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Full title

Family caregiver challenges in dementia care in a country with undeveloped dementia services

Running head

Family caregiver challenges in dementia care

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FAMILY CAREGIVER CHALLENGES IN DEMENTIA CARE IN A COUNTRY WITH UNDEVELOPED DEMENTIA SERVICES

ABSTRACT

Aims. To examine socially, culturally, and politically constructed factors affecting family caregiver practice in dementia care and to identify possible changes in a country with undeveloped dementia services.

Background. In China and many other low- and middle-income countries, social transformations are weakening the family care model, which impacts the population with dementia. Exploring the challenges that caregivers face may help the international healthcare community to improve dementia services.

Design. A double hermeneutic approach informed by Giddens' Structuration Theory was used.

Methods. In-depth semi-structured interviews with 23 family caregivers of people with dementia were conducted in 2012. The interviews were audiotaped, transcribed and analysed.

Findings. Analyses revealed three consequences of socially constructed factors in dementia care, which constrained caregiver practice. Firstly, caregivers were unable to manage behavioural and psychological symptoms of dementia. Untreated aggressive behaviours caused harm to the person with dementia and endangered the caregiver and the public. Secondly, the burden on the primary caregiver was evident, and caregivers received limited support. Thirdly, there was little coordination between primary and specialist care services for people with dementia. Upon critical reflection of potential changes that could improve dementia services, caregivers suggested that community nurses have a leading role in coordinating dementia services and supporting caregivers.

Conclusion. Relying on family caregivers to care for people with dementia without the provision of dementia services by the public healthcare system generates negative health outcomes for both care recipients and caregivers. The nursing workforce should be developed to support dementia services.

SUMMARY STATEMENT

Why is this research or review needed?

- Caregiver practice for people with dementia is socially, culturally, and politically constructed. However, studies on dementia care predominantly come from high-income countries.
- Two thirds of people with dementia live in low- and middle-income countries, including China, which have undeveloped dementia service systems and underreported caregiver challenges.
- Social transformation is weakening the family care model, affecting dementia care in countries with undeveloped dementia services. Exploring the challenges that caregivers face may help to improve dementia services.

What are the key findings?

- Caregivers are unable to manage behavioural and psychological symptoms of dementia, and the untreated aggressive behaviours by the person with dementia cause self-harm and endanger the caregiver and the public.
- The burden on the primary family caregiver is evident, and the family caregivers receive limited support within and outside the family.
- There is little coordinated treatment for the person with dementia or support for caregivers in the healthcare system. Caregivers suggested the need for dementia services supported by community nurses.

How should the findings be used to influence policy/practice/research/education?

- Government-funded dementia services should be considered as a viable solution to support the rapid increase of people with dementia. In addition, dementia policies and resources should be developed.
- Community nurses are in an ideal position to coordinate dementia services, and their role and responsibilities should be further investigated to reflect consumer-directed dementia services.
- Education programmes and home-based coaching for caregivers led by community nurses should be established to prepare caregivers for their role.

Keywords: behaviour management, care burden, caregiver, critical hermeneutics, dementia, community nursing care

INTRODUCTION

Dementia, including Alzheimer's disease and related disorders, is a syndrome caused by a degenerative brain disease that affects higher cognitive functions, such as emotional and social behaviour (Ballard & Bannister 2010). It is estimated that in 2010, 35.6 million people worldwide live with dementia, and that this number will double every 20 years (Alzheimer's Disease International 2009). Approximately, two thirds of people with dementia live in low- and middle-income countries (LMIC) (Alzheimer's Disease International 2009). Furthermore, China, a low and middle-income country, has the largest number of people living with dementia in the world, yet has an undeveloped dementia service system (Ferri *et al.* 2005, Alzheimer's Disease International 2009).

People with dementia are increasingly dependent on family caregivers to provide daily care and to maintain their dignity (Sousa *et al.* 2010, Chien & Lee 2011). While evidence shows that caregivers in LMIC experience the similar level of burden as those in high-income countries, government-funded dementia services are undeveloped in LMIC (Gavrilova *et al.* 2009, Pattanayak *et al.* 2010). Dementia caregiver practice is socially, culturally, and politically constructed. However, studies on dementia care predominantly come from high-income countries, which have a different social context than LMIC. Exploring the challenges that caregivers face in LMIC, using China as a case study, provides valuable data for the international healthcare community, which can be used to improve consumer-directed dementia services.

