

Article

Dementia care in rural China

Shulin Chen MD PhD

Department of Psychology, Zhejiang University, Hangzhou, China

Lisa L Boyle MD MPH

Department of Psychiatry, University of Rochester School of Medicine, Rochester, NY, USA

Yeates Conwell MD

Department of Psychiatry, University of Rochester School of Medicine, Rochester, NY, USA

Helen Chiu MD

Department of Psychiatry, Chinese University of Hong Kong, Hong Kong

Lydia Li PhD

Department of Social Work, University of Michigan, Michigan, USA

Shuiyuan Xiao MD PhD

Public Health School, Central South University, Changsha, China

ABSTRACT

Dementia is a major cause of disability and has immense cost implications for the individual suffering from the condition, family caregivers and society. Given the high prevalence of dementia in China with its enormous and rapidly expanding population of elderly adults, it is necessary to develop and test approaches to the care for patients with this disorder. The need is especially great in rural China where access to mental healthcare is limited, with the task made more complex by social and economic reforms over the last 30 years that have transformed the

Chinese family support system, family values and health delivery systems. Evidence-based collaborative care models for dementia, depression and other chronic diseases that have been developed in some Western countries serve as a basis for discussion of innovative approaches in the management of dementia in rural China, with particular focus on its implementation in the primary care system.

Keywords: collaborative care, chronic disease management, dementia, rural China

Introduction

The earliest description of dementia can be traced to Hua Tuo (AD 140–208) in the Han Dynasty who described the illness as an insufficiency of Qi, a flowing energy.¹ Almost two millennia later, China has taken its place among leading nations of the modern world in its understanding of dementia. Alzheimer's disease and related dementias are now better understood as neurodegenerative processes and scientists worldwide are aggressively seeking a cure. Nonetheless, our ability to manage the illness remains poor. Traditional Chinese medicine has

developed approaches to the treatment of dementia – some have been tested in clinical trials for their efficacy;² however, there remains no cure. Dementia is a major cause of disability and has immense cost implications for the individual suffering from the condition, family caregivers and society. The estimated annual direct cost in 2003 per person with dementia in East Asian countries (including China) was US\$4007. Indirect costs, such as the time caregivers spend with patients and associated loss of productivity in the workplace, are even greater. As

the world's most populous country with the largest ageing population, China is increasingly concerned with how best to provide care for the most prevalent and costly health conditions of later life. This paper discusses the challenges of managing dementia in rural areas of China, where more than 70% of the population lives. We examine the role of primary care providers in dementia care and propose strategies that may help to improve the care and services provided to individuals with dementia and their family caregivers residing in rural China.

Prevalence of dementia in China

According to the National Bureau of Statistics, the number of people aged 60 years and older in China has risen to 185 million.³ Mental disorders associated with ageing are a substantial component of the challenge of caring for this growing population of elderly people. Dementia is one of the most common neuropsychiatric disorders in older adults, in whom the prevalence doubles every five years over the age of 65. The prevalence of dementia among older adults in developed countries has been reported to be around 5–6%.⁴ The pooled prevalence of dementia in China for the population aged 60 years and older was 3%, similar to that of developed countries.⁴ In rural China, the adjusted prevalence of dementia was 0.33%, 0.89%, 3.43% and 8.19% in people in the age groups 50–54, 55–64, 65–74 and ≥ 75 respectively.⁵

Social factors and the burden of dementia

In addition to considering the epidemiological changes in the number of Chinese older adults living with dementia, understanding the trends in the burden of dementia care must consider important social transitions underway in rural China.

Economic reforms since the late 1970s have brought significant changes in China. While the pace of development is rapid in urban areas, rural regions lag behind. China faces enormous challenges – almost 75% of its residents live in rural areas and almost 20% of village residents are over the age of 60.³ The true proportion of those over the age of 60 is likely to be far higher when one takes into

account that younger and middle-aged adults have moved to the cities to find work yet remain identified by the national registry system as village residents. There has been a massive shift of rural residents from agricultural to non-agricultural employment; over 250 million migrant workers moved from rural to urban areas in China in 2011, representing an increase of 4.4% from 2010.³ These migrant transitions mean that older adults are 'left behind' in their rural homes to live alone without immediate family support.

