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A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China

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Abstract

Ageing in place is a key principle of older care services in many countries, especially in China where the social convention, cultural expectation and legal obligation emphasise that looking after parents is the children's responsibility. As a result, the majority of older, frail Chinese have been cared for at home by their families. Previous studies have argued that being cared for at home contributes positively to the well-being and quality of life of older people and to economic cost. However, due to the sociocultural, economic and demographic changes in China, older people and their family caregivers are facing many challenges as they 'age in place' at home.

This study aims to explore the meaning of family supported home care in China from the perspectives of people with dementia and family caregivers. The study is based on qualitative data collected from 24 people with dementia and family caregivers recruited from one mental health centre in Shandong province, China. Three main themes and nine subthemes were found: home care may create a sense of social isolation; home care is a burden; home care versus institutional care. The study suggests that while home care may

bring social and psychological benefits, it also can be a barrier to building social connection, receiving social support, and other related services in China.

What is known about this topic

- In China, family-supported home care is the dominant care service for people with dementia.
- There are a limited number of studies that report the experiences of home care for people with dementia and family caregivers in China.
- Home care contributes positively to the well-being and quality of life of older people and to economic cost.

What this paper adds

- While home care may bring social and psychological benefits, it also can be a barrier to building social connection, receiving social support, and other related services in China.

Keywords

Dementia, family caregivers, home care, ageing in place, China

Introduction

China has one of the fastest growing proportions of older people in its population and an associated increasing number of people with dementia. It reports that China had 9.19 million people with dementia in 2012 - over 20% of the dementia population of the world (Chan et al., 2013). Traditional Chinese culture, social convention and law considers caring for older people to be a family's responsibility (Wu, Carter, Goins, & Cheng, 2005; Zhan, 2005). However, China is currently undergoing a range of sociocultural and demographic changes which influence the capacity and availability of traditional family-support care, including the '4-2-1' family structure (four grandparents, two parents and one child), migration and urbanization (Zhang, Clarke, & Rhynas, 2018). In addition, a lack of the

necessary rules and regulations to support dementia care and the current financially insufficient healthcare system puts family-based dementia care in a difficult situation (Feng, Liu, Guan, & Mor, 2012). Therefore, understanding the meaning, the problems and challenges of people with dementia and family caregivers who remain 'age in place' at home has significant implications for the development of support services for family-based care in China.

Most research on 'ageing in place' has been conducted in a Western context (Lui, Everingham, Warburton, Cuthill, & Bartlett, 2009; Means, 2007; A. Sixsmith & Sixsmith, 2008), in which many studies (Cutchin, 2005; J. Sixsmith et al., 2014; Van Dijk, Cramm, Van Exel, & Nieboer, 2015; Wiles, 2011) indicated that home is a hub for building social connections with relatives, neighbours and friends which brings the person a sense of security, comfortability and independence. For example, Wiles (2011) claims that 'being greeted by known people' or 'knowing local shops' were evidence of belonging and security within the community for older residents. This is not only about familiarity with the place, but also brings the sense of knowing people, and involvement in the community. Research with a focus on the 'neighbourhood' demonstrates the potential to play an extremely important role in social health, engagement and well-being (van Dijk, Cramm, & Nieboer, 2013; Ward et al., 2017). On the other hand, a number of studies (Clarke & Bailey, 2016; Herron & Rosenberg, 2017; Soilemezi, Drahotá, Crossland, Stores, & Costall, 2017), posit that there can be detrimental aspects of 'ageing in place', indicating that home may be a potentially risky or unsafe place for some frail, older individuals; a place that can hide their voices; a barrier to getting support; and a place that can create isolation and loneliness.

Echoing Clarke and Bailey's study, relationships and attachments to the community can be influenced by how people with dementia position themselves in relation to others. These influences could be positive in some ways and negative in others. The authors also claimed that a familiar place can be a supportive factor in supporting the narrative citizenship of people with dementia, but may at the same time be a source of estrangement (Clarke et al., 2016).

Despite previous studies about 'ageing in place' that offer us a better understanding of the benefits, challenges and barriers for older people who stay at home, there has been very limited investigation on the effects of 'ageing in place' for Chinese people with dementia.

