



## Investigating psychological health of family caregivers of dementia people in the Chinese context: A literature review

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### ABSTRACT

*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. Accordingly, it is appear that quite a few of family caregivers of dementia people tend to have psychological issues. This review aims to explore suitable measurements to improve family caregivers' psychological well-being.*

**Key words:** Chinese old people; family-based dementia care; caregivers' burden; psychological health

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### 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 reports that the proportion of elderly will nearly double between 2008 and 2025 [1].

The World Health Organisation defines dementia as symptoms associated with brain degeneration, including the deterioration of the function of cortical-subcortical and sensorimotor cortical areas [2]. As a consequence of this pathology, a person's capacity to function cognitively, socially, physically, and emotionally declines gradually [3]. 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 [4]. According to Ferri et al., it is projected that the number of Chinese people with dementia will increase from 6 million in 2001 to 26.1 million in 2040 [5].

The aim was therefore to review the current literature, in particular family-based dementia care to identify a feasible way to alleviate family caregivers' psychological problems.

### SEARCH STRATEGY AND OUTCOMES

A literature search was performed using the following electronic databases: MEDLINE, CINAHL, Expanded Academic ASAP, ProQuest Central. We included studies published from 1980 to 2012 and used the following keywords, namely family-based dementia care, Chinese old people, Chinese caregivers' psychological problems, interventions and clinical implications. We also examined the reference lists of included articles to identify additional studies.

#### 2.1 FINDINGS

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 rising funding from the investment of private companies, charity donations and governmental subsidies.

## 2.2 THE TRADITIONAL MODEL OF CARE IN CHINA

Chinese people think that taking care of the elderly family members is their unshakable duty, which is influenced by Confucianism. According to Chen, Confucius thoughts have significant effects on Chinese behaviours and values by Ren (benevolence), Yi (justice), Zhong (loyalty), Xiao (filial piety) and De (virtue) [6]. Woo et al. report that this traditional model of care was reinforced by the Chinese Governmental legislation [7].

## 2.3 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 under greater pressure to provide care for their aged family members [8].

According to Gu et al., there are two forms of financial support for the elderly person in China including subsidies and pensions as well as financial support from the family [9]. Shi reports that a subsidy is offered by the local community but that this kind of financial support tends to be insufficient [10]. Li and Tracy's study shows that some rural elderly persons can receive financial support from the Five-Guarantee Program in rural communities [11]. This support is available for rural old people 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 people by the state or companies to meet their basic living needs [10]. Li and Tracy contend that countryside people in China tend to have more than one child to prepare for their old age [11].

On the other hand, Liu et al. report that in China, there is a scarcity of formal long-term care facilities for older adults with dementia [12]. Wang 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 demand [13]. Therefore; this unavoidably poses problems for the family-based care model.

## 2.4 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 demonstrates that with a growing number of young adults move from rural areas to urban cities to pursue employment opportunities and better living standards, ratio of working age adults available to support each old person is declining rapidly [11]. China Alzheimer's Project reports that currently in China, there is a shortage of 10 million caregivers [14]. Furthermore, Gu et al. state that sources of support for the elderly were defined as possible coming from spouse, son, daughter, son-in-law, daughter-in-law and others [9]. Zhang and Goza point out that the eldest sons in Chinese families should be responsible for their parents' late years and therefore; rural families without sons tend to worry about their old age [15]. Arguably, this disproportionate male to female ratio could result in a worrying trend that increasingly more sons cannot find wives in the future.

## SOCIAL RELATIONS AND PROPERTY RELATIONS

### 3.1 KIN RELATIONSHIP & CAREGIVER BURDEN

All of the family caregivers of people with dementia experience different levels of burden and distress. A study conducted by Cooney and Di reports that the wife suffers from the greatest burden among family carers, and then followed by husband, daughter, son and daughter-in-law [16]. An interpretive descriptive study conducted by Ward-Griffin et al. demonstrates 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 [17].

## 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.

### 3.3 FAMILY CAREGIVERS SUFFERING FROM SERIOUS PSYCHOLOGICAL PROBLEMS

According to Yu, care for people with dementia is the most stressful kind of family caregiving in terms of physical tiredness, psychological distress and financial burden [18]. Zhan reports that when looking after people with dementia; family carers tend to experience general health deterioration including physical tiredness and emotional distress, role overload, family financial strain and family conflict [19]. Furthermore, Wang's study demonstrates that

Chinese family carers are more likely to suffer from chronic back pain, sleeplessness and migraine due to bathing, cleaning and repositioning [20]. In short, Chinese family caregivers urgently need to get support from communities, especially for those rural family caregivers.

#### 3.4 ATTACHMENT OF STIGMA

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

Braun and Browne report 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 [21]. Braun and Browne conclude that the existence of these superstitious thoughts erroneous ideas may lead to a delay in seeking professional assistance [21].

### 4 STRATEGIES FOR REDUCING FAMILY CAREGIVERS' PSYCHOLOGICAL PROBLEMS

#### 4.1 CAREGIVER-ORIENTED MODELS

According to Corcoran et al., Environmental Skill-Building Program (ESP) focuses on empowering American family carers to identify and manage dementia behavioural problems by installing grab bars to resolve resistance to bathing, and using bright colors for the key signs to reduce abnormal behaviours of people with dementia [22]. This is probably because the wandering people are better able to find their way around.

According to Bjerkholt and Zhu, 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 [23].

#### 4.2 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 [24].

A pilot study conducted by Taiwan researchers reports 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 [25]. 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.

#### 4.3 A MUTUAL SUPPORT GROUP FOR FAMILY CAREGIVERS OF PEOPLE WITH DEMENTIA

A study conducted by Fung and Chien in Hong Kong shows that a mutual support group, a 12-hour session including group discussion, offering psychological support and problem-solving skills, is useful to improve family carers' social well-being [26].

Fung and Chien state that a mutual support group plays an imperative role in helping family caregivers cope with care for people with dementia in Hong Kong [26]. Fung and Chien report that this program focuses 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 [26]. Arguably, this mutual support groups would be one way of increasing social support for carers because overtime the extended family will be much smaller.

#### 4.4 ACTIVITY PROGRAMMES FOR PERSON WITH DEMENTIA AND CAREGIVER

According to Brooker, 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 and simultaneously; ensuring their rights, values, shared decision-making are supported [27].

Wang reports 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 this year [13]. Accordingly, it is feasible to generalise person-centred care to more Chinese communities including Chinese rural communities in the future.

#### 4.5 AN INPATIENT RESPITE PROGRAMMES FOR PEOPLE WITH DEMENTIA

According to Kim and Hall, an inpatient respite program is a short-term out-of-home caregiving service, which not only offers recreational time to American family carers but also brings benefits to American people with dementia including physical examination, basic laboratory tests, drug regimens and cognitive assessment [28].

Obviously, this programme can be beneficial to both family carers and people with dementia. Wang reports 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 [13]. 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

I maintain that the focus of the Chinese government should be 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 family caregivers' psychological problems will be alleviated; as long as the government, communities and local residents make coordinated efforts for improving family carers' physical, mental and social well-being, offering public resources to meet their educational requirements, support needs including respite, as well as financial aids.

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