Tensions in dementia care in China: an interpretative phenomenological study from Shandong province

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Abstract

Aims: The study aims to analyse the tensions and the challenges of dementia care that are experienced by people with dementia and their family caregivers in China.

Background: China has the largest dementia population in the world, however dementia care services and related support services are still developing. Caring for a person with dementia is very challenging, as evidenced by many studies. As the majority of people with dementia are looked after by their family in their homes in China, it is very important to understand what people with dementia and their family caregivers are experiencing in the context of dementia care services that are in the process of developing.

Design: Interpretative phenomenological analysis (IPA) was used.

Method: Semi-structured individual interviews with 24 participants (10 people with dementia and 14 unrelated family caregivers) recruited from a mental health centre in Shandong Province.

Findings: Three main themes emerged that highlighted unmet need: (a) Lack of support services. (b) Insufficient institutional care. (c) Social attitude and social stigma toward dementia.

Conclusions: These themes reveal the challenges that the participants face in the context of dementia care services that are in the process of development in China; and how their lived experiences have been affected by the constraints of social support, public services, healthcare access, long-term care services and social stigma.

Implications for Practice: This study highlights the tensions that are identified by people with dementia and family caregivers. The research recommends that more support services would be beneficial for this group and would also enhance family support dementia care in China. Looking after an older family member is a culturally, socially and legally embodied norm in Chinese society, so it is important to address education for dementia awareness and the sustainability of family support care services in China by providing dementia services and resources to support both people with dementia and family caregivers.

Keywords

Dementia care, tensions, social support, interpretative phenomenological analysis, health education, China.

What does this research add to existing knowledge in gerontology?

- This study highlights that there are tensions for people with dementia and their family caregivers under the current culture and healthcare system in China.
- It indicates that the lack of understanding of dementia, financial burden, social stigma and limited support services are the main problems for families supporting someone with dementia in China.
- The study identifies the need for the sustainability of family support dementia care services in China.

What are the implications of this new knowledge for nursing care with older people?

- Nursing plays a key role in addressing the study's identified need to improve social and health care support for people with dementia and family caregivers who live at home in China.

How could the findings be used to influence policy or practice or research or education?

- This research suggests that economic, service and psychological support are needed in order to enhance the quality of family support care services and to meet the care needs of this group of the population.
- It indicates the need to enhance the sustainability of family support dementia care services in China.
- The participants' accounts of their experiences emphasize the importance of developing a supportive, equally accessible dementia care service in a country with the largest dementia population globally.
- Achieving these things requires attention to public health education to raise awareness of dementia and service use.

Introduction

China has the largest dementia population in the world (Chan et al., 2013; Tang et al., 2013), linked to the ageing population profile (Flaherty et al., 2007). Despite mental health services having been prioritised in the National Mental Health Work Plan (2015-2020) in China (Xiong & Phillips, 2016), dementia care services are still in developing. As most Chinese people with dementia rely on their family to care for them, there are few dementia support services provided by health professionals or voluntary organisations for either people with dementia or family caregivers (Wu, Gao, Chen, & Dong, 2016; Zhang, Clarke, & Rhynas, 2018). Zhensheng’s support group at the Peking University Institute of Mental Health in Beijing was the first to be established in China (WHO, 2014). However, such support services have only occurred in some economically developed urban cities (Chen, Boyle, Conwell, Xiao, & Chiu, 2014), such as Beijing, Shanghai and Guangzhou, but are rarely available in the second tier cities and rural areas (Feng et al., 2011).