This study aims to analyse the meanings, problems and challenges that exist in providing family-based care in China from the perspectives of people with dementia and family caregivers.

Methods

Study design

The qualitative research design used in-depth, semi-structured individual interviews with people living with dementia and with (unrelated) family carers.

Ethical issues and Recruitment

Ethical approval was gained from the University of Edinburgh and Shandong Mental Health Centre. The names used in the manuscript are pseudonyms for participants. Shandong was selected as the recruitment site because it is the hometown of Confucius where the traditional culture of 'Xiao' (filial piety) originated from. Shandong has the second biggest population of China's 34 provinces and 13.67% of its population are over 65 years old (National Bureau of Statistics, 2011).

The inclusion criteria were that people with dementia (i) had a recorded diagnosis of dementia (with the severity of dementia ranging from mild to moderate, (ii) had the communication capacity to take part in an interview, and (iii) had capacity to provide informed consent. Family caregivers had to have over 6 months caring experience (in order to have sufficient experiences to share). Potential participants who met the inclusion criteria were referred by psychiatrists (from their caseloads) who work at the Shandong Mental Health centre and their capacity to give consent were assessed by their doctor. An information sheet of the detailed study aims and procedures was sent to potential participants, along with a consent form. Those who showed interest were invited for a meeting to discuss the study and answer any questions with XZ. Written consent was signed by the individual participants before conducting the interview.

Fourteen family caregivers (FC) and 10 people with dementia (PWD) participated in the study. There is one care dyad of father and daughter but the others are not related.

Data collection

Semi-structured individual interviews were conducted in the mental health centre or in the participants' own houses according participants' preferences. The interviews were conducted in Mandarin and the interviews lasted 30-60mins. Interviews were audio-recorded and addressed the following topics: negative and positive experiences of home care; how caring at home has affected quality of care and life. Interview questions were designed with open-ended question to allow the participants to fully express their viewpoints and to provide an opportunity for new themes to emerge (Turner, 2010). Interviews were conducted between August 2016 and January 2017 by XZ.

Data analysis

A thematic analysis was used to identify themes and explore patterns of meaning within the data (Braun & Clarke, 2006). Thematic analysis is suited to gather knowledge of the meaning of a specific phenomenon from a given group to establish a conceptualisation of people's thinking, feeling and behaviour (Joffe, 2012). It is suited to answer the research questions of participants' view of self- management and has potential for researchers to identify social and psychological processes (Braun & Clarke, 2006). First, the researcher listened to the recordings and read the transcripts several times to familiarise with the data and fully engage with the participants' accounts. Then an initial coding framework was developed to organize the data into meaningful groups of each transcript. Once all individual interviews were analysed, all codes were listed and categorised into meaningful groups and then refined to form themes and subthemes.

To enhance the credibility of the analysis, the accuracy of transcription was checked by going back to listen the recordings by XZ, the codes and the thematic map was reviewed by all researchers (XZ, CC, SR). In order to preserve the originality of content and meaning, the initial coding was done in the language of the interviews (Mandarin) by a bilingual researcher (XZ). As part of the quality assurance of the analytic process, four interview transcripts were translated into English so that CC, SR (who are not familiar with Mandarin) could review the coding. NVivo10 software was used to assist with data analysis and management.

Three main themes and nine subthemes (Table 1) were identified:

(A) 'Home care may create a sense of social isolation' due to the wider social and cultural changes that create the potential isolation of homecare, which mainly is reflecting on the changing community setting and family links.

(B) 'Homecare is a burden' reflects how both caring at home is a burden for family carers and perceiving oneself as burdensome is also a burden for people with dementia.

(C) 'Home care versus care home' indicates the intense challenge of seeking positive alternatives to ageing in place and finding a positive meaning of home care.

