

## GUEST EDITORIAL

# The challenges of dementia care in rural China\*

Many countries face policy challenges related to the well-being of their aging populations, and China, with the world's largest aging population, is no different. Over the past 40 years, China has experienced demographic transition toward an "aging society." According to the National Bureau of Statistics in China (NBSC), the number of people aged 60 years and older in China has risen to 185 million, with rural areas aging more rapidly during China's demographic transition (National Bureau of Statistics of China, 2013). In 1982, the proportion of population aged 60 years and older was 7.8% in rural China and 7.1% in urban China. However, by 2011 these proportions had risen to 12.6% and 15.4%, respectively, with a national average of 13.26% (National Bureau of Statistics of China, 2013). Difference between rural and urban areas in the proportion of the population aged 65 years and older in China has shown a similar trend over time. Rapid economic reforms since the 1980s, associated with increased rural-to-urban migration, especially the outflow of rural young population, have resulted in a larger proportion of elderly adults in rural areas (Cai *et al.*, 2012; National Bureau of Statistics of China, 2013). These same social forces have resulted in relatively fewer people available to take care of the growing population of older adults as well. The "elderly dependency ratio" (the ratio of older adults in China to those in the population of working age) has increased from 8.0% in 1982 to 12.7% in 2012 (National Bureau of Statistics of China, 2013). The economic and social impact on caregiving will be profound.

With growth in the number of older adults in rural areas, the prevalence of disabling conditions associated with aging, such as dementia, is increasing exponentially. A 2008–2009 study estimated the prevalence of dementia among individuals aged 65 years and older in China to be 5.14% (95% CI, 4.71–5.57), with the prevalence of dementia being significantly higher in rural than in urban areas (6.05% vs. 4.40%; Jia *et al.*, 2014). A systematic review of dementia epidemiological studies in China found that 3.68 million people lived

with dementia (95% CI, 2.22–5.14) in 1990, more than doubling to 9.19 million (95% CI, 5.92–12.48) in 2010 (Chan *et al.*, 2013). We can anticipate that these numbers will continue to rise.

Besides the growing population of older adults, China faces several other challenges associated with addressing the needs of individuals with dementia in rural settings. There is currently no national policy on dementia and how best to address it. Without acknowledgment on a national platform in China, there has been poor awareness in mainstream culture as well as professional circles of the growing public health problems associated with the illness. Culturally, there is stigma associated with memory loss and dementia; for example, the Chinese translation for the word "dementia" is a variant of "crazy" with pejorative connotations. People with dementia face ridicule, misunderstanding, isolation, discrimination, and even abuse. As in other countries, stigma poses barriers to recognition as well as allocating resources to help patients, families, communities, and governments to address the needs of individuals suffering from this condition.

Traditionally, members of Chinese family take care of their elderly adults. With social and economic changes in the past 30 years, however, the family care model in rural China has eroded. Decreasing family size and increased job mobility have contributed to the segregation and isolation of older adults in rural communities, resulting in the family assuming less responsibility toward care of elderly people (Xie *et al.*, 2007), including the growing number of older adults with dementia. For instance, there are now over 230 million internal migrants from rural areas working in cities. This massive migration of young people has led to many "left-behind elderly adults" in rural areas. Elderly care provided by the family has become increasingly less feasible in the past ten years (Zhang *et al.*, 2012). These changes can have a devastating impact on the well-being of older adults with dementia. Paired with the lack of social services or other supportive infrastructure in rural areas to step in when family is unable to take care, people having dementia have few options available.

Nursing homes represent an alternative approach when family is unable to provide care. However, there are almost none in rural settings. Even in

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urban areas where long-term care facilities are being developed rapidly, need far exceeds capacity. At the end of 2010, according to the National Committee on Aging (NCoA, 2012), the country's nursing homes operated a total of 3.19 million beds, but the number of older people who were in need of nursing home facilities was nearly 12 million. Among the nursing homes that do exist, many are ill-equipped to manage physical and psychological needs of individuals with dementia, and staff's formal training for dementia care is also rare. It has been the practice of nursing homes in China to exclude admission to those exhibiting symptoms of dementia.

Even though China faces enormous challenges in managing the population with dementia, especially in rural areas, there are strengths and resources in place that will help forge the path for real policy and practice change. On the policy level, the "Twelfth Five Years Plan for China Aging Development" (issued by Central Government of China (CGC) on September 11, 2011) is expected to increase the identification rate of mental disorders such as dementia and depression (Central Government of China, 2011).

In addition, infrastructure to serve the healthcare needs of older adults with chronic illness is being established in rural areas of China, which will help enable comprehensive dementia care as well. In 2006, the Chinese Central Government reformed the primary care system to emphasize the centrality of primary care physician 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 constituted by the primary care clinic, while 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 (Wang *et al.*, 2007; 2012). In the "Twelfth Five Years Plan for China Aging Development," establishing the health records for all elderly adults in the primary care service system, and mental health, and psychological well-being were three policy components to direct National Health Service in aged population (Central Government of China, 2011). The implementation of this plan is through community-based elderly care services. These services, still under development, include the village primary care clinics, mainly for aging population, the annual health examination for all older people, and chronic disease management for older people. However, even with these reforms, dementia and its associated problems are not directly addressed in China's healthcare policy or reforms.