Economic reforms and migrant workers have led to the modernisation of urban China, but also a change to traditional family values that is most pronounced in rural areas. Modernisation theorists, from Karl Marx to Daniel Bell, have argued that economic development brings pervasive cultural changes.⁶ Chinese society has traditionally placed great importance on the children's roles and duties in the family as part of the larger Chinese value of filial piety, of which family obligation is a component. The rural elderly generally are cared for by their family; however, with the social and economic changes that transpired at the end of the 20th century, many observers believe the family care model is weakening. Analyses of studies of Chinese attitudes since 1985 indicate a declining emphasis on obedience and loyalty to family members.^{7,8} Another study found that young people in China today adopt a more liberal view towards family than their parents, they prefer to maintain independent households, they adhere less to filial beliefs and commit less to their parents.⁹ The same transition is underway in both urban and rural areas. Decreasing family size and increased job mobility add to the segregation and isolation of older adults, resulting in the family assuming less responsibility for the care of their elders,¹⁰ including the growing numbers of older adults with dementia.

The challenge is clear, before new approaches can be developed to manage the growing epidemic of elderly people living with dementia and diminished supports in rural settings, it is necessary to understand the healthcare system in rural China and the current state of dementia care.

The evolving healthcare system in rural China

Market reform began in China in 1979, but before this the rural population was covered by the Cooperative Medical Scheme (CMS), which provided

basic health and preventive care to almost all rural residents. The financing and structure of the CMS was tied to the collectivisation of agriculture and the commune system of agricultural cooperatives. The CMS collapsed following market reforms as economic policy promoted a shift from collectivism to household responsibility that gave family units the task of production and entitlement to sell their surplus in the marketplace after fulfilling their procurement quota obligations. Consequently, health insurance coverage in rural China diminished dramatically. In 1975, approximately 85% of the rural population had health insurance, by 2003 that figure had dropped to 9.5%.¹¹ In response, the central government launched the New Cooperative Medical Scheme (NCMS) to specifically target rural residents, with funding from the central and local governments as well as enrollee contributions. The NCMS is a voluntary programme focusing largely on inpatient care costs. Local governments have discretion to design the programme, which varies the benefit package widely from region to region.¹²

In the NCMS there are three tiers of institutions for delivering healthcare in rural China – village clinics, township hospitals and county general hospitals. The village clinic is the primary care setting for the elderly, and has been expanded rapidly in the last ten years. In 1990, there were village clinics in 87% of rural villages; by 2010 the proportion of villages with clinics had grown to 92.3% nationwide.¹³ According to the database provided by the China Ministry of Health, there were 594 658 villages that year, served by just over 1 million village physicians. The number of village physicians per 1000 residents has shown a steady increase. From ‘barefoot doctors’ in 1985 – now officially named ‘rural physicians’ – village doctors have dramatically improved rural emergency care, immunisation rates, infectious disease control and infant and maternal mortality rates.¹³ The training and professionalisation of rural physicians has also been raised.¹⁴ Rural physicians in government-funded institutes have been enrolled in the standard three-year medical school programme and are required to pass the Ministry of Health exam and acquire the certificate to practice as village doctors.¹⁵

Overall, these reforms have led to easier access to primary care for older adults living in rural China. Patients, especially elderly ones, have higher rates of health insurance coverage and drop-by visits have resulted in greater utilisation of primary care services in both urban and rural China.

Primary care managing dementia care in rural China

In 2006, the Chinese central government announced additional reforms to the primary care system that further emphasised the centrality of the primary care physician (PCPs) in patient care management in rural areas. Guidelines were published on the development of community health services, referred to as ‘one body, six aspects’. The ‘body’ is the primary care clinic and village clinic in urban and rural areas respectively. The six ‘aspects’ of care consist of prevention, health education and promotion, birth control, outpatient evaluation and management of common illnesses, case management of chronic disease and physical rehabilitation.^{15,16} Anticipating the impact of these changes on health-care costs, the Chinese government insist on significant changes to its service delivery models. Recent policy reforms underscore an interest in shifting primary responsibility for chronic disease management to the village doctors.