Table 1 Themes and subthemes

Themes	Subthemes	Examples
Home care may create a sense of social isolation	<p>Changes to communities and customs create disconnection</p> <p>Physical environment limit peoples' access to social activities</p> <p>Ageing in place is like a prison</p>	<p>'Nowadays, the neighbours have no contact...</p> <p>'Most buildings have many stories but have no lift...'</p> <p>'...why should I live in this house, when there is nobody at home/ I cannot go anywhere... I cannot go anywhere; I can only stay at home.'</p>
Home care is a burden	<p>Homecare is a burdensome for family caregivers</p> <p>Being dependent at home is being a burden for people with dementia</p>	<p>'I feel very tired since he got ill, my health is going down because of this...'</p> <p>'The children's burden would be reduced if I am dead'.</p>
Home care versus institutional care	<p>Caring at home is a traditional value</p> <p>Caring at home makes the family close</p> <p>Homecare continues my normal life</p> <p>Quality of care cannot be ensured at care homes</p>	<p>'I think being filial should be a thing most are willing to do...'</p> <p>'My sisters and my brother often come to visit her, we can see each other, and this is a connection between us.'</p> <p>'Life is alright for me, I can look after myself, I live with my wife. We have one son who lives on another side of road...So life is alright for us.'</p>

		'...care home is worse... if we send her there, she would be dead soon...'
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Findings

Participants' characteristics (table 2 and 3).

All of the participants were of Chinese origin and they represented a range of social, geographical and educational backgrounds.

Participants with dementia included two females and eight males, whose ages ranged from 67 to 87. Six of the participants with dementia lived with their children, two lived with spouses, one lived with a home carer and one lived alone. Six had retired from jobs such as teaching, civil service and the industrial sector with a varied level of pensions; four of them did not have pensions, one was an unemployed urban resident and the other three were farmers in rural areas.

The family caregivers consisted of nine females and five males; whose ages ranged from 39 to 78. Five cared for their spouses, eight cared for a parent and one mother cared for her sons. Four family carers who participated were retirees and ten other family caregivers were either unemployed or farmers and had no pension.

Table 2 Characteristics of participants -family caregivers (FC)

Participant	Age	Education level	Location	Relationship with people with dementia	Occupation and income
FC1 Guang	60	high school graduate	urban	daughter	retired with pension
FC2 Xue	42	high school graduate	urban	daughter	unemployed, no-income
FC3 Ying	73	illiterate	urban	wife	unemployed, no-income
FC4 Liu	65	high school graduate	urban	wife	retired with pension
FC5 Ling	59	secondary school graduate	urban	son	retired with/very low income
FC6 Mie	60	master degree	urban	daughter	retired with high pension
FC7 Wan	73	illiterate	urban	wife	unemployed, no income

FC8 Huan	76	illiterate	rural	husband	farmer with very low income
FC9 Yu	51	primary school graduate	rural	son	farmer with low income
FC10 Shou	50	secondary school graduate	rural	son	farmer with medium income
FC11 Xu	64	diploma	rural	son	retired with pension
FC12 Gui	72	illiterate	rural	mother	farmer very low income
FC13 Yan	39	diploma	rural	daughter	unemployed average income
FC14 Jin	78	illiterate	rural	wife	farmer with low income

Table 3 Characteristics of participants -people with dementia (PWD)

Participant	Gender	Age	Education level	Type of dementia and medical report of dementia stage	Location	Income	Care provider
PWD1 Wen	male	72	diploma	VaD/mild	urban	high income	daughter
PWD2 Yi	male	85	primary	AD/mild	urban	high income	son
PWD3 Jing	male	67	high school graduate	AD/mild	urban	average income	daughter
PWD4 Liang	male	78	illiterate	VaD/mild	urban	average income	home carer
PWD5 Chuan	female	73	illiterate	VaD/ moderate	urban	low average income	home carer
PWD6 Yie	female	76	secondary school graduate	AD/mild	urban	no income	son

PWD7 Yin	male	87	diploma	AD/moderate	urban	no income	daughter
PWD8 Shen	male	72	illiterate	PDD/mild	rural	low average income	sons and daughters
PWD9 Zong	male	80	secondary school graduate	AD/moderate	rural	high income	daughter and son
PWD10 Shao	male	72	primary	AD/mild	rural	low average income	wife

Vascular dementia=VaD, Alzheimer's disease=AD, Parkinson's disease Dementia=PDD

Results

Home care may create a sense of social isolation

Changes to communities and customs create disconnection

In the study, the changes in social environment in communities lead people to interact with each other less and less. With this change, the participants perceived a feeling of disconnection from the communities. For example, one participant said:

'...nowadays, the neighbours have no contact, unless we've lived together for a long period of time. New neighbours don't even know each other's name.' [Guang, caring for her mother].