Background

It is widely recognised that caring for people with dementia at home is challenging due to the nature of 24-hour supervision, the difficulties in managing behavioural and psychological symptoms of dementia, and the high dependency of people with dementia on caregivers for

the performance of activities of daily living (ADLs) (Huang *et al.* 2012). The care needs of people with dementia can be further compounded by comorbidities and complications. In many LMIC, caring for older people is viewed as the family's responsibility (Chou *et al.* 1999, Pattanayak *et al.* 2010, Wang *et al.* 2012). In fact, in China, caring for older people is assigned to family members by law (The 11th Standing Committee of the National People's Congress 2012). Because countries place importance on family-driven elderly care, government-funded dementia care services are undeveloped.

However, the traditional family role of caring for people with dementia is becoming less prominent due to rapid societal changes, such as the 'one-child policy', the rapid growth of internal migration for employment, and the improved social status of women in the workforce, who were traditionally the home-based caregivers (Chang *et al.* 2011, Xiao *et al.* 2013). The number of older people living in an 'Empty Nest' has increased by more than 9% during the past 10 years, reaching 31.77% of the population in 2010 (CNCA 2012). This suggests an increasingly high demand for dementia care services through the public healthcare system.

Dementia care in high-income countries is mainly provided in primary care settings led by general practitioners (GPs) and community nurses to achieve timely diagnosis, early interventions and caregiver support (Callahan *et al.* 2006, Brodaty & Cumming 2010, Lee *et al.* 2010). In China, Community Care Centres currently function as mini acute hospitals with minimal function for disease prevention, chronic disease management, and assisted living for older people (Wei *et al.* 2005, Ministry of Health 2012). In addition, dementia is not included as a chronic disease under the government's pharmaceutical benefit scheme, resulting in greater financial burden on the family (Ministry of Human Resources and Social Security 2009). Paid caregivers are often paid to substitute family caregivers by those who are able to afford the cost (Liu *et al.* 2009, Prince *et al.* 2012).

Nurses in countries with established dementia services play a leadership role in coordinating dementia treatment, supervising paid care staff, and educating family caregivers about dementia care (Callahan *et al.* 2006, Chien & Lee 2011). Nurse-led dementia intervention programmes, which include home visits and assessments, psycho-education programmes, telephone support, and caregiver support groups, enhance caregiver performance, reduce caregiver burden, and reduce the number of hospital admissions for people with dementia (Chien & Lee 2011, Ducharme *et al.* 2011, Wang *et al.* 2012). In China, nurses are in an ideal position to lead homecare for people with dementia and support caregivers because they make up the majority of health professionals in Community Care Centres and have more contact and closer relationships with the local residents compared to other health professionals (Wei *et al.* 2005, Ministry of Health 2012). However, currently, they mainly help doctors to deliver medical treatment and have limited autonomy in leading primary care (Wei *et al.* 2005, Ministry of Health 2012). Furthermore, there are no services provided by psychiatrists, psychologists, or social workers, or dementia care services provided by the Alzheimer's Association of China (Alzheimer's Disease Chinese 2012). The roles and responsibilities of nurses in dementia care have therefore not been fully established.

Structuration Theory as a framework guiding this study

While evidence suggests that dementia caregiver practice is shaped by factors that are socially, culturally, and politically constructed, studies that examine social structures affecting their practice are sparse. Giddens' Structuration Theory provides one avenue for analysing social structures that shape people's actions, and identifying changes that are realistic and practical. Social structure, as used by Giddens, refers to the 'rules and resources' associated with the exercise of power over people's actions (Giddens 1984, p.25). The rules in a society are either formal (such as legislation and policies in dementia care) or informal (such as cultural norms in dementia care). Resources are divided into allocative and

authoritative resources, with the former concerned with the material resources (such as infrastructure, equipment, and written information for caregivers) used to aid care practice, and the latter dealing with human activities (such as caregiver training for dementia care). Social structures and people's actions (or agency) are not separated as 'a dualism', but are 'a duality'; they are inseparable and shape each other (Giddens 1984, p.25). Structures enable the shaping of people's actions in a specific manner, but may also constrain people's rational actions. As a consequence, the outcomes of people's actions include both 'intended' and 'unintended' consequences.