Awareness of dementia among the public is poor. For example, a survey in Shanghai (Li et al., 2011) found that the public lacked knowledge of dementia (45% of family members and caregivers regarding dementia as a normal process of ageing and thinking that medical care could not benefit people who already had dementia) and stigma was common (with more than half of the participants reporting that they would feel ashamed if their family member had dementia). The Chinese are less likely to seek help for their cognitive impairments due to fear of “losing face” (Lam et al., 2010). The rate of diagnosis and treatment is low. According to Dai (2013), even in large urban hospitals, medical staff lack knowledge of cognitive impairment and more than half of the healthcare professionals did not know the criteria for diagnosing dementia. In a survey of family caregivers in the four largest cities (Beijing, Xi'an, Shanghai and Chengdu), it found that only 26.9% of people who had cognitive symptoms formally received a dementia diagnosis, and of these, only 2% received medical treatment (Zhang & Goza, 2006). Therefore, many studies strongly recommended that improving public awareness about dementia is needed (Chen et al., 2014; Tang et al., 2013; Wu et al., 2016; Yang et al., 2016).

Health providers' knowledge and skills in the diagnosis and management of dementia is low in China (Hsiao, Liu, Xu, Huang, & Chi, 2016). The majority of care homes have no qualified doctors and nurses and most of their care staff are poorly educated migrant workers (Dai, 2013; Wu et al., 2016). These institutions can only provide assistance with daily activities, but lack the skills and knowledge to manage the behavioural and psychological symptoms of dementia (Feng et al., 2011). Consequently, many institutions simply refuse to admit anyone with dementia (Chen et al., 2014; Wong & Leung, 2012; Wu, Dong, Ding, Chen, & Pang, 2011). A study in the city of Chengdu found that half of the ten long-term care institutions investigated rejecting people with advanced dementia (Wu et al, 2016). Dementia care services have been largely neglected in both the primary care and hospital sectors in China but most research in dementia is located in counties with established services for people with dementia, and it is, therefore, important to understand the subjective experience of people with dementia and family caregivers in this context.

Methods

Study design

The study aims to understand what challenges and tensions people with dementia and their family caregivers are facing in the context of dementia care services that are in the process of developing in China. Interpretative phenomenological analysis (IPA) has been used to identify what challenges the participants were facing and the meaning of what they experienced (Smith, 2009). IPA was used to produce a thematic account by explanation and interpretation of the participants' subjective experience of living with dementia at home. When people are engaged with an experience of something major in their lives, they begin to reflect on the significance of what is happening and IPA research aims to engage with these reflections. IPA commits to the examination of how people make sense of their major life experiences and is, particularly concerned with the experience of important events or significant changes in a person's life (Smith, 2009). In this research study, we consider the diagnosis and care associated with dementia to be a significant life experience and therefore, IPA provides a way of understanding the subjective experience of people with dementia and family caregivers and offers a theoretical foundation and a detailed procedural guidance.

Inclusion criteria and recruitment

The participants were recruited from one mental health centre providing in-patient and out-patient services in Shandong province, China. The health centre services a wide area of mixed urban and rural communities. The people with dementia had been diagnosed with early or middle stage dementia by the psychiatrists there. The patients and unrelated family caregivers who met the inclusion criteria and were interested in the research received an invitation letter and research information sheet. Inclusion criteria were:

- people with dementia who: (i) had been diagnosed by a psychiatrist, (ii) were assessed by doctors to be capable of taking part in an interview, (iii) have capacity to consent; or
- adult caregivers with: (i) over 6 months experience of being the main care provider to someone with dementia, (ii) capacity to consent to participate.

Thirty people received an invitation letter and six declined to participate (two because of family disagreements, one had no interest, two were concerned that the research would be harmful and one had difficulty traveling). The participants were not recruited as dyads – those with dementia were not necessarily related to the caregivers who were recruited.

Ethical approval was given by the University of Edinburgh and Shandong Mental Health Centre. Informed consent was obtained individually, and confidentiality and anonymity were assured.

Participant's characteristics

The sample included 14 caregivers and 10 people with dementia. Two participants were a care dyad of a father and daughter, and none of the other participants were related to each other. Surprisingly, in the dementia group, there were only two females out of ten participants, this may be due to gender inequality in the forms of education, medical care etc (Bauer, Feng, Riley, & Xiaohua, 1992; Lei, Hu, McArdle, Smith, & Zhao, 2012), which may affect female patients' access to medical services. As the sample was recruited from a mental health centre, this possibly indirectly affected the gender rate in the participants in the study. However, this may need further study. The participants’ characteristics are shown in Table 1 and Table 2.