## **The Worldwide Universities Network (WUN) workgroup meeting: dementia care in rural China**

To help develop a consensus on priorities to address the challenges of dementia care in rural China, Zhejiang University, the Chinese University of Hong Kong, and the University of Rochester collaborated to hold a meeting sponsored by WUN, entitled Dementia Care in Rural China. Internationally recognized experts from the United States, Australia, Hong Kong, Taiwan, Beijing, and Changsha, along with more than 60 local mental health professionals, primary care physicians, and public health policy-makers met in Hangzhou, China from September 5–7, 2013. The meeting comprised a series of presentations followed by two panel discussions to develop an agenda for future research and practice priorities for the next five years.

### **Recommendations from the WUN Workgroup meeting**

1. *Develop a national policy that identifies dementia as a public health priority, helps increase public awareness, and allocates resources to address the needs of people and communities affected by the disorder.*

The workgroup stressed the need for additional policy initiatives, the goals of which are to increase public awareness of dementia as an urgent public health problem, help de-stigmatize the illness, dedicate existing resources to the care of older adults with dementia and their families in rural areas, and allocate additional resources to the development of solutions for individuals with dementia, their families, and rural communities in which they live.

Public awareness of dementia, and the will to address it, is essential for population level prevention and management. The current level of public awareness about dementia is very low. The name of "dementia" is not new to most Chinese people, but only few recognize it as a disease. In traditional Chinese medicine, the pathogenesis of dementia could be generalized as insufficiency of Qi, a flowing energy; the stagnation of phlegm, a harmful liquid substance in the body; and the blood stasis (Liu *et al.*, 2012). Moreover, because of stigma, little attention is paid to dementia in public forums. As it has not been identified as a national priority, health and aging services providers generally receive little dementia-specific training, including how to prevent, detect, evaluate, and manage individuals with dementia. It is imperative

that a national policy must be developed, which in turn prioritize public education and training programs to address these needs.

According to Alzheimer's Disease International, public awareness promotion should target the general public, political leaders, and media. The dementia renaming campaign in Mainland China, initiated in 2012, is an initial step to improve public perception of dementia by adopting a formal and widely acceptable name for "dementia" to be used in Chinese-speaking areas. In addition, models of public awareness campaigns that use popular celebrities, who disclose their experiences with dementia, have been successful in other countries, and could potentially be explored for acceptability in Chinese culture. More research conducted by multidisciplinary collaborators to identify the extent of the problem nationally as well as in rural areas is necessary to inform possible approaches that are culturally acceptable and feasible. We need to help people to better understand dementia and how to prepare for the impending crisis in the coming years. Enormous number of people with dementia, diminishing family support for older adults, and lack of services and trained personnel for dementia care, especially in rural areas, are all major challenges.

Research needs to be conducted to provide the data to inform policy development and demonstrate financial and other impacts on suffering that this illness has on individuals, families, communities, and society. Researchers will need to partner with policy-makers, economists, and other public stakeholders to be successful in these endeavors. The second major recommendation to come from the workgroup, therefore, is for the conduct of research.

*2. Conduct research that (a) establishes the social and economic impacts of dementia in rural China, and (b) examines potential solutions that can be applied in real-world settings. Emphasis should be placed on development and testing of approaches to detection, treatment, and prevention of dementia that are acceptable and accessible to older adults in rural China, and innovative models that support aging in place for affected elders in rural areas.*

*Quantifying social and economic impact of dementia on China:* There is substantial evidence of the enormous economic impact of dementia care in developed countries (Wimo and Prince, 2010), and some preliminary data on the cost of dementia care in China. A 2008 study in Shanghai indicated that the direct cost per dementia patient per year averaged approximately 8,432 RMB (US\$1,058), and the indirect cost was 10,568 RMB (US\$1,326) (Wang *et al.*, 2008). Further studies are necessary

to ascertain the social and economic impact of dementia care in China.

*Detection:* A number of dementia screening instruments have been adapted for use with Chinese patients. They include the Mini-Mental State Examination (MMSE), the Mental Status Questionnaire (MSQ), the Abbreviated Mental Test (AMT), and the 6-item Cognitive Impairment Test (6-CIT). Each instrument, however, has limitations, which make them poorly suited to the context of rural primary care (Chen *et al.*, 2013). One exception may be the Community Screening Instrument for Dementia (CSI-D), which has been extensively validated in a variety of low-middle income countries (LMIC; Prince *et al.*, 2011). However, the CSI-D has yet to be tested in Chinese rural primary care clinics administered by clinic personnel. A screening tool for dementia should be developed and validated for use in this setting that is culturally congruent, acceptable to older adults and populations with low literacy levels, with strong psychometric properties.