Conversely, this theory also acknowledges that people have the capability, generated from a 'reflexive form of knowledgeability' (Giddens 1984, p.3), to re-develop structures to improve practice. Therefore, this theory allows researchers to identify possible avenues of change for dementia care through collaborative reflection with caregivers. This is a strategic approach in countries with undeveloped policies, services, and nurse roles in dementia care. The Figure summarises the 'duality' relationship by means of human reflexive circles based on an understanding of the theory, and is modified from one of the authors' (XY) previous work.

[Insert Figure 1 here]

THE STUDY

Aim

The aims of this study were to examine socially, culturally, and politically constructed factors affecting family caregiver practice in dementia care and to identify possible changes in a country with undeveloped dementia services.

Design

This study used a double hermeneutic approach, based on the work of Giddens, to address the stated aims. A “double hermeneutic” is described by Giddens (Giddens 1984, p.374) as ‘the intersection of two frames of meaning as a logically necessary part of social science, the meaningful social world as constituted by lay actors and the metalanguages invented by social scientists’. This methodology enabled the researchers not only to empirically document the caregiver’s self-described practices and social conditions (interpretive hermeneutic), but also to uncover structural constraints on the caregiver’s rationality and autonomy in dementia care (critical hermeneutic) using social theories or so-called ‘metalanguages’. Double hermeneutic is viewed as a critical hermeneutic, a form of critical methodology used to critique structural domination and illustrate ways to reform social structures.

Qualitative and quantitative approaches have been widely used in studying dementia care (Liu *et al.* 2009, Chien & Lee 2011, Davis *et al.* 2011). Although these approaches have advantages in analysing issues affecting caregiver practice, such as caregiver burden and experience, they have limitations in capturing the structural constraints on caregiver performance and in identifying areas of potential changes due to a lack of ‘metalanguages’ developed by critical theorists. The double hermeneutic approach underpinned by Giddens’ Structuration Theory provides the authors with a suitable theory and methodology to overcome these limitations.

Participants

Twenty-three primary family caregivers with at least 1 year in the role were recruited from February to August 2012. These caregivers were recruited via geriatric clinics in the three large university-associated teaching hospitals in China. Nurses working in the geriatric clinics helped to distribute letters of recruitment to potential participants. Caregivers who met the selection criteria and were willing to participate in the interview were asked to provide their

contact details on the 'participant's response slip' and return it to the author (XY). The first author contacted participants to negotiate the time and venue for interview. Of the 45 caregivers invited, 23 agreed to participate in an interview.

Data collection

Data were collected by in-depth face-to-face interviews lasting up to 90 minutes. Before the interview, the medical records and diagnosis certificate of the people with dementia were reviewed. The interview was conducted in quiet private rooms in the participants' respective homes. A semi-structured interview guide was developed to elicit key information on the challenges that caregivers face (see Appendix 1). Interviews were audio-taped and transcribed verbatim for analysis.

Ethical considerations

Ethical approval was granted by the two universities that funded the project. Informed consent was obtained from all participants, and confidentiality and anonymity were ensured. All participants were given a description of the study and their role and expectations as a participant. Guarantees of confidentiality, the right to refuse to participate or to withdraw from participation, and the freedom to refuse to discuss particular questions were ensured.

Data analysis

Data analysis and interpretation were based on Giddens' four levels of understanding of how social structures enable and inhibit people's actions (Giddens 1984, p.327). These were modified into three levels to suit the context of this study and included: 1) identifying caregiver awareness of conditions influencing their performance; 2) analysing unintended consequences and unacknowledged social structures; and 3) identifying social structures that could improve caregiver performance in dementia care. The interpretive hermeneutic is achieved via the first level of understanding, while the critical hermeneutic is achieved through the second and third levels of understanding. A table that reflects the three levels of

understanding as described above was created for the purposes of analysing codes and themes (see Appendix 2).