Table 1. Caregiver sample characteristics (N = 14)

Characteristic	n
Age group	
30s	1
40s	1
50s	3
60s	4
70s	5
Gender	
Female	9
Male	5
Relationship with person with dementia	
Spouse	5
Children	8
Mother	1
Location	
Rural	7
Urban	7
Occupation and income	
Retired with pension	5
Unemployed without income	4
Farmer in lower-income	5

Table 2. People with dementia sample characteristics (N = 10)

Characteristic	n
Age group	
60s	1
70s	6
80s	3
Gender	
Female	2
Male	8
Type of dementia	
AD	6
VaD	3
PDD	1
Relationship with care provider	
Spouse	1
Parent	7
Hired home carer	2
Location	
Rural	3
Urban	7

Occupation and income	
Retired with pension	5
Unemployed without income	4
Farmer with lower-income	1

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

Data collection

Data were collected from August 2016 to January 2017 using semi-structured individual interviews conducted in Mandarin. Reflection and open-ended questions were used to facilitate conversation and allow interviewees to tell their story in their own way. Interviews were conducted in the health centre and participants’ own houses depending on their preferences. The interviews lasted between 30 and 60 minutes and were audio-recorded for transcription.

If there were concerns for the welfare of any participants, action was taken in accordance with a protocol developed for this study. The researchers ensured that all participants understood the potential risks that may emerge in the research, gave the opportunity to the participants to ask questions which they were concerned about at any time and informed them about their right to withdraw at any time. A list of contacts, such as China Association for Alzheimer’s Disease which provides a help line services for people with dementia and family caregivers was prepared and made available to each participant should they wish to seek further support. In any situation of specific concern, and following discussion with each other about the level of response that would be proportionate to concerns, the researchers encouraged participants to seek additional support, contacts statutory services on behalf of the participant (with their consent) and, if necessary, would have sought intervention from services to ensure the safety of participants and their family members.

Data analysis

The IPA process involves a double hermeneutic as the participants make sense of their experience and the researcher makes sense of what is said by the participants. IPA not only presents a descriptive account of the subjective experience, but it is also expressly interpretative (Larkin, Watts, & Clifton, 2006). Therefore, the researcher needs to reflect on their own values, assumptions and beliefs, which may affect the interpretation of data.

The process of data analysis was adapted from Smith's (2009) six steps of IPA: (1) familiarising with the transcripts through reading and rereading; (2) detailing line-by-line coding of each transcript at a time; (3) listing and grouping of codes into initial emerging themes; (4) searching for connections across emergent themes and identifying patterns between them; (5) analysing the rest of the transcriptions in the same way; (6) developing a master table to present the emerging themes across all of the transcripts, making connections and finalising the main themes. Subsequently, the emerging themes of each transcript are clustered into groups to identify the main themes and compile the master themes.

Data analysis was conducted in Mandarin until emergent themes were developed and then translated into English. To consider the translation challenge, the researcher (XZ) did the first coding of data analysis in Mandarin in order to preserve the originality of content and meaning. To resolve the issue that other two researchers (CC, SR) were not familiar with Mandarin, four example interview descriptions were translated into English to allow discussion together of the process of data analysis. In order to keep the accuracy and correctness of the translation, XZ frequently went back to the coding to check the interpretation, keep record of any issues and discuss them between other researchers. NVivo10 software was used to assist the analysis and the researchers met regularly to discuss any issues raised from the data analysis. Three main themes emerged:

Main theme	Theme summary
Lack of support	• perceived lack of support from health professionals, community and government • conflicted relationship between family financial responsibility and burden
Insufficient institutional care	• perspectives of long-term care services • challenges experienced in accessing long-term care services
Social attitude and social stigma	• social attitudes toward people with

	dementia and caregivers and how it affects their lives

These themes highlight the challenges that the participants' faced in the context of contemporary dementia care services in China; and how their lived experiences have been affected by the constraints of social support, public services, healthcare access, long-term care services and social stigma.