The participant described the changing customs leading people to become more private and having less connection with other people than they used to in the past. Modernization seems to negatively affect Guang's life and has influenced the meaning of her lived experiences of caring at home, creating a sense of disconnection and isolation. Jing also expresses a similar opinion. He said:

'At least I think the local community centre could organize a meeting for older people to meet and chat together once or twice a month, it would feel like we would have a connection, not like now, nobody cares... everybody only cares about himself.' [Jing, people with dementia].

A feeling of isolation, being lost or discarded is reflected in the phrases 'nobody cares... everybody only cares about himself'. This has had a more significant effect on older people as most of the young people and adults move to different cities for studying and working. Apart from the changing custom, community support seems to be very important for Jing as it brought him a feeling of belonging and being supported.

Physical environment limits peoples' access to social activities

In the study, 'ageing in place' has not only left impacts on social relationships and social roles, but it also effects the ability of moving around or participating in social activities. For example, a lack of appropriate equipment and physical environment at homes limited participants' access to social events or services. For example, one participant said:

'Most buildings (where her mother lives) have many stories but have no lift. It is difficult to go down and up. This problem is difficult to deal with' [Mei, caring for her mother].

This quote reflects the unsuitable physical environment for people with dementia who live in communities and are cared for at home. This not only restricted the participations' abilities to take part in social activities and build social connections, it may also have stopped people with dementia and family caregivers getting help from social services.

Ageing in place is like a prison

Social changes due to migration and shrinking family size are occurring in China. Many adults now move away from their older parents or there is only one child within the family, which makes the possibility of providing physical care more and more challenging for family caregivers. These factors have not only affected the capacity of family-based home care, but also have changed the traditional value of home as a place for 'being together' and 'unity'. Participant Zong has only one child, who works in another city - he said:

'Although I have a big house which is more than 200 metres squared and has two stories, why should I live in this house, when there is nobody at home.' [Zong, people with dementia].

Zong's situation is the same as many other families in contemporary China. For some participants, the traditional meaning of 'home' has been changed as their children have

moved away from them and their house seems to have lost its value as a family home. Living and caring at home becomes a prison for them without children.

One family caregiver said:

'I had to give up it, had to give up it. It is not possible for me to go out for a job. You know, I need to cook two meals or three meals, do this and do that for her [mother]...I cannot go anywhere... I cannot go anywhere; I can only stay at home.'
[Yu, caring for his mother].

Yu had to stay at home looking after his mother, it not only means being trapped at home, but also the perception of self-sacrifice and giving up of self-development. 'I cannot go anywhere' means losing freedom and losing the opportunity to earn money for himself and for the whole family.

Home care is a burden

Home care is burdensome for family caregivers

Many family caregiver participants have talked about how looking after a person with dementia has had a significant impact on their life. The impact resulted from not only everyday life activities (such as assisting with toileting, washing or handling a fall and managing behavioural problems), but also resulted from the feeling of being out of control over their lives, the stress they perceive and the helplessness of their situations. For example:

'I rush to go shopping, rush for everything, this causes stress. I feel very tired since he got ill, my health is going down because of this...This has resulted in a deterioration in my health.' *[Liu, caring for her husband].*

The quote from Liu not only illustrates the negative impacts of the caring role on her physical health, but also about the perceived experiences of how she has lost control of her life and being stressed by her caring role.

Similarly, the participant, Ying said:

'It has been a big effect on me since he got ill. I cannot do anything else except looking after him. I liked to go outside, playing poker with other older people; I like to

go for walks... I cannot go anywhere since he has been injured, I have no free time now. I cannot go outside to see my friends. Nobody is available to look after him except from me...' [Ying, caring for her husband].

The quote indicates how the caring role has significantly affected her normal life by disrupting her social connections with her peers. The repeated sentence, 'I cannot play with others' emphasises the sense of isolation and stress. This experience leads to feelings of loss of connection with others as well as loss of self-attribute for the participant. In this case, 'ageing in place' has become a burden and is a source of stress for family caregivers.