Although there has been increasing emphasis on primary care to manage chronic diseases, mental health and memory disorder services remain minimal and difficult to access. In fact, the majority of rural patients with mental illnesses receive no psychiatric care at all. The same is true for dementia care.¹⁷

Moreover, awareness of dementia among the public is poor. For example, a recent study showed that lack of knowledge about dementia and stigma regarding the illness are common among urban residents in Shanghai¹⁸ – almost half of family members and caregivers considered dementia to be a normal part of ageing and 45% did not think that medical care could benefit those with dementia.^{18,19} The likelihood of feelings of shame for having relatives with dementia was common, especially amongst older people and those with a lower education level.^{18,19} Another cross-cultural study showed that stigmatisation of people with dementia was higher in the Chinese compared with African Americans and Latinos.²⁰

Knowledge and skills in the diagnosis and management of dementia are also low among healthcare providers. As in the US,^{21–23} patients with dementia in China are underdiagnosed and undertreated. A population-based door-to-door caregiver survey in four Chinese cities showed that only 26.9% of patients with dementia reported receiving a diagnosis.¹⁹ Among 428 family caregivers, only 21.3% reported receiving a recommendation that their relative with dementia take medication for their impaired cognitive function, and only 2% used

medication. These few studies indicate general education is needed to increase both the public and providers' awareness and understanding of dementia in China.

Studies conducted in Western countries designed to explore barriers to dementia care in rural settings identified problems with limited availability of transportation and limited access to both specialists and to community resources for individuals with dementia and their families.^{24–27} These barriers are likely to also apply to China but adequate studies have not been undertaken. In addition to the lack of knowledge, skills and resources of primary care providers, there are other obstacles to optimal dementia care in primary care settings.²⁴ These obstacles include the complex biomedical, psychosocial and ethical nature of dementia and health, as well as systemic and structural barriers such as insufficient time, an inadequate reimbursement structure, limited decision support, consultation and communication resources.

To overcome these barriers for dementia care in primary care, more comprehensive and co-ordinated care management approaches should be considered.

Collaborative care models for dementia care in rural China

Evidence-based models to help manage chronic diseases within primary care settings have been developed, studied extensively and shown effective for illnesses other than dementia, including depression, anxiety and a range of chronic medical conditions.^{28–34} Core elements of chronic care models include accessing community resources, a health system that values improved quality of care for chronic conditions, enhancing the patient's capacity to self-manage his or her illness, healthcare delivery system redesign and providing decision-support tools and clinical information systems for providers; all to support the collaboration across providers and systems of care.^{29,30}

In recent years, randomised clinical trials conducted in the West have demonstrated, in a preliminary fashion, the effectiveness of collaborative care in improving outcomes in primary care settings for older adults with dementia as well.^{31,34} Key components commonly shared by these evidence-based collaborative care approaches for dementia include:

- the provision of appropriate education and support for patients and their caregivers
- dementia training for primary care providers
- multidisciplinary teams led by primary care providers that include nursing and social work ex-

pertise, as well as access to specialty consultation as needed (e.g. psychiatry, neurology)

- the use of standardised screening, decision-support tools and electronic medical records
- ongoing care management to help access additional community and health services and support patients and their caregivers.

However, no such interventions have yet been tested in the Chinese primary care setting.