Rigour

Four criteria of trustworthiness should be met in research mainly using qualitative methods: credibility, transferability and dependability, and confirmability (Lincoln & Guba 1985). Three methods were used to achieve credibility in the study: (1) Participants were invited to review and modify their transcripts and 16 participants completed the transcript checking; (2) Transcripts in Chinese were translated into English and the translations were validated by two bilinguals; and (3) Codes and themes were crosschecked within the research team. Transferability addresses the applicability of the study. To fulfil transferability, we explicitly discussed the context of dementia care, setting, participants, interview guide, and data analysis framework. Dependability is concerned with consistency. Strategies we applied to achieve this criteria include adhering to Giddens' Structuration Theory and double hermeneutic methodology when developing the semi-structured interview guide, coding data, analysing and presenting themes. Confirmability in a study using critical theory refers to developing intersubjective understanding on issues of concern by participants and researchers (Kincheloe & McLaren 2000). Two key research processes were undertaken to achieve confirmability: critical reflection with caregivers on factors affecting their practice (interpretive hermeneutic), and critical reflection on how these factors were associated with social structures informed by Structuration Theory within the research team (critical hermeneutic). The demonstration of relationships between findings from the two levels of hermeneutic in table 3 has made the development of intersubjective understanding of factors affecting caregivers' practice transparent.

FINDINGS

Of the 23 primary caregivers interviewed for the study, the majority were women, spouses of the people with dementia, aged 60 or above, and had chronic health conditions themselves. The average length of time as a caregiver was 5 years. The mean age of the care recipients was 78.8 years and the mean duration of living with dementia was 5 years. Many of the care recipients had several chronic comorbidities. The demographic information of the caregivers and the care recipients are summarised in Tables 1 and 2, respectively.

[Insert Table 1 here]

[Insert Table 2 here]

The four themes in this study identified three unintended consequences of caregiver practice (Themes 1 to 3; Table 3) and identified potential changes to dementia care (Theme 4). These unintended consequences are the result of inadequate social structures supporting dementia care in the home care environment and are described as follows: untreated behavioural and psychological symptoms of dementia, burden on the primary caregivers, and uncoordinated treatment for the people with dementia. Theme 4, described as suggested dementia services, highlights potential structural changes based on collaborative reflection with caregivers. The categories identified in the interpretative hermeneutic and the themes developed in the critical hermeneutic are outlined in Table 3.

[Insert Table 3 here]

Untreated behavioural and psychological symptoms of dementia

Behavioural and psychological symptoms of dementia were identified as a major factor contributing to caregiver burden. People with dementia manifested aggressive behaviours that resulted in self-harm and endangered family caregivers and the public. Behavioural and psychological symptoms of dementia were the most common reason for family caregivers to

seek help from health professionals. However, family caregivers thought that they got little support or resources to manage severe behavioural and psychological symptoms of dementia at home.

As an example of behavioural and psychological symptoms of dementia endangering the people with dementia, a caregiver stated:

He ate food from the garbage, cursed, and hit others. We have no choice but to lock him at home. He urinated and defecated everywhere in the house: on the television, sofa, everywhere... [P18].

Untreated behavioural and psychological symptoms of dementia could also pose harm and risk to the caregivers and the public. Two caregivers described their husbands' behaviour as follows:

He often looks for the lighter and burns things in the house, claiming that there are snakes and wrangling throughout the night [P21].

He threw everything from the window of second floor, everything including waste, tore the window curtains into small pieces ... He did not listen to me, but bit me ... It is fretful to care for him [P18].

Most caregivers took the people with dementia to see medical doctors, who prescribed antipsychotic medications to treat aggressive behaviour. A caregiver stated:

I have taken him to doctors and psychiatrists for help, but received no useful instructions. They (the doctors) only prescribed sedatives, but I decided not to give him the medication because people have told me that this type of medication could be harmful to his health [P21].