Being dependent at home is being a burden for people with dementia

Being dependent and cared for at home by their children created the sense of 'uselessness' and 'being a burden' for most of the participants with dementia. For example,

'I am 87 years old, I become older and older, day by day, and next year I will be 88 years old. It is just a waste of time to be alive, I cannot contribute anything to the state and children, I cannot give them any help, and there is no meaning to be alive.'
[Shen, people with dementia]

Shen's definition of himself as a useless person can be interpreted as not being able to take responsibility for others which is reflected in the phrase 'cannot contribute' or unable to take responsibility for himself. In consequence, many participants indicate that death would be a relief from living with dementia and (as they perceive it) relief of a burden for others as there is no alternative care approach for them. This idea might be a consequence of the current health care system in China where the cost of the long-term care services needs to be paid for by the family members. One frequently occurring quote reflects this:

'I hope I can die soon... The children's burden would be reduced if I am dead. It is a burden for me as I am alive. They should go to work, but they cannot go to work...'
[Yin, people with dementia].

In the study, half of the participants who had dementia (n=5) spontaneously expressed their wishes to be dead in order to reduce the burdens that they bring to their family. Three family caregivers also felt that the only way for them to reduce their care burden is if the person with dementia whom they look after passes away. As looking after older parents is

the children' responsibly, taking care of a person with dementia has caused the family financial burden. This has limited the family caregiver's employment options, therefore, both people with dementia and family caregivers have perceived death as a way to reduce family financial and caring burden. Furthermore, in China, children are explicitly taught that they should take care of their parents. This cultural norm of filial responsibility leads children to feel obliged to care, an obligation which may affect their care behaviour. This also reflected the limitations of the current health and social security system which does not support adult children to care for their parents.

Home care versus care home

Caring at home is a traditional responsibility

Having been influenced heavily by Confucianism, Chinese people hold a strong sense of family responsibility. In the study, all the participants felt that looking after their relative is their responsibility. For example, Guang said:

'I think being filial should be a thing most are willing to do. Compassion from your heart can create a good mood for you too. As a result, the stress will go as well...'
[Guan, caring for her mother].

For participant Guang, looking after her mother is not only a traditional value, but also believes that it enhances her spiritual life and has brought her joy. However, some participants viewed their caring responsibility as an obligation that was not always desired, as in the following quote.

'erm... I have to do it (looking after his mother), what can I do? She is my mother, who would look after if I don't look after her? It is not possible to give the responsibility to others.' *[Shou, caring for his mother].*

For Shou, the meaning of looking after his mother is a task which Shou has to do as a child. Therefore, the caring responsibility here reflects a regulation/ principle that binds caring responsibility so that it can be carried out. For a family caregiver, this traditional role of looking after people with dementia was perceived as a compulsory and personal duty.

Caring at home makes the family close

In the study, apart from the practical challenges and burdens faced when living with dementia or caring for a person with dementia at home, care at home was reported as bringing the family closer together, for example, Yan said:

'Despite her not knowing anything, she is the connection among the big family. My sisters and my brother often come to visit her, we can see each other, and this is a connection between us.' [Yan, caring for her father].

For Yan, ageing in place has created a close relationship and bond within family. It is consistent with another participant, Xu, who said '...a family with older parents is a happy family...' (Xu, caring for his mother). From these extracts, we can see that 'ageing in place' has the potential to strengthen family connection and family responsibility.

Homecare continues my normal life

Staying at home and continuing with past life routines has made Shao feel satisfied with his life.

'Life is alright for me, I can look after myself, I live with my wife. We have one son who lives on another side of road, they (son and daughter-in-law) work on the land. They built the house on that side because a road has been built in there. We raise some chicken and ducks to keep our living cost...So life is alright for us.' [Shao, people with dementia].

Continuity with the normal life role is reflected in Shao's daily life story, being able to continue to live in and be cared for at his own home makes Shao perceive the feeling of satisfaction and settlement. Shao has also raised an issue about care homes as a place where people with no children to look after them go. For example,

'... I have a son and daughter. I have no need to go to a care home, do I?' [Shao, people with dementia].

Having two children reassures Shao that staying at his own house for his care is a normal and natural arrangement. The Chinese tradition and culture make him believe his later life would be to carry on as normal as possible at his own home.