Collaborative care models for depression in urban China

Although primary care-based collaborative care models for dementia have not yet been tested in China, early efforts to test the approach for management of late-life depression have been mounted.³⁵ As background, a preliminary investigation was conducted of primary care doctors' experience with common late-life mental disorders in China in 2009, which found that PCPs did not diagnose and treat patients with mental disorders. Rather, if they had concerns that mental disorders may be present in their older patients, PCPs suggested that their patients visit mental health specialists. However, there was often no protocol for referral of patients by PCPs to mental health specialists, and most PCPs were not aware of mental health specialists in their areas. Based on these preliminary data, a study was proposed that involved the collaboration of PCPs, nurses as care managers and psychiatrists as mental health specialists – as well as the promotion of treatment guideline-driven care – as a collaborative care management intervention for depressed, older patients in urban China primary care settings. The 12-month follow-up outcomes of patients in the care management trial indicated that the collaborative care model for late-life depression in urban China primary care was effective.³⁶

Lessons learned from both collaborative primary care-based dementia care management trials in the West and from late-life depression care management models applied in Chinese primary care clinics may guide the further development of dementia care management by primary care providers in China.

Strategies for development of collaborative dementia care models in rural China

For rural China, and many other low-income countries, the most cost-effective approach for

healthcare will be community primary care to support and advise family caregivers.³⁷ The new health reform in China puts the responsibility for dementia care, as a chronic disease, on the primary care and village doctor. Can a dementia collaborative care model be adapted in order to manage the large numbers of Chinese older adults with this complex, progressive and devastating condition? If so, how should China adapt and implement the intervention? What components of the collaborative care model are most critical to the success of dementia care, and what special considerations need to be incorporated, given that rural communities in China are heterogeneous yet possess unique challenges compared with urban settings?

Government, community and healthcare stakeholders would need a shared understanding that dementia is an epidemic that has an urgent need for a redesign of the approach of health systems and communities to care for individuals with the disorder. They must embrace the need for health system changes to improve the quality of dementia care in rural areas, which in turn would require financial resources to accommodate care managers who could collaborate with village physicians to help manage patients with dementia, as well as other support structures (e.g. informatics and communications infrastructure, provider education and decision support services).

Both the government and community stakeholders would need to designate resources to build and/or enhance health systems' relationships with community resources, including the provision of care managers that would assist village physicians, helping them link their patients and families with community resources. A potential challenge in rural settings is the lack of adequate community-based resources for individuals living with dementia and their caregivers (e.g. day treatment programmes, support groups and other senior services). The wide geographic distribution of people and resources in rural areas is another potential challenge.

Innovative ways of using specialist resources need to be developed. In a review of WHO demonstration projects regarding the treatment of mental disorders in primary care, Cohen concluded that the most successful programmes were those that provided regular supervision and continuing education of health workers.^{38,39} With appropriate training and support, Chinese village doctors could make an enormous contribution to front-line mental health and dementia care. One initiative to scale up rural mental healthcare introduced much-needed psychiatric education for 11 000 rural physicians.⁴⁰ Outcomes showed that the initiative produced meaningful positive attitude changes toward psychiatry. The change of attitudes may reflect the

usefulness of mental health training in the daily practice of village doctors. However, dementia was not a focus in this training programme. In a collaborative care intervention for late-life depression in urban China primary care settings, many PCPs were willing to share the risks and responsibilities of mental disorder diagnoses and the on-going care of their patients with other care providers.

Besides providing the village physicians with resources to help them better screen and manage patients with dementia, incentives to reward physicians to improve the quality of care delivered for individuals with dementia may also facilitate implementation.

Wide-spread public health education to target improved awareness and knowledge about dementia could help reduce the public stigmatisation. Additionally, educational resources and tools that the village physicians and care managers could use to help support patients and their family caregivers' ability to manage symptoms of dementia would need to be developed. Previously designed self-management approaches from Western countries would need to be adapted to address cultural, educational and language differences. These adaptations would then need to be studied to determine their acceptability and validity when used in rural Chinese primary care settings.