The non-compliance with the treatment regime is evidence that caregiver education on both pharmacological and non-pharmacological management of behavioural and psychological symptoms of dementia is important to ensure medical treatment is appropriately administered. In this study, nurses were not involved in educating caregivers or in coordinating care in behavioural and psychological symptoms of dementia management in the Community Care Centre.

Burden on the primary caregivers

The majority of the people with dementia lived in “Empty Nests” and mainly relied on their spouses to care for them. A small proportion of family caregivers were adult children and some of them were aged 60 or above. The lack of family caregiver resources was evident, and paid caregivers were used in care crises.

Older people had different expectations for their sons versus their daughters regarding their supportive role in home care, with daughters expected to undertake more care activities than sons. In addition, older people without daughters expected to experience more care burden. As one caregiver stated:

Unfortunately, I have no daughters, only three sons living in the same city. One of my sons has a disability and the other two need to work long hours to keep their jobs. In addition, they have school-aged children to support, so they do not visit us very often [P5].

For families with daughters, the most mentioned types of support were financial support or receiving a sick parent in their homes during a care crisis. One caregiver said:

She received us in her house for a period of time when my husband was in a severe condition after a stroke. She left the house early in the morning and returned in the evening. By the time she returned from work, I had already bathed my husband on my own and helped him to get into bed [P23].

Furthermore, a significant physical burden was associated with caring for people with dementia who were completely dependent on caregivers, especially when the caregiver was also older. One caregiver explained:

He has been bed-ridden since he suffered a hip fracture 2 years ago. I am too old to turn him on my own. He has large bedsores and I try my best to change the dressings for him. I am unable to clean him properly each time he has bowel movements; I have to wait for my daughter to come and help me. She has a job and family and is not available for most of the day [P6].

In cases like this, or in the case of older couples who do not have children to help, maintaining basic hygiene and protecting the dignity of the people with dementia would not

be possible without government-funded dementia services. Although employing paid caregivers in a care crisis was mentioned, not all families could afford this option, as pointed out by a caregiver:

I tried to hire a private caregiver to assist me with his daily care, especially when he was hospitalised. However, I was unsuccessful as they [paid caregivers] were unwilling to care for him due to his aggressive behaviour [P22].

There are no government-regulated agencies that fund paid caregivers for families in need. Therefore, caregivers were forced to find suitable paid caregivers themselves and to negotiate payment and working hours, which led to further psychological burden during the care crisis.

Uncoordinated treatment for the people with dementia

Most people with dementia had comorbidities and needed frequent medical treatment and hospitalisation. However, there was little coordination between primary and specialist care services to prevent acute episodes or reduce the number and length of hospital visits. Treatment for the people with dementia was further compounded by financial strain. As a caregiver stated:

During that time (when he was hospitalised), he took so many medications that I could not remember the names of all the medications. [After discharge] We couldn't afford all of the medications and decided to reduce to the essential ones to treat only his diabetes [P5].

In this case, the caregiver selected which treatments to continue, meaning that some potentially important medications were not used. This may have contributed to the care recipient's frequent readmission due to repeated falls, hallucinations, and cerebrovascular accidents, for which the public healthcare system shared the burden and costs.

Participants described that they rarely visited doctors and nurses at the Community Care Centre as they found it poorly resourced and did not trust the health professionals. One participant stated:

People living in this community have had negative experiences with them [health professionals], and always remark that they are not skilled and are unable to treat patients properly [P5].

Due to this lack of trust in the health professionals at the Community Care Centre, most older people with chronic conditions, including dementia, bypassed the Community Care Centre and sought medical treatment from specialists in major hospitals. This situation contributed to the overload of those major hospitals as described by one caregiver:

It was impossible for me to get a doctor's appointment for my wife at XXX hospital due to the long waiting list. Even though we had an appointment, the doctor was too busy to give us helpful instructions besides some lab tests and prescriptions [P7].

In the present study, only 1 of the 23 people with dementia was taking medication specifically for dementia. Overcoming the fragmental nature of treating dementia and other comorbidities requires government planning and action to improve primary care and the coordination between primary and specialist care services.