Quality of care cannot be ensured at care homes

For some participants, there was concern that the quality of care is not assured in long-term care facilities. For example, when talking about choosing a care home for her mother, Yan said:

'...care home is worse... if we send her there, she would be dead soon. In care homes, there is nobody to look after her... Therefore, I don't want to send her to a care home or psychiatric hospital...' [Yan, caring for her mother].

Quality is a big concern for family caregivers and lots of care homes were perceived to not meet a desired standard. There is a sense of 'home care is better than care home'. The participant's strong feeling of distrust, insecurity and the disapproval of long-term care facilities reveals how people with dementia have been viewed and treated by long-term care services, and contributes to the reason why they are choosing home care. Therefore, despite the fact that participants have perceived some negative experiences of home care, some of them still think that caring at home is better option than staying in a care home. For example:

'Family care is good. Older people like to stay at home as well. However, there are more limitations of it. Such as, the flat where we live in is difficult for a wheelchair to move around... This problem is difficult to deal with. In most families, children take responsibility for the care cost. It is a burden as the adult children have their own children that they need to bring up and have jobs to do, they can hardly manage all of these things...' [Mei, caring for her mother].

Several issues were raised that were associated with disability access, living environment and older care costs and burdens. It indicates tension between the traditional cultural and contemporary values. These factors also reflect some significant factors of lack of public services, dissatisfaction with older care services and the limited capacity of family care. The findings of this study illustrate a conflicted relationship between people with dementia's interest in staying at home and the difficulties which are faced by families in meeting their care needs.

Discussion

This study highlights how ageing in place in China is shaped by wider social and cultural changes, with the weakening of social connections challenging the traditional meaning of ageing in place. This change of social norms has created tension between traditional culture and contemporary values and leads to questions such as whether older people should be cared for at home or in a care home. It also indicates the challenges and problems of current family-based care that could inform the practical and political services on how to better support people with dementia and family caregivers.

In the study, participants highlight how the changing neighbourhood, migration and social spaces have influenced their quality of life and the meaning of 'ageing in place' for them. Even if the children live together with their parents, they still have no time to spend with their parents. The findings also show that the meanings of 'home' and 'family care' have been changed due to changes in family life style and a sense of community networks. As a result of increased social mobility, more and more adult children migrate to bigger cities seeking job opportunities, which has sometimes left older parents in the family home without their children nearby (Shang & Wu, 2011). This has considerably influenced the traditional family care services and care quality, and consequently changed older residents' sense of 'home'. For instance, in the theme 'home care creates a sense of disconnection', some participants thought that they would prefer to be in a care institution than staying at home alone, reflecting the feeling of loneliness caused by not having their children around and not having community support, a state of affairs in conflicting with traditional Chinese family life and culture (Shang and Wu, 2011). This means that even though the older people stay in their own home and own community, their feelings of connection to home and to the community is getting weaker than before – exemplified by Zong in saying 'why should I live in this house'. The findings are consistent with previous studies, which indicate that 'changing' neighbourhood creates disconnections in the changing sociocultural context (Clarke and Bailey, 2016). Therefore, when we think about 'ageing in place' and ways to support people to 'stay in place', we need to recognize that place is a mediator to maintain one as an insider and to connect a person to the outside. If this connection had been broken, we need to reconsider the meaning of 'home' and the function of 'ageing in place'.

These suggest that a supportive and dementia friendly community that reduces social and physical limitations on community inclusion need to be encouraged from a political level.

Furthermore, both participants with dementia and family caregivers encountered great difficulties 'ageing in place' at home because of limited capacity or resources for everyday activities. Some previous studies related to neighbourhood changes indicate that not being able to attend outdoor activities with their peers evidences isolation and exclusion because of migration and demolition or resettlement, which changes a community's physical environment and makes them feel like 'strangers' (Burns, Lavoie, & Rose, 2012). This illustrates some similar key points to the study by Burns (2012), where the author investigated physical and social environment changes which made older residents experience feelings of strangeness and insecurity even though they had stayed in the same place.