Findings

Lack of support services

Most of the participants raised the issue of lack of service support. In the following quote, Guang reflected on the lack of support services in the area. He expressed his eagerness for home visit services for people with dementia in the future and indicated that the current supporting services from health professionals did not meet his needs.

> *'I hope there will be some staff (health professionals) who can do home visits.… However, there are no such services that exist now. I hope that we will have some social support in the future' [Guang, caring for his mother].*

Similarly, Xue said:

> *'What community will help? There are staff (social worker) who work for the government, I have never heard them helping with these kinds of things.' [Xue, caring for her father].*

This extract highlights how people with dementia and caregivers feel neglected by social services, and reveals the participant's negative view of social support.

Participants with dementia also expressed their expectations of getting little support from the local authority or the government. Jing's wish for such support services from the government was tempered by the sense of low expectation in using the words 'cannot imagine it', illustrating the lack of dementia support services for people with dementia in rural areas.

'If the government can arrange healthcare for older people (with dementia) in the rural area, it would be the best thing in the world for them. However, I cannot even imagine it, who would give them money?' [Person with dementia (PWD), Jing, living alone]. Some issues associated with service support related to social connection and disability access. Xue reflected on the difficulty of going down the stairs and transportation to hospital because of the physical environment. The difficulty in going outside in general placed participants at risk of social isolation.

> *'I have many times pushed my father (in a wheelchair) to see the doctor. In the old building, there is no elevator, it is not easy to go down stairs. Every time, I pull my father down by pulling his arm as he leans on me.' [Xue, caring for her father].*

> *'I would like to go outside, however, the wheelchair cannot go down and up the stairs because there is no lift.' [PWD, Wen, living with his daughter].*

While both urban and rural participants perceived there were a lack of social support services and inappropriate physical environments when live in their own homes, rural participants seem to have perceived more negative experiences as the living conditions were likely to be less advantageous than in urban areas. For example, in Shandong, winter temperatures drop to minus 4 or 5°C and only a few homes in rural areas have central heating, with most homes reliant on a single open fire – as highlighted by Shao:

> *'It is freezing, we lit a coal stove. Yep, it is freezing...' [PWD, Shao, living with his wife].*

Shou, too, emphasized about how the cold weather and poor quality of living conditions affected their daily life:

> *'…Now that the weather has become cold, I cannot get her up.' [Shou, caring for his mother].*

As poor living conditions stopped people with dementia from getting up from bed, this not only affected physically going outside, but more importantly caused psychological problems due to social isolation. The living environment for people with dementia and the family caregivers played an important role in their quality of life and was not alleviated with appropriate physical resources to meet the specific needs of people with dementia at home.

Lack of psychological support. This sub-theme reflects how psychological factors, such as stress, hopelessness and loneliness influenced the participants' lives. For example, Wan noted:

> *'…I have no solution. I sometimes cry during the night because of the stress, sometimes I wish he could die soon…' [Wan, caring for her husband].*

Wan was 73 years old and without a pension. She experienced the physical and financial burden of caregiving but without the psychological support from family members (as her children were busy with jobs) or other support services. She described experiences of stress and helplessness and demonstrated her despair as a caregiver without support. In experiencing symptoms of caregiver burnout, Wan was at risk of mental illnesses such as depression and anxiety.

A sense of being unsupported by health professionals was evident for all participants. For example, in the following quote, Shen illustrated the health professional's attitude of dementia as a medical futility, which may lead Shen to feel neglected, unsupported and lose hope to live.