*Treatment:* There is no access to dementia care specialists in China's rural areas, and currently primary care providers typically lack even basic training for its diagnosis and management. In recent years, randomized 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 (Callahan *et al.*, 2006; Vickrey *et al.*, 2006). Key components commonly shared by these evidence-based collaborative care approaches for dementia include: (1) the provision of appropriate education and support for patients and their caregivers; (2) dementia training for primary care providers; (3) multidisciplinary teams led by primary care providers that include nursing and social work expertise as well as access to specialty consultation as needed (e.g., psychiatry, neurology); (4) the use of standardized screening, decision-support tools, and electronic medical records; (5) on-going care management to help access additional community and health services and support patients and their caregivers. Components of the collaborative care model may be applicable to rural China. For example, investigators at Zhejiang University, in collaboration with diverse components of the Zhejiang Provincial government and colleagues at the University of Rochester, are conducting a randomized controlled trial of collaborative care management for comorbid depression and hypertension in rural elderly adults (Conwell, 2013). However, no results are yet available from this study, and no such interventions that target dementia have been tested in the Chinese primary

care settings. Adapting the model to incorporate screening and decision support for treatment of dementia in rural settings would be an important focus for future research. Illustrative questions to address include the following: (1) Can the dementia collaborative care model be adapted for use in rural China? (2) If so, how should rural China go about adapting and implementing the intervention? (3) What components of the collaborative care model are most critical to the success of dementia care? (4) What special considerations need to be taken, given that rural communities in China are heterogeneous yet share unique challenges compared with urban settings?

*Aging in place.* As noted previously, the combination of internal migration of the working age population from rural to urban areas, low birth rates, and increasing longevity in rural China will require intense development of creative new solutions to help older adults, including those with dementia, manage independently in their homes as long as possible. Research is needed to develop and test cost-effective technologies to support independent functioning, such as remote behavioral monitors and adaptation devices for homes to make them safe and secure for elderly adults with cognitive disorders. More important, however, will be the mobilization of indigenous resources of the community in a systematic effort to keep disabled elderly adults functioning independently: for example, education of the village doctor and residents of the village responsible for meeting social needs of elderly adults (the “aging worker”) in dementia assessment and care, and creation of cadres of friends and neighbors to provide supportive services. Consistent with the cultural mores of rural China, peer-supported communal organization to support aging in place reflects aspects of the “Village Movement” in the United States. (Snelling, 2012).

However, for some older adults with more advanced dementia whose families are unable to take care, alternatives must be developed and evaluated that are economically feasible and acceptable to rural Chinese elderly population. Research has shown clearly that interpersonal and community engagement is important for health maintenance and quality of life, including that of older adults with dementia. Creation of small home-based congregate living options with appropriate financial incentives and village support may serve as an alternative to construction and maintenance of more costly institutional long-term care facilities. Again, cultural congruence and public acceptance of the need to care for affected elderly adults will be the key.

*Prevention.* Ultimately, however, the optimal approach to addressing the impending public health crisis of dementia in rural areas would be prevention of onset and progression of the disease. Given that current dementia treatments can only target the symptoms of dementia and do not offer cure or modify the underlying disease process, research focusing on prevention of dementia is essential to mitigate future sufferings and costs. General prevention strategies that are being tested include reducing vascular risk factors, such as hypertension, diabetes, dyslipidemia, that are associated with both vascular and Alzheimer’s disease type dementia (Middleton and Yaffe, 2009). For instance, a recent European study on antihypertensive treatment in older adults with hypertension demonstrated some protection against developing dementia (Forette *et al.*, 2002). Whether findings such as these would translate to rural Chinese older adults with hypertension could be answered in future research. A review of both risk factors and protective factors for developing or preventing dementia identified that although data overall are limited, risk factors, such as diabetes, Apo E4, smoking, and depression, and protective factors, such as cognitive and physical activities, showed consistent associations with dementia. The authors concluded that additional research was necessary to develop recommendations for prevention (Williams *et al.*, 2010). Prevention research that targets modifiable risk factors in China, and in particular in the rural Chinese population, is needed. Further, studies on lifestyle interventions, including culturally appropriate physical exercises such as Taichi, cognitive, and leisure activities in the prevention of cognitive decline should be conducted. Besides prevention research that targets modifiable risk factors, other prevention strategies include developing disease-modifying therapies that can be used prior to onset of symptoms. As part of the United State’s National Plan to Address Alzheimer’s disease, research funding to support two new prevention studies now includes testing of novel pharmacotherapeutics that target beta-amyloid in symptom-free volunteers with genetic risk for developing both early- and late-onset Alzheimer’s disease (Vaughn, 2013). These are among the examples of how instituting a national policy can generate momentum toward developing a cure for Alzheimer’s disease.

## Conclusions

China faces a growing epidemic caused by dementia, and rural areas of China, which have the largest older adult population and less access

to specialized health and dementia care resources, will face even bigger challenges. The time is now for China to develop a national policy that identifies dementia as a public health priority to help increase public awareness and provide resources for research. The Workgroup recommends that a series of policy-related discussions be initiated immediately to bring together stakeholders from multiple disciplines to tackle this growing crisis. Also, future research is needed to better understand social and economic impacts of dementia in rural China, to examine possible solutions, and to help mitigate suffering and rising costs associated with this disease. Dementia's impact can no longer be ignored, and China and its citizens cannot afford to do nothing.

### Conflict of interest

None.

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