Ageing in place is not only about the sense of familiarity with the places, but also the sense of knowing people as well as involvement in the community environment (Hampson, 2009; Keady et al., 2012). The Enable-Age Project conducted by Sixsmith and Sixsmith (2008) suggests that home is recognised as a place that helps to maintain independence and autonomy, which is especially important in Western cultures where "independence" is seen as being very important in human nature. It provides support to the current findings which the community environment seems to become negative for the participants because of the socioeconomic and demographic change in China. The participants do not perceive attachment or connection to place alone, even though they still live at home. It may mean that 'ageing in place' becomes a sense of disconnection and exclusion or even threat for the participants in some rapidly developing and changing areas in China. Consequently, the political influence of older residents in neighbourhoods' planning would become invisible if they lose their voice and role in the community (Buffel, Phillipson, & Scharf, 2012).

Being able to get out and about does not only refer to safe physical environments for people with dementia (Davis, Byers, Nay, & Koch, 2009). Important factors are being able to access a social environment that enables people with dementia to actively participate in social events and activities, equal access to health services, and being respected and understood by family caregivers. However, in the current study, the sense that 'nobody cares' appeared in participants' descriptions. In consequence, the sense of not being supported by family

members, the community or society not only created feelings of disconnection and exclusion from others, but also made participants feel useless to others and society. One qualitative study about resilience in older spousal dementia carers illustrates that family caregivers who were more actively engaged with services and supported by family and friends, were more likely to be resilient (Donnellan, Bennett, & Soulsby, 2015). This phenomenon challenges us to understand the very dynamic change of the sense of connection and disconnection of older people in the changing Chinese sociocultural context when 'ageing in place'. It indicates that a positive experience of being at home requires an inclusive community setting and strong family links or support systems. It shows that both the quality and quantity of family-based care services in China are not currently able to meet the needs of older people. This suggests that these wider social and cultural changes need to be understood as contributing to the potential isolation of those in need of home care.

Although the participants perceived some negative experience of home care, they still believed that home care is better than care home. For example, some participants believed that looking after family members is a traditional value whilst others taken it as a family connection. However, with the declined availability and capacity of caring for them, home care has become a controversial topic. Chinese participants were very conscious of the cultural and social conventions of looking after older relatives, some participants viewed filial piety as an obligation. Unlike family duty in the West, where filial responsibility has been viewed as affection rather than obligation. In China, not looking after older parents is frowned upon in Chinese society as well as law which left a feeling of obligation for some family caregivers. This also reflects some of the complex cultural and moral pressures such as 'only people without children stay in care homes' or 'looking after parents is being filial for children', which affect the very complex and conflicted lived experiences of people with dementia and family caregivers. As the Chinese traditional value (filial piety) and social constraint (legal requirement) plays a very important role in sustaining home care in China, a modernising reappraisal of filial piety which aims to reduce its negative influence on family caregivers is very important for modern day China.

With limited social connection and community support, 'ageing in place' becomes a place for burden and being a burden, and having no choice may make this situation worse.

Therefore, as family care provision is dominant approach to meeting care needs in China (as in much of the world), in order to enhance positive experience of ageing in place for people with dementia and their family caregivers, it not only requires the availability of social support services, dementia friendly communities and strong family links, but also a need to understand some of the complex cultural and moral pressures on them.

Limitations

This study is from just one part of China, and so cannot claim to represent the views of all in China. In addition, Thematic analysis as a method, its flexibility may lead to a lack of coherence when developing themes (Nowell et al, 2017). However, it does provide an opportunity to gain interpretation of the broader meaning from participants' responses, language and behaviour.

Conclusion

The paper presents the meaning of 'ageing in place' for people with dementia and family caregivers under the current healthcare system in China, which have important implications for the debate on family-support care and policy concerning dementia friendly and supportive communities. Although many positive factors associated with home are important to people with dementia, the current research offers a specific insight into what 'ageing in place' means to people with dementia and family caregivers by identifying the participants' feelings of disconnection and loneliness in a changing neighbourhood as well as the intense challenging of traditional values in China. The study indicates that while family-support care is still contributing its benefits of well-being and economic cost, it has also become a barrier to social connections and a burden for both people with dementia and their family caregivers in China. It offers some specific information about the impacts of the changed social and cultural environment on their lived experiences of home care.

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We state that data collected by XZ; data analysed by XZ, CC, and SR; manuscript prepared by XZ, CC and SR.

Conflict of interest

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