Suggested dementia services

Due to impaired mobility and cognition of the people with dementia and difficulties in getting an appointment with specialists in major hospitals, most caregivers expressed that they preferred to use local healthcare services. However, they were also concerned about the quality of care and the affordability of services.

Most spouse caregivers and the people with dementia were isolated at home and had limited contact with others. They sought interactions with others for the health and wellbeing of both the people with dementia and themselves. One caregiver stated:

The Community Care Centre should establish a rehabilitation centre so that we can take people with dementia for rehabilitation activities and psychological counselling [P11].

This was further supported by a statement from another caregiver:

I am hoping nurses can provide regular home visits to assess my husband and give me instructions on care [P8].

Caregivers wanted respite care and community elderly care to be available. One caregiver said:

I wish that nurses would provide regular home visits to assess my husband and give me instruction on how to best care for him [P20].

Another caregiver also stated:

The Community Care Centre should provide homecare as an important part of aged care. Medical treatment for people with dementia should be an important part of homecare [P8].

Family caregivers recognised both their limitations and their learning needs as they mainly used a self-directed learning approach. They believed that the Community Care Centre should offer them further training. One caregiver said:

I am always learning new nursing skills on my own. This enables me to better look after her at home. I wish that nurses from the Community Care Centre would offer training programmes on dementia care [P16].

Most caregivers had few opportunities to socialise with other caregivers and share their experiences of caring for people with dementia. Televised health education programmes were frequently mentioned as the main learning resource:

I learned a lot from TV programs, which is a good way for elderly people to learn as we can't see written materials clearly or don't have the ability to read [P3].

Most caregivers in the study learned about dementia care through their own experience and were very eager to learn more, motivated by the challenges they faced. The ways in which we can meet caregiver expectations are discussed in the following section.

DISCUSSION

This study supports previous studies showing that behavioural and psychological symptoms of dementia are a major factor contributing to caregiver burden and reveals a lack of behavioural management that contributes to the situation. The estimated prevalence rate of behavioural and psychological symptoms of dementia in the community setting is 61–88% in high-income countries (Brodaty *et al.* 2003), where people with severe behavioural and

psychological symptoms of dementia are sometimes admitted to residential elderly care facilities. The prevalence of behavioural and psychological symptoms of dementia is estimated to be higher in LMIC due to the underdevelopment of elderly care facilities. Behavioural and psychological symptoms of dementia are treatable through effective intervention by dementia specialists, GPs, and geriatric nurses in collaboration with caregivers (Brodaty *et al.* 2003, Callahan *et al.* 2006, Johnson *et al.* 2012). In high-income countries, Alzheimer's associations also provide 'Dementia Behavioural Management and Services', which include home-based assessments and individual counselling sessions delivered by a multidisciplinary team (Brodaty & Donkin 2009, Brodaty & Cumming 2010). The untreated behavioural and psychological symptoms of dementia identified in the present study reveal two structural issues in caregiver practice that require policy intervention: the absence of government-funded services for behavioural management (a crucial resource) and the lack of coordination between primary and specialist care services (no rules to govern coordinated care).

The present study found that financial burden is a major concern for caregivers, which prevents them from seeking treatment for behavioural and psychological symptoms of dementia. The findings suggest that including dementia in the list of government-funded chronic diseases through policy intervention is one solution, which would meet the rapid growth in the number of people living with dementia. We also identified a lack of resources in the primary care setting, as evidenced by caregivers bypassing the Community Care Centre when seeking medical treatment for people with dementia. Addressing this issue requires government investment in the workforce and equipment in Community Care Centres to meet caregiver demands on locally available dementia care services.

