

# INVESTIGATING FAMILY-BASED DEMENTIA CARE IN THE CHINESE CONTEXT: A LITERATURE REVIEW

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## ABSTRACT

**Background:** Like many other countries, China has an ageing population. Along with this trend, there has been an increase in the number of people suffering from dementia. At present, the traditional family-based dementia care approach is encountering great challenges due to the 4-2-1 family structure probably brought about by the Chinese Government's one child policy.

**Aim:** This review aims to explore suitable model of family-based dementia care in China.

**Methods:** Search strategies were employed to identify relevant studies published from 1980 to 2012. Multiple keywords were used to perform literature searches in various electronic databases.

**Results:** The literature review has examined 31 articles and identified three themes, namely family caregivers-oriented model, activity programmes for person with dementia, and an-inpatient respite programme.

**Conclusion:** Rural communities should focus time and energy on improving social network and public resources by garnering funding from private companies, charity organizations and government institutions.

**Keywords:** *Chinese Old People, Caregivers' burden, Family-based Dementia care, Literature Review*

## INTRODUCTION

China has become an ageing society due to a rapidly declining fertility rate attributed to the one-child policy introduced in 1980 and improvements in public health and living conditions brought about by the Reform and Open-up policy introduced in 1978. Hays (2012) reported that the proportion of elderly will nearly double between 2008 and 2025.

The World Health Organisation (2007) defines dementia as symptoms associated with brain degeneration, including the deterioration of the function of cortical-subcortical and sensorimotor cortical areas. As a consequence of this pathology, a person's capacity to function cognitively, socially, physically and emotionally declines gradually (Jacques and Jackson 2000). Alzheimer's disease (AD) is the most common type of dementia, diagnosed in over 50% of cases of dementia and also a leading cause of death in

the elderly population (Hayashi *et al.*, 2009). According to Ferri *et al.* (2005), it is projected that the number of Chinese people with dementia will increase from 6 million in 2001 to 26.1 million in 2040.

The aim was therefore to review the current literature, in particular family-based dementia care and the 4-2-1 model to identify a feasible pattern of care which could be adopted in the Chinese context.

## METHOD OF STUDY:

31 studies have identified three themes including family caregivers - oriented model, activity programmes for person with dementia and an -inpatient respite programme. Additionally, this paper also finds out that rural communities need to improve their social network and public resources by raising funds from the investment of private companies, charity donations and governmental subsidies.

### **The traditional model of care in China**

Chinese people think that taking care of the elderly family members is an unwavering duty, which is influenced by Confucianism. According to Chen (2001), Confucius thoughts have significant effects on Chinese behaviours and values by Ren (benevolence), Yi (justice), Zhong (loyalty), Xiao (filial piety) and De (virtue). Woo *et al.* (2002) reported that this traditional model of care was reinforced by the Chinese Governmental legislation.

### **Social change and the 4-2-1 model of care in China**

Chinese policies and social context lead to the 4-2-1 model of care. A married Chinese couple could be responsible for taking care of 4 parents, 8 grandparents plus the demands of work and a child. Compared to the previous times, the younger generations are in under greater pressure to provide care for their aged family members (William & Hong-kin 2008).

According to Gu *et al.* (1995), there are two forms of financial support for the elderly person in China, which includes subsidies and pensions along with financial support from the family. Shi (1993) reports that a subsidy is offered by the local community. But that this kind of financial support tends to be insufficient. Li and Tracy's (1999) study showed that some rural elderly persons can receive financial support from the Five-Guarantee Program of the rural communities. This support is available for the old people in the rural area who do not have children or relatives to support them and who have lost the capacity to work. In urban areas, pensions to meet the basic living needs are provided for the majority of retired aged individual by the state or companies (Shi 1993). Li and Tracy (1999) contend that countryside people in China tend to have more than one child to look after their parents in their old age.

On the other hand, Liu *et al.* (2012) reported that in China, there is a scarcity of formal long-term care facilities for older adults with dementia. Wang (2012) maintains that although the number of nursing home beds in Shanghai China had been increased to 100,000 by the end of 2010, it is still far from meeting the demand. Therefore this unavoidably poses problems for the family-based care model.

### **Creating a great challenge for the Chinese rural families**

With a dramatic change in socio-demographic structure in China, the previous effectiveness of intergeneration care model has been questioned.

A study conducted by Li and Tracy (1999) demonstrated that with a growing number of young adults moving from rural areas to urban cities to pursue employment opportunities and better living standards. The ratio of working age adults available to support each old person is declining rapidly. China Alzheimer's Project (2012) reported that currently in China, there is a shortage of 10 million caregivers.

Furthermore, Gu *et al.* (1995) stated that sources of support for the elderly was usually coming from spouse, son, daughter, son-in-law, daughter-in-law and others. Zhang and Goza (2006) pointed out that the eldest sons in Chinese families should be responsible for looking after their parents in the late years. Therefore rural families without sons tend to worry about their old age

### **Kin relationship & caregiver burden**

The family members of the caregivers of people with dementia experience different levels of burden and distress. A study conducted by Cooney and Di (1999) reported that the wife suffers from the greatest burden among other family members, and then followed by husband, daughter, son and daughter-in-law. An interpretive descriptive study conducted by Ward-Griffin *et al.* (2007) demonstrated that adult daughters tend to be the principle caregivers if their mothers are widowed, the daughters are unemployed or they live close to their mothers.

## **DISCUSSION**

As shown above, kin relationship is closely related to subjective burden and negative impacts. In today's society, as a result of the prevalence of 4-2-1 model, one child is less likely to afford to look after their parents due to their own health condition, income and geographic locations. Therefore, these may lead to a series of family conflicts and social problems.