Development of screening and symptom monitoring tools

Screening to enhance case detection is important for improving dementia diagnosis in rural primary care settings.⁴¹ The Mini-Mental State Examination (MMSE) is the most extensively studied screening instrument for dementia, including in China where a Mandarin version has been validated and used in several studies.^{42,43} A recent meta-analysis of MMSE accuracy reported a sensitivity and specificity of 77% and 90% for application in high-prevalence specialist settings and 81% and 87% for application in low-prevalence settings respectively.⁴⁴ However, it is not adequate for many PCPs because it takes too long to administer.²⁵

Several alternatives to the MMSE have been validated in large samples with favourable psychometric characteristics in primary care and in the community,^{45,46} including the telephonic interview-based Mental Status Questionnaire (MSQ) and the Six Item Cognitive Impairment Test (6-CIT). However, these instruments were developed in Western countries and have not been validated for use in urban or rural Chinese samples.

Although instruments such as the MSQ, 6-CIT and Abbreviated Mental Test (AMT) have been validated

in different Chinese groups (Chinese in Western countries, Chinese in Taiwan and Hong Kong),⁴⁷⁻⁴⁹ there are still few studies of the validation of such instruments in Chinese primary care and community settings. Recommended instruments in the Guidelines for Dementia Prevention and Management include the MMSE, Brief Screening Scale for Dementia (BSSD, 30 items) and Hasegawa's Dementia Scale (HDS).⁵⁰ However, they are mostly used by specialists and in hospital settings, not by community-based PCPs. There have been no studies to test these recommended instruments in community settings in China thus far.

One measure, the Community Screening Instrument for Dementia (CSI-D), is the most extensively validated dementia screening assessment across a variety of low-middle income countries (LMIC).⁵¹ It has favourable cultural and educational screening properties and was validated in China and other LMICs by the 10/66 dementia research group. However, the administration of CSI-D in this study was carried out at home by research workers, rather than in primary care by non-specialist healthcare professionals. Consequently, there is currently no screening and early detection of dementia used in rural primary care clinics. A screening tool for dementia should be developed and validated for use in this setting.

Many specific factors such as culture, language and educational level should be considered when using a screening test. Test norms standardised for age and gender for specific rural Chinese groups are also needed. These norms must take into account language, education level and literacy as well as educational equivalency between cultures and countries of origin.

Developing a dementia-specific decision support system: continuing medical education for PCPs

Culturally, education- and language-sensitive adaptations of dementia-specific decision support system elements would need to be developed. Routine continuing medical education (CME) and other tests for PCP qualifications have been developed and implemented; however, traditional passive strategies such as lectures, educational meetings, guidelines and other printed materials have generally proved to be less effective for providing good care for dementia patients.²⁴ New approaches should think about the interaction between PCPs and

specialists as educators,⁵² education through case studies,⁵³ problem-based and solution-focused training⁵⁴ and computer-based learning methods.⁵⁵

Moreover, to reach more geographically spread-out providers, adoption of distance-learning approaches should be considered. Education alone as an intervention has limitations to change PCPs' practice. Educational interventions need to also incorporate decision-support tools to help facilitate action on the part of the PCPs, as well as incorporate additional resources and team members to help alleviate the burden on the PCP. These programmes to educate and train village physicians and care managers to improve attitudes, knowledge and practice behaviours to enhance the quality of dementia care, to help implement screening and use of decision-support tools would need to be developed, studied and then disseminated. Identifying and implementing incentives to change physician behaviour should be considered.

Conclusion

Currently, there has been no study of dementia care in rural China primary care settings. It is important to undertake a careful review of local resources in rural China, to examine experience from evidence-based studies in Western countries, and then to develop clear and innovative approaches to improve dementia care in rural areas in particular. Primary care clinics will be an important resource on which to draw, given their wide distribution, easy access for the older adult population and government-designated role as the focus for chronic disease management.

Much work remains, however, to define the optimal approaches to detecting and facilitating management of dementia in the primary care setting, which then needs to develop the capacity to deliver the care. Collaborative dementia care models based in primary care, drawing on the design and results of their use in other parts of the world and informed by the early success of collaborative late-life depression care management trials, should be an important focus for further study.

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CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

ADDRESS FOR CORRESPONDENCE

Shulin Chen, Department of Psychology, Zhejiang University, 148 Tianmushan Rd, Hangzhou, China 310028. Email: chenshulin@zju.edu.cn

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