Management System](image)

In the UK, the total number of unpaid cares for dementia patients is 1.34 billion hours, and the annual economic cost of dealing with dementia in the country exceeds 26.3 billion pounds, of which 21.9 billion pounds are spent on social care [6]. On the other hand, the government will give the demented elderly in the community the same subsidies as the hospitalization. At the same time, the day care centers or community activity centers scattered
in the community can provide so-called "wheezing" care services for family members taking long-term care of
disabled or demented elderly. This not only greatly relieves the pressure of disability and dementia family
members, but also encourages the elderly to participate in community activities and get rid of loneliness.

3.3 Dementia Friendly Communities and Dementia Friends

It is estimated that two-thirds of dementia patients in the UK today live in the Communities [7]. In order to
break down the stigma attached to dementia and popularize the concept that the demented elderly can be helped,
the UK launched a national action plan for dementia at the end of 2012 relying on the successful experience
accumulated in community care in the country. One important content is to build more than 100 Demented
Friendly Communities and train more than 40,000 Dementia Friends by 2020 [8]. The purpose of Dementia
Friendly Communities and Dementia Friends is to create a friendly community with a broad knowledge and
understanding of dementia, increase public awareness of dementia, and encourage demented elderly to
participate in social activities on an equal footing. At the same time, the community will rely on the information
sharing network such as the elderly hotline to share and disseminate information on the care and treatment of
demented elderly people online, so that everyone can become a caregiver for the elderly.

4. Analysis of barriers to elderly care intervention in communities in China

At present, there are many obstacles in the elderly care intervention of dementia care in communities in China.
First, because China has not yet formulated a medium and long-term strategic plan for dealing with the risk of
dementia, community service intervention lacks policy guidance. Secondly, the content of community elderly
care services in China is less and the level is low, making it difficult to meet the care needs of demented elderly
people. Finally, there is a lack of civil society organizations participation, which has made the development of
community medical services less dynamic, and it is difficult to form a demented friendly social environment
with multi-subjects participation.

4.1 Policy support for community services for the demented elderly is lagged behind

In China, due to the lack of special legal policies for patients with dementia, the involvement of community
services lacks policy motivation. In the newly revised Law on the Protection of the Rights and Interests of the
Elderly in 2018, it only stipulates the support responsibilities of family members and the responsibilities of
government at all levels to provide nursing subsidies for the elderly who are unable to take care of themselves
for a long time. However, there is no specific regulations for the prevention and treatment of demented elderly.
The Medium and Long-Term Plan for the Prevention and Treatment of Chronic Diseases in China (2017-2025)
only focuses on chronic diseases such as cancer, cardiovascular and cerebrovascular diseases, but neglects
dementia which is harmful to the life quality of the elderly and the cost of prevention and treatment is equally
high. In China, the protection of dementia is in the vague area of long-term care insurance coverage. Today,
only Qingdao, Chengdu, Shanghai and some other places include the demented elderly people in long-term care.
China has not yet formulated a national strategic plan to address the challenge of dementia. In various local governmental policy documents for the development of community care services, there is only a macro plan for the development goals of the future elderly care community, without specific measures for demented elderly care. As a result, the integration of service resources for dementia is low, and community professional care is seriously lagging behind.

4.2 The role of community neighborhood committee is not clear

Community health service should be the basic link of social welfare undertakings. However, due to the embarrassing status of the community neighborhood committee's own administrative system, it often conflicts with its roles when providing elderly service, which leads to insufficient stamina for the development of community welfare for the elderly. On the one hand, the community is managed by the civil affairs department, the health department and other departments, and is often tired of coping with various tasks. On the other hand, it should be the community committee of the mass autonomous organization. Due to excessive administration, the initiative of residents to participate in community affairs was severely suppressed. This is the main institutional obstacle to the community's inability to provide appropriate welfare resources for people with dementia. The primary diagnoses and treatment of the community is basically lacking, and there is no mechanism for screening and prevention of dementia, thus resulting in less early diagnosis at the community level and basically zero early intervention and prevention of dementia.