### **Family caregivers' experiences**

According to Yu (2011), care for people with dementia is the most stressful kind of family caregiving in terms of physical tiredness, psychological distress and financial burden. Zhan (2005) reported that when looking after people with dementia; family caregivers tend to experience general health deterioration including physical tiredness and emotional distress, role overload, family financial strain and family conflict. Furthermore, Wang's (2006) study

demonstrated that Chinese family caregivers are more likely to suffer from chronic back pain, sleeplessness and migraine due to bathing, cleaning and repositioning. Thus, Chinese family caregivers urgently need to get support from communities, especially for those among the rural family caregivers.

### **Attachment of stigma**

Literally, Dementia can be interpreted as 'Chi Dai' in Chinese language, meaning 'fool' or 'dim-wit'.

Braun and Browne (1998) reported that the Buddhist perspective of dementia symptoms, such as memory loss and confusion, can be a manifestation of family sins, imbalance of yin and yang, or improper geographic location of the house. Braun and Browne (1998) conclude that the existence of these superstitious thoughts and erroneous ideas may lead to a delay in seeking professional assistance.

### **China's intergeneration care facing a great challenge**

According to Ineichen (1998), China's intergeneration care model is confronted with a big challenge due to decreased levels of filial care, a lower level of medical care and gradually weakening relationship of the extended family.

Chu and Chi (2008) said that as there are currently only 1.5% of Chinese old people with the need of care facilities, therefore, nursing home care will become an option for these Chinese old people. Pei (2007) reports that there are four types of Nursing Homes in Beijing, namely homes directly funded by the Chinese governmental bodies, homes run by street committees as well as township government, homes run by state or collective enterprises and homes funded by private companies.

### **Caregiver - oriented models**

According to Corcoran *et al.* (2002), Environmental Skill-Building Program (ESP) focuses on empowering American family caregivers to identify and manage dementia related behavioural problems by installing grab bars to resolve resistance to bathing. Moreover, bright colors can be used for the key signs to reduce abnormal behaviours of people with dementia to help these wandering people to find their way around.

According to Bjerkholt and Zhu (1993), compared to rural accommodations, the urban housing in China tends to be small and is often confined to narrow living quarters. Chinese rural families could adopt

reasonable modification under the help of occupation therapists in order to alleviate potential unsafe factors caused by their family surroundings.

### **Educational training programmes**

There have been greater needs for the vast majority of family caregivers of people with dementia to get support from societies in terms of providing them with educational training programs (Hepburn *et al.*, 2003).

A pilot study conducted by Taiwan researchers reported that this two-session in-home caregiver training program is valuable for improving family carers' problem-solving skills and social well-being and simultaneously to reduce abnormal behaviours of people with dementia (Huang *et al.*, 2003).

It is feasible to generalise this educational training programs to more Chinese communities since Chinese people tend to have similar concept of values, ethics and behavioural code.

### **A mutual support group for family caregivers of people with dementia**

A study conducted by Fung and Chien (2002) in Hong Kong showed that a mutual support group, a 12-hour session including group discussion, offering psychological support and problem-solving skills, is useful to improve family caregivers' social well-being.

Fung and Chien (2002) stated that a mutual support group plays an imperative role in helping family caregivers to cope with care for people with dementia in Hong Kong. Fung and Chien (2002) reported that this program focused on equipping caregivers with knowledge by sharing feelings and experiences about similar concerns in a supportive surrounding, educating and informing caregivers about community resources and helping families address their concerns. Arguably, this mutual support groups would be one way of increasing social support for caregivers because with time the extended family will be much smaller.

### **Activity programmes for person with dementia and caregiver**

According to Brooker (2007), person-centered care can be described as establishing a supportive environment and collaborative partnership with shared power and responsibility between the service provider and the person receiving care. Simultaneously this will ensure their rights, values, shared decision-making.

Wang (2012) reported that the suburb of Shanghai plans to build or re-model about 300 recreation rooms including painting, playing chess and cards for Chinese people with dementia. Accordingly, it is feasible to generalise person-centred care to more Chinese communities including Chinese rural communities in the future.

### **An inpatient respite programmes for people with dementia**

According to Kim and Hall (2003), an inpatient respite program is a short-term out-of-home caregiving service, which not only offers recreational time to American family caregivers but also brings benefits to American people with dementia including physical examination, basic laboratory tests, drug regimens and cognitive assessment.

Obviously, this programme can be beneficial to both family caregivers and people with dementia. Wang (2012) reported that Shanghai will build 20 day-care centers and 40 meal centers for Chinese elderly people in local communities this year in order to reduce family caregivers' burden. Accordingly, it is possible to widely use this program for more Chinese communities in the future.

### **LIMITATIONS**

Some limitations to this review of the literature need

to be addressed. First of all, the search strategy may not have identified all the relevant literature. Furthermore, the relatively small number of eligible articles met the inclusion criteria and exclusion criteria.

### **CONCLUSION**

From the above study it can be concluded that the focus of the Chinese government should be on the Chinese rural families. A pivotal recommendation regarding the findings would be to implement pilot studies in two or three rural communities, whereby local communities can make a judgment whether these models suit the rural context.

I propose that China's intergeneration model of care will keep pace with time; as long as the government, communities and local residents make coordinated efforts for improving family caregivers' physical, mental and social well-being, offering public resources to meet their educational requirements, support needs including respite, as well as financial aids. Lastly, with the amendment of China's one-child policy, the younger generation is now allowed to have a second child; so it would be helpful in reducing adult children's burden in the support of their elderly parents because there will be siblings to share the load.

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