In this study, caregivers showed an evident knowledge gap regarding the causes and triggers of behavioural and psychological symptoms of dementia, and held false beliefs on

the use of medication to treat aggressive behaviour. The findings agree with previous studies reporting a high level of under-preparation of family caregivers in countries where dementia education programmes are available, but are not easy to access or are not relevant (Brodaty *et al.* 2003, Ducharme *et al.* 2011, Gallagher-Thompson *et al.* 2012). This study further suggests that a lack of knowledge on dementia care leads to undeveloped caregiver education and a low level of health literacy. Poor health literacy is associated with poor health and non-compliance with medical treatment (U.S. Department of Health and Human Services 2009, Lee *et al.* 2010). In addition, caregivers believe that nurse-led homecare assessment and one-to-one coaching for caregivers is necessary. A body of evidence shows that nurse-led caregiver education is a crucial component of non-pharmacological intervention for behavioural and psychological symptoms of dementia, through which caregivers learn to identify behavioural triggers and to manage them in partnership with health professionals (Johnson *et al.* 2012, Wolfs *et al.* 2012). Meeting caregiver expectations on the role of community nurses in dementia care requires that the current nursing workforce be prepared to lead dementia care.

In this study, the desired dementia services were similar to those provided by memory clinics in primary care settings in high-income countries. These clinics are designed to provide early diagnosis, caregiver education, dementia treatment, and timely intervention for behavioural and psychological symptoms of dementia, and to prevent dementia-associated psychiatric crises (Greening *et al.* 2009, Lee *et al.* 2010). Geriatric nurse specialists play a key role in these clinics. This approach to dementia care can be implemented in LMIC, but requires government policies and resources to support advanced nursing training in primary care settings and to improve nurse status in these settings.

The caregiver suggestions regarding community nurse-led homecare identified in this study reflect caregiver interventions led by community nurses in previous studies (Chien &

Lee 2011, Waldemar *et al.* 2011, Van Houtven *et al.* 2013). The “Helping Caregivers to Care” programme was specifically designed for family caregivers in LMIC, where dementia services are very limited (Dias *et al.* 2008, Gavrilova *et al.* 2009). The home-based approach was used to build caregiver skills with respect to performing ADLs and managing behaviour, providing emotional support, and maximising the use of locally available health and human resources.

In this study, older spouse caregivers were unable to fully perform ADLs for people with dementia, as evidenced by severe complications such as repeated falls, severe decubitus, and unmanaged faecal and urinary incontinence. These caregivers were unable to afford paid caregivers to substitute their roles. Failing to intervene in the poor health conditions of people with dementia can maintain or worsen existing health disparities in a society determined by social status (World Health Organization 2008, World Bank 2009). Nurse-led community aged care programmes should be considered in LMIC to relieve burden for those older caregivers, reduce dementia-associated complications and avoid hospitalisation.

Limitations

This study has several limitations. First, only 23 caregivers agreed to participate in an interview among the 45 caregivers invited. One of the barriers contributing to the low response rate might be stigma attached to dementia (Alzheimer's Disease International 2012). Therefore, this study might not capture the whole range of caregiver challenges. Future studies on dementia caregivers should consider strategies to overcome factors affecting the recruitment. Second, the findings cannot be generalised to all family caregivers of people with dementia in rural and remote areas in China or in other countries due to the use of a qualitative approach to data collection and because family caregivers were sampled from one capital city in China. However, the findings may be transferrable to similar social and cultural contexts. Third, the use of the Structuration Theory to interpret structural domination in

family caregiver practice restricted the researchers in analysing issues outside this theory. Therefore, the findings of the present study represent only one of many critical perspectives on how undeveloped dementia policies and services affect family caregiver practice. The researchers acknowledge there may be other interpretations of the problem under study, suggesting further research is needed in this area.

CONCLUSION

Caregivers of people with dementia face many challenges due to limited caregiver support within and outside the family. This lack of support is due to social changes that have weakened the traditional family care model, and the situation is further complicated by a lack of established dementia services. The use of Structuration Theory and double hermeneutics enabled the researchers to not only examine socially, culturally, and politically constructed factors affecting caregiver practice, but also to identify structural changes that could improve dementia care. As suggested by the caregivers, government-funded services for people with dementia and community elderly care should be considered as long-term solutions to the rapidly ageing population, the increase in the number of people living with dementia, and the decrease in the number of family caregivers in China and other LMIC. Community nurses are in an ideal position to work with caregivers to manage behavioural and psychological symptoms of dementia and provide clinical nursing care, education, and coaching. Dementia care policies and resources, and the roles and responsibilities of community nurses, should be developed through rigorous studies that reflect major stakeholder expectations in dementia care.

