

Review of Dementia Caregiving Experience and Interventions in Chinese Communities

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Abstract

As population continues to age, the number of persons with dementia has been increasing rapidly. It is a common practice in Chinese communities for family members to provide the majority of dementia care. Literature from developed countries reveals that dementia caregivers experience significant stress and burden, which adversely affects the psychological and physical health of care providers as well as care recipients. This paper aims at understanding family caregiver experience among Chinese caregivers and reviewing interventional studies conducted in Chinese communities, which are pivotal in the design of effective carer support services appropriate to local context.

Keywords: Chinese, dementia, carer stress, carer burden, carer interventions

Introduction

The world's population has been ageing rapidly (Population Division, Department of Economic and Social Affairs, United Nations, 2009). In 2009, one out of every nine persons were aged 60 or above. It is estimated that one in five will be 60 or over by 2050, which will translate into two billion older persons in total. Chinese communities are no exception to this trend. Older persons constituted 12%, 18% and 15% of the population in China, Hong Kong and Singapore respectively in 2009. United Nations predicts that as many as 31%, 39% and 40% of the population in these Chinese communities will be elders in four decades' time. Since prevalence of dementia increases significantly with age, the number of Chinese older adults suffering from dementia will inevitably increase with the remarkable changes in demographics.

It has long been recognised that the impact of dementia goes far beyond the affected individuals. Alzheimer and other dementia affect the society at large. Together they have emerged as the fourth leading cause of burden of disease in high-income countries, accounting for 3.6% of total disability-adjusted life year (DALYs) (World Health Organization, 2004). They are also associated with substantial care costs (Jönsson et al., 2009).

Wellbeing of caregivers of dementia persons is another growing health concern. Numerous studies have illustrated that dementia affects the psychological and physical health of family caregivers (Donaldson et al., 1997). It may account for the rising number of research in recent years looking into the effectiveness of interventions to alleviate their stress and burden. But assumptions about caregiving experience and effectiveness of interventions based on overseas data may

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not be appropriate because of the significant differences in cultural values and societal practices between Chinese and non-Chinese communities. Compared with developed countries, caregiving for older persons has largely remained the responsibilities of families in Chinese communities. For example, 98.1% of elders are cared for by their families while only 1.9% are by welfare agencies in Mainland China (賈, 2001). It may be partly due to strong traditions of filial piety prevailing among Chinese, and the relative shortage of institutional care facilities in Mainland China. Evidence also shows that Chinese are more likely to view increased dependency and cognitive and behavioural problems as part of the ageing process (Yu et al., 1993), which may further modify dementia caregiving experience among Chinese population.

This review aims at understanding caregiving experience and interventions for carers of dementia persons in Chinese communities.

Method

A search in Medline, PsycINFO, Taiwan Electronic Periodical Services (台灣電子期刊服務網), WanFang Data (萬方數據), and China Journals Full-text Database (中國期刊全文數據庫) was conducted in May 2010 for articles published in English and Chinese. Articles related to "dementia", "Chinese", "family caregiver", "carer burden / stress", and "carer intervention" were included in the review.

Results

Assessment instruments of caregiver burden

One of the key issues in dementia caregiving studies is the availability of validated measures of carer burden. Several generic instruments have been adopted to assess distress or burden among caregivers of persons with dementia in Chinese

communities. Examples include General Health Questionnaire (GHQ) (Kua et al., 1997; Rao et al., 2002), Symptom Checklist-90 (SCL-90) (Zhang et al., 2006; Lan et al., 2008), and World Health Organization Quality of Life Measure - Brief Version (WHOQOL-BREF) (Fung et al., 2002; Zhang et al., 2007).

Apart from these generic measures, a number of instruments tailor-made for dementia carers have also been validated to measure the experience of Chinese caregivers in recent years. Among them, Chinese version of Zarit Burden Interview and Caregiver Burden Inventory are the most widely studied. Zarit Burden Interview (ZBI) was developed by Zarit and colleagues in 1980. It is a 22-item self-administered instrument designed to measure caregiver's health, psychological well-being, finances, social life and relationship between caregiver and care recipient. Each item is rated from 0 ("not at all distressing") to 4 ("extremely distressing"), making the total score ranging from 0 to 88. The administration time is about 20 to 25 minutes. Chan et al. (2005) validated the Chinese version of ZBI in a sample of 40 caregivers of persons with mild to moderate dementia in Hong Kong. The intraclass correlation coefficient was reported to be 0.99 and the split half correlation coefficient was 0.81, suggesting a high inter-rater reliability and internal consistency. Besides, the correlation between ZBI and GHQ was 0.59 and the correlation between ZBI and Caregiver Activity Survey was 0.57, suggesting a high conceptual validity. Chinese ZBI was also validated in 181 patient-caregiver dyads in Taiwan (Ko et al., 2008), and 523 caregivers in Liaoning (Lu et al., 2009). Both demonstrated satisfactory psychometric properties, and suggested that it is a useful tool to objectively measure the burden experienced by Chinese caregivers of persons with dementia.