4.3 The involvement and support of civil organizations is low

Community care in the UK leverages formal resources and informal social support networks within the community to form an action coalition of governments, communities, research institutions, and civil society groups to address the challenges of dementia. Every year, 48% of people in the UK participate in volunteer activities and serve the community's old-age care. At the same time, the government provides professional training for dementia care for local social service workers and NHS employees, and strives to improve the society's awareness of dementia. In China, although the special elderly welfare institutions have been developing, the community old-age services are still very limited. The non-profit organizations and professionalized elderly social work are developing slowly, lacking certain autonomy and independence, and cannot be effectively mobilized. In this context, the professional ability of civil society organizations to participate in the provision of elderly care services for the demented elderly in the community is inevitably affected, and its function as an important subject is also greatly reduced [9]. The lack of participation of non-profit public organizations is still one of the main problems in the community elderly care in China.
5. Suggestions for community care intervention for elderly dementia services

5.1 Give play to the leading role of the government and clarify the orientation of community care responsibility

The collapse of the “unit system” that originally assumed responsibility for the elderly care in the country and the family is likely to lead to the risk of disengagement of family-society-state entity care. Therefore, the government should formulate prevention and control strategies at the national level as soon as possible, clarify the main responsibility of community care, and improve the supporting policies for community care of dementia patients to cope with the risk of dementia. At the same time, the government should include the demented people in the scope of long-term care insurance; include dementia in the chronic disease help list, expand the scope of medical insurance reimbursement for related treatment drugs; and give families with dementia patients certain tax deduction, so as to provide policy support for demented elderly to enjoy basic life care and medical care in the community. It should promote the development of community care system, give full play to the functions of mass residents' self-government within the community, clarify the role of the community in the provision of old-age care services, and strengthen its administrative personnel reform. To actively break the institutional and logical contradictions between power and responsibility, administration and autonomy in the work of the community committee [10]. Only in this way, the challenge of dementia can be effectively coped with, and the dementia patients can be provided with long-term community care.

5.2 Expand the publicity of knowledge about dementia and improve the primary diagnosis and treatment system

It is suggested to strengthen the popularization of the knowledge of dementia, establish a three-in-one primary diagnosis and prevention system including families, community committees and community health service institutions, and conduct regular and universal screening for dementia, which will undoubtedly plays an important role in improving the early diagnosis ratio of dementia. At the same time, it should improve the functions of community medical institutions in preventive education, primary diagnosis and transfer treatment; conduct pilot projects for dementia-friendly community projects, make full use of idle public facilities, build and renovate professional care areas for dementia patients, and incrementally and roundly improve the ability of the communities to provide public services, relying on day care and other medical care facilities in the community to provide “wheezing” service for the demented elderly and their families.

5.3 Guide social forces to participate and create a demented friendly community environment

The social forces should participate in the sharing the risks and care costs of dementia at multiple levels and with multiple subjects. Following the market-oriented mechanism, a community micro-fund, so as to establish a healthy and sustainable fund-raising system. To enhance the informal care support, explore the establishment of a long-term care system for social workers volunteers, strengthen the construction of professional volunteer teams, and record the caregiver’s service time according to certain rules, and store it in its “time bank” in order
to redeem corresponding services or rewarding; To reduce or even eliminate the prejudice and construction of the community environment for the demented elderly, and to build a dementia friendly community environment.

6. Conclusion

From the above research, we can find that to clarify the responsibility of community and establish a long-lasting and continuous community intervention mechanism can appropriately liberate the heavy care pressure of family members and effectively delay the course of dementia. In the future theoretical and practical exploration, it should further explore the increasing supply medical-nursing combined services of communities and community support measures for the family members of the dementia patients.

References


  https://www.alz.co.uk/research/world-report