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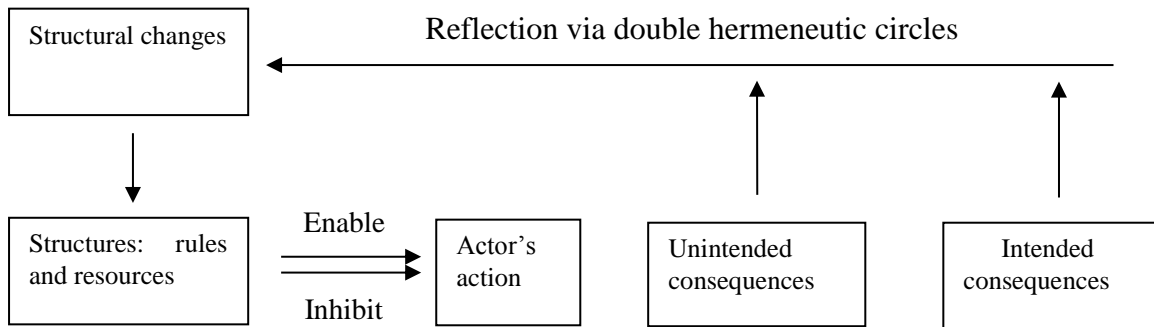


Figure 1 Giddens' Structuration Theory used to guide this study

Table 1 Demographic information of caregivers (n=23)

Items	Older Caregivers (≥60 yrs)	Adult Caregivers (<60 yrs)
Caregivers (%)	16 (69.6)	7 (30.4)
Male (%)	5 (31.3)	1 (14.3)
Female (%)	11 (68.8)	6 (85.7)
Mean Age (range)	71.8 (60-93)	49.3 (45-56)
Mean Duration of Caregiving (range)	5.9 (1-16)	3.1 (1.5-7)
Mean Number of Chronic Disease (range)	2.3 (0-4)	0.7 (0-2)
Relationship with people with dementia		
Spouse (%)	13 (81.3)	0 (0.0)
Son (%)	1 (6.3)	1 (14.3)
Daughter (%)	0 (0.0)	1 (14.3)
Daughter-in-law (%)	1 (6.3)	5 (71.4)
Sibling (%)	1 (6.3)	0 (0.0)
Live in the same household	15 (93.8)	5 (71.4)

Table 2 Demographic information of people with dementia (n=23)

Items	Data
Male (%)	11 (47.8)
Female (%)	12 (52.2)
Mean Age (range)	78.8 (59-100)
Care recipients with BPSD (%)	14 (60.9)
Mean number of chronic diseases (range)	2.3 (0-6)
Common BPSD	Aggressive behaviour, wandering, repeated requests or demands, changes in personality, depression
Common chronic diseases	Hypertension, stroke, prostatitis, diabetes, cerebral infarction, heart disease, Parkinson's disease

Note: BPSD= Behavioural and Psychological Symptoms of Dementia

Table 3 Categories from interpretive hermeneutic and themes from critical hermeneutic

Categories from interpretive hermeneutic	Themes from critical hermeneutic
C1.1: Worrying about the safety of the person with dementia, the caregivers and the public	T1:Untreated behavioural and psychological symptoms of dementia
C1.2: Feeling ashamed of the dementia behaviours in the public place	
C2.1: Difficulties experienced by older spouse caregivers	T2: Burden on the primary caregivers
C2.2: Daughters are expected to care for parents in a family	
C2.3: Difficulties experienced by adult child caregivers	
C2.4: Using paid caregivers in a care crisis	
C3.1: Not seeking help from the Community Care Centre	T3:Uncoordinated treatment for the people with dementia
C3.2: Non-compliance with medications	
C4.1: Accessible and affordable dementia services	T4:Suggested dementia services
C4.2: Demands for community aged care services	
C4.3: Demands for dementia education programs for caregivers	

Note: C=Category T=Theme