Caregiver Burden Inventory (CBI) is a multidimensional self-administered instrument developed by Novak and Guest (1989). It

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consists of 24 items assessing five domains, viz. time-dependence burden, developmental burden, physical burden, social burden, and emotional burden. Each item is rated from 0 (not at all descriptive) to 4 (very descriptive), making a total burden score ranging from 0 to 96. The administration time is around 15 to 20 minutes. Chou et al. (2002) examined Chinese CBI in 150 primary caregivers and care recipients dyads in Taipei, and reported adequate internal consistency reliability, appropriate content validity and concurrent validity. Yue et al. (2006) evaluated the psychometric properties of Chinese version of CBI in 59 caregivers in Beijing. The test-retest reliability was 0.93, and the correlation between CBI and ZBI was 0.85. Both were satisfactory.

Other commonly used measurements of carer burden that have been validated in Chinese populations include Relative Stress Scale (Li et al., 1990), Caregiving Burden Scale (Fuh et al., 1999b), Marwit-Meuser caregiver grief inventory (Ye et al., 2008), and Neuropsychiatric Inventory – Caregiver Distress Scale (NPI-D) (Fuh et al., 2001).

Dementia caregiving experience in Chinese communities - Qualitative studies

There have been two approaches to understand the experience of Chinese caregivers of dementia persons, viz. qualitative and quantitative methods. The former allow us to investigate participants' attitudes, beliefs and preferences, and bridge the gap between scientific evidence and clinical practice (Green et al., 1998). Using qualitative method, Shyu, Yip and Chen (1996) reported that Taiwanese family caregivers commonly encountered difficulties in assisting dementia persons with activities of daily living, managing incontinence, and handling health problems. Besides, they had trouble in caring for dementia persons' memory and behavioural problems, in particular suspicion/accusation, forgetfulness and wandering.

Similar findings were reported in a recent qualitative focus group study in Hong Kong (Chan et al., in press). Confusion of diagnosis, emotional impact, difficulty to cope with care-recipient's behaviours, provision of care-recipient's daily care needs is demanding, and conflicts among social roles were themes pervasive across the focus groups. Besides, the needs of carers changed as their care-recipients' disease progressed.

Dementia caregiving experience in Chinese communities - Quantitative studies

The past decade has seen a substantial growth in quantitative data in caregiving experience in Chinese communities. Much of the research has been devoted to comparing carer stress between dementia and non-dementia caregivers, and understanding of predictors of carer burden.

A number of studies have proved that Chinese caregivers of cognitively impaired older persons suffered from more stress than those who cared for physically impaired family members. He et al. (1995) compared the psychological and physical health of 110 caregivers of dementia persons with 110 age-, sex- and education-matched caregivers of older persons without dementia. The former reported significantly more physical and psychological impairment than the latter. Similar findings were reported by Zhang and colleagues (2006), who compared 75 caregivers of dementia persons with 65 caregivers of older adults with cerebrovascular disease but no dementia. There was no significant difference in age, sex, and educational level between the two groups. But significantly more dementia caregivers suffered from depression (46.7% vs. 35.4%) and anxiety (53.3% vs. 41.5%). Authors attributed the difference to behavioural and psychological symptoms associated with dementia (BPSD).

Determinants of carer stress can be grouped under characteristics of care recipients and caregivers respectively. Among the

attributes of care recipients, the most consistent predictors of carer burden include BPSD (Kua et al., 1997; Fuh et al., 1999a; Rao et al., 2002; Zhang et al., 2004; Lan et al., 2008), poorer activities of daily living (Wu et al., 1995), and severity of dementia (Wu et al., 1995). In addition, studies show that older carers (He et al., 1995; Rao et al., 2002), female carers (He et al., 1995; Wu et al., 1995; Lan et al., 2008), and carers with less education or knowledge of dementia (He et al., 1995; Rao et al., 2002; Lan et al., 2008) suffer from more stress.

There has also been evidence suggesting that carers' quality of life is associated with longer duration of care (Wu et al., 1995; Kua et al., 1997; Fuh et al., 1999a; Rao et al., 2002; Lan et al., 2008), availability of tangible help such as paid assistants (Huang et al., 2006), and social support (Zhang et al., 2007). The effect of social support on caregivers may be mediated by their self-efficacy. Au et al. (2009) interviewed 134 caregivers in Hong Kong with Self-Efficacy Scale assessing their self-efficacy in obtaining respite, responding to disruptive patient behaviours, and controlling upsetting thoughts about caregiving. Findings suggested that self-efficacy was a partial mediator between social support and depressive symptoms of caregivers.

While dementia caregiving affects carers' psychological and physical health adversely, emerging evidence has shown that dementia caregiving may also be associated with positive experience. In a cross-sectional study examining 176 dyads of elders with dementia and their caregivers in Taiwan, Chang et al (2009) found that family carers reported a moderate level of rewarding experience in caregiving. Furthermore, family caregivers with higher level of caregiving rewards had a better quality in family care. After controlling for demographic variables, caregiving rewards was able to explain 12.7% of the variance in overall quality of family care.

Furthermore, needs of caregivers of dementia persons are often neglected. Cheng et al. (2008) interviewed 108 family caregivers who were the major caretakers of persons with dementia attending psychiatry / neurology clinics in Taiwan. On average, caregivers spent 15.9 (SD = 9.2) hours per day to look after their family members with dementia. More than half of them were either retired or unemployed. About 70% voiced personal needs including "knowledge and skills", "need to take a break", and "time to manage personal affairs". More than half reported formal needs including "experience sharing with other caregivers", "financial aid", and "support groups gathering". However, most of their needs were not fulfilled.

Cross cultural comparison of dementia caregiving experience

Studies investigating the caregiving experience of different ethnic groups living in the same community have been reported in developed countries (Wang et al., 2005). However, the effect of acculturation may mask some of the cross-cultural difference. To have a thorough understanding of this issue, studies directly comparing caregivers from Chinese and non-Chinese communities have been conducted.

Patterson et al. (1998) assessed informal caregivers from Shanghai and San Diego. Chinese caregivers used more problem-confronting and emotional-confronting coping than their US counterparts did, and reported less access to emotional support. Though coping style differed, they found that family caregivers from both cities experienced strikingly similar negative physical and psychological consequences.

Using NPI-D, Pang and colleagues (2001) investigated the effects of BPSD on caregivers recruited in Los Angeles, Taipei and Hong Kong. They reported that Chinese carers were

less affected by depression and apathy in care recipients than American carers. However, to the authors' surprise, American and Chinese caregivers exhibited similar distress or lack of distress to a wide range of symptoms among care recipients, including delusions, hallucinations, agitation, anxiety, euphoria, disinhibition, irritability, aberrant motor behaviour, sleep and appetite symptoms.

In a recent study examining the differences in psychological morbidity among Australian mainstream, Australian-Chinese and Chinese caregivers of persons with dementia in residential care, Wu et al. (2009) reported that Shanghai caregivers had higher depression scores than their Australian-Chinese counterpart, who in turn scored higher than Australian mainstream caregivers. Authors postulated that difference in reasons for institutionalisation, health policies, supportive services, and stigma associated with dementia might account for the lower levels of depressive symptoms in the latter. In contrast to Pang's findings, this study did not demonstrate significant associations between BPSD in care recipients and psychological morbidity in caregivers. It might be because persons with dementia in Wu's study were institutionalised.

Caregiver interventions

So far, carer intervention research in Chinese communities has focused mainly on information and support intervention.

Behavioural problems are one of the major contributors to carer burden. Huang et al. (2003) looked into the effectiveness of a community-based training programme in improving caregivers' competence in managing BPSD in Taiwan. Participants of the study were caregivers providing care to persons with dementia who exhibited significant behavioural problems as exemplified by Cohen-Mansfield Agitation Inventory score

equalled or higher than 50. The experimental group (n=24) underwent training on management of behavioural problems which were conducted during domiciliary visits and phone consultation sessions. When compared with control group (n=24), caregivers in experimental group demonstrated significantly greater improvement in care competence. It echoed the findings of an earlier study (Huang et al., 1993) which showed that health educational programmes could improve the knowledge and behaviours of primary caregivers.

Apart from informational strategies, studies have also been conducted to evaluate the effectiveness of support group in Chinese. Fung et al. (2002) compared 12 weekly group sessions with standard family services in Hong Kong. Support group sessions comprised education, sharing, discussion, psychological support and problem solving. Comparing with control group (n=26) who received standard care, experimental group (n=26) exhibited significant improvement in distress level and quality of life.

In another study in Taiwan, Shyu, Yang & Yip (1996) examined the effectiveness of integrated home care, which consisted of home health care, support group, community resources referral and regular medical visits, for persons with dementia and their caregivers. A total of 81% of the 25 participating families reported that home nursing care services helped them to develop skills and knowledge, and 70% of caregivers found telephone consultation provided them with information as well as emotional support. But unlike Fung's findings, caregiver burden did not significantly decrease in this report.

However, most of the aforementioned studies were limited by their small sample sizes and/or convenience sampling strategy. Two recent studies in Hong Kong therefore deserve particular attention because both have

adopted longitudinal, randomised controlled designs. Chien et al. (2008) assessed the effectiveness of a disease management programme for Chinese dementia caregivers over a 12-month follow up period. Eighty-eight caregivers were randomly assigned to the 6-month disease management programme (intervention group) or standard care (control group). The disease management programme was primarily an education and support group for family members, together with a case manager assigned to each family. Caregivers' quality of life and burden were evaluated at recruitment, and six and 12 months after group assignment. Compared with the control group, family caregivers participating in the disease management programme reported significantly greater improvement in quality of life and burden 6 months and 12 months later. Family service utilisation in the intervention group also reduced significantly.

In a pilot study, Au et al. (2010) evaluated the effectiveness of cognitive-behavioural strategies in handling caregiving stress. Twenty-seven dementia caregivers were randomised to treatment group (i.e. coping with caregiving (CWC) group programme) and waitlist control group. CWC programme employed a skill-building, psychoeducational approach. It aimed at reducing caregivers' psychological distress through learning and practising specific cognitive and behavioural skills. After 13 weekly sessions, CWC group significantly improved self-efficacy in responding to disruptive behaviours of care recipients, and controlling upsetting thoughts. They also reported a significant increase in the use of problem-focused and emotion-focused coping strategies.

Discussion

With a rapidly ageing population, the prevalence of dementia has been escalating across Chinese communities. Since formal care like institutional services are in general

less developed in these communities, most of the burden of caregiving falls on family carers. As shown by studies conducted in Chinese communities, Chinese family caregivers of dementia persons are as significantly burdened as their counterparts in Western countries. In recent years, a number of measuring instruments have been validated to assess the stress among Chinese caregivers, which range from generic measures (e.g. GHQ) to instruments tailor-made for dementia caregivers (e.g. ZBI, CBI). Determinants of carer stress include care recipients' characteristics (e.g. BPSD, activities of daily living, and severity of dementia), and those of caregivers (e.g. age, gender, education or knowledge of dementia) have been identified. It is also evident that carer burden is affected by care arrangement (e.g. duration of care, availability of tangible help and social support). Interventions including information and support, and cognitive-behavioural strategies have been shown to be effective in relieving stress among Chinese caregivers.

Elders are traditionally venerated in Chinese societies, and well supported by extended families. It is therefore speculated that Chinese caregivers experience less distress when providing care for persons with dementia. However, as indicated by abundant research findings, this assumption is no longer valid. It may partly be due to the dramatic changes in demographics, social structures and economic development over the past few decades, e.g. nuclear families have replaced extended families as the dominant form of family units, young couples tend to live apart from parents, and more women join the workforce. In addition, changes in family values may also account for the significant stress experienced by Chinese carers. For example, filial piety, which used to be the most treasured value in traditional Chinese culture, has been modified or even eroded in the younger generation in Hong Kong (Ng et al., 2002).

Despite these, emerging evidence has showed that dementia caregiving is also associated with positive experience. Moreover, tremendous progress has been made lately in the development of validated measuring instruments in Chinese, and interventions that can effectively alleviate carer stress. Further research will be required to evaluate the effectiveness of other interventional strategies (e.g. day care, respite care), and ways to incorporate these components into health and social services.

摘要

華人社區的失智症患者照顧經驗及介入

隨著人口不斷老化，失智症患者的數目正快速增長。在華人社區，家庭成員提供大部分失智症患者照護的做法甚為普遍。已發展國家的經驗表明，失智症照顧者承受重大的壓力和負擔，這對照顧者及失智症患者的生理及心理健康都會帶來不利影響。本文旨在了解在華人社區護老者的經驗，並分析照顧者干預的研究，作為設計適合本地情況及有效的護老者支援服務的基礎。

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