> *'I have asked the doctors about the illness. The doctors told me to go home and said that it is not useful to take any treatments as this cannot be cured.' [PWD, Shen, living alone].*

In China, health care services are paid for by the patient and consequently, once a person is discharged from hospital they hardly have any contact with health care professionals. Wen's quote below reflects his dissatisfaction and unhappiness because of lack of information about his condition. It also reveals his low expectations of getting both information and psychological support from healthcare services.

> *'The doctor or nurse will only tell me a little bit of information about the illness unless I*

> *ask, otherwise, they never tell me anything.... I have no social relationship left, no connections. I cannot do anything in return. Why do they care about me?' [PWD, Wen, living with his daughter].*

Lack of economic support links either directly to financial problems of care costs or indirectly to the lack of care resources. Participants interpreted money as an indicator of quality of life or care. Money became a focus of stress or a source of guilt for them. For example, in the following extract, Ye indicated that she is not only concerned with financial issues related to the stress, but that unavailable health service and health care costs were also a great concern for her. Lack of money resulted in Ye experiencing feelings of worry as well as financial dependence and insecurity.

> *'Currently, we have little money, I have no pension, no income, (the government) gives me 85 yuan (£9) each month, what can this amount of money be spent on? It is not enough for spending on medicine… I depend on my husband to buy medicine for me. The medications are too expensive. My husband is stressed, there is no solution, we have no money… the medications are too expensive.' [PWD, Ye, living with her husband].*

Care for older people is not included in the Chinese healthcare insurance system, it is paid for by the patients, and this cost was a big burden for most participants. This situation left people with dementia and family caregivers in vulnerable financial situations as highlighted by Xue, for whom the lack of money had left a shameful, stressful feeling and had also created a strain in her relationship with her father.

> *'…Another is the financial issue… Now he often visits the doctor or stays at the hospital, the money is not enough for us.' [Xue, caring for her father].*

Gui lived in a village with her two sons, who were 43 and 48 years old, and both had early onset dementia. Gui had no pension and her two sons had lost the ability to work on the land, resulting in poverty. In her interview, Gui described how the financial burden had left her in a desperate situation.

> *'I have no solution… I cannot let them be starving once I am here. I am just thinking, I will kill them and myself together if one day I can do nothing… I have no money to send them to hospital, we only can live like this, helpless …' [Gui, caring for her two sons with dementia].*

Monetary issues had left Gui and her sons with a poor quality of care and with a hopeless future. Gui had lost confidence in sustaining their lives, and expressed acute despair and helplessness in her wish of dying together as a family. This also reflected the limited psychological support and the limitations of the current health and social security system. In line with the study's protocol for managing untoward information, as discussed above, with Gui's consent, the village clinic physician was informed of Gui's expressed concern for her sons' future and she was also given the contact number of the China Association for Alzheimer's Disease for further support.

Even for people with a good pension and living in an urban area, the feeling of financial burden still existed due to the high cost of healthcare services. For example, Wen was retired and had a good pension, however, he still experienced financial stress that was associated with care and hospital costs.

> *'Despite having a large pension, it is not enough for living because of the big (hospital) expenditure. It would be better if I can get some financial support…' [PWD, Wen, living with carer].*

Overall, these extracts highlight the significant role that financial burden played in the lived experiences of people with dementia and caregivers, and how it affected their quality of care and quality of life.

In the study, most participants thought that the government should take greater care of people with dementia or at least provide some support to the caregivers or people with dementia. Descriptions from the participants about the government's responsibility were mostly associated with policy making on health support, social support and financial support.

For example, one caregiver said:

> *‘This is the current situation of older care. I hope that the government can pay attention and do something about it in the future…’ [Mei, caring for her mother].*

Insufficient institutional care

‘Institutional care’ is associated with the lack of availability of care homes, the quality of care service and attitudes toward care homes. For example, Wan’s husband rejected by a care home as it lacks capacity to accept people with dementia. This forced her to take care of her husband even though she was physically frail, resulting in health problems and mental stress for her.

> *‘I am too older and lost the physical ability to look after him. I wish to send him to the care home, however, they wouldn’t accept him [Wan, caring for her husband].*

The traditional attitudes towards privileging care within families, and of limited use of care homes also limited the accessibility of long-term care institutions as it is frowned upon in Chinese society. This put pressure and stress on Yu as he was struggling with looking after his mother at home.

> *‘Care homes wouldn’t accept her (because of her dementia). Anyway, it is not possible to send her to a care home, she has daughters and a son. The neighbours would laugh at me if I sent her to a care home… only people without children are sent to care homes’ [Yu, caring for his mother]*

Participants expressed their concerns about the quality of care within a care home and their distrust with long-term care services. For Yan, the quality of care was not assured in care homes. She said:

> *‘No, a care home is worse… if we send her there, she would be dead soon. For her condition, walking around and disturbing everyone while they are sleeping, a care home would give her sleeping pills to sleep in bed for the whole day.’ [Yan, caring for her mother].*

A strong feeling of distrust, insecurity and disapproval of care home services disclosed how people with dementia have been viewed and treated by long-term care services in the participants' experiences. Xue described a similar scene of poor conditions in care homes.

> *'…I have looked at a few private care homes, however the conditions of these care institutions are too bad. Once I step inside, there is an extremely bad odour. There are also no facilities, along with other problems' [Xue, caring for her father].*

The lack of availability of care facilities was a concern, with several family caregivers expressing concern for their own old age. In the following quote, Ling is not only worried about his future care arrangements, he is concerned about the next generation. His statement reveals the current unique family structure in China, which is affected by the one-child-policy and migration from rural to urban areas in search of employment, and raises the unanswered question of who would look after the older population if individual families are unable to take on caring responsibilities.

> *'…if one day when I am old, I get the same problem as my dad…I only have one child; he is working in another city. He cannot leave his job and life behind to look after me. What are we going to do in a situation like this?' [Ling, caring for her father].*

Social attitude and social stigma towards dementia

This theme illustrates the attitudes of the lay population and healthcare professionals toward people with dementia and family caregivers, and how it creates a sense of social stigma and isolation. For instance, one participant felt frustrated by not being trusted and used the word 'trick' to illustrate the lack of understanding of dementia among family members.

> *'I told my family that I forgot something because I am ill… they didn't believe it, they said that I just tricked them… this makes me really cross'. (Voice raising) [PWD, Yin, living with his son].*

When Ye talked about the neighbour's attitude toward her, she said:

> *'They all said that I am demented, what can I do?... [her neighbour said in front of her] "She could do everything before, but now she cannot do anything as she is demented, it is ending". [PWD, Ye, living with her husband].*

These two extracts illustrate a negative social attitude toward dementia with neighbours' false assumption that someone with dementia is useless and is near the end of life. Ye seemed sad and stressed by this situation, and her response 'what can I do' showed her vulnerable situation in the face of being stigmatised and labelled, putting her at risk of isolation and exclusion from society.

For Yan, taking her mother to a public place was an embarrassing thing, reflecting a negative attitude toward dementia from family members and the wider public. She says:

> *'There is no support of this kind (group support services). Even if there were, I wouldn't take her there because she would shout or speak nonsense.' [Yan, caring for her mother].*

Gui felt that having family members with dementia makes her feel hopeless in life and shameful in the neighbourhood. Looking after her two sons with dementia, Gui had to bear the hardship of caring duties and the burden of the cost of caring, but the hardest thing for her was losing hope for her future life, a shameful feeling of having family members with dementia and taking care of people with dementia. In interviews, participants shared the impact on them of the social stigma which was associated with a lack of understanding of dementia in the lay population.

> *'…Who can I rely on? I cannot rely on anybody…I not only need to go through the hardship, but also I lose face…' [Gui, caring for her two sons].*

The conversations between health professionals and family members revealed that social stigma was also evident in the healthcare field. For instance, one caregiver says:

> *'…the doctors don't tell me anything. They just discharged him from the hospital. They said… there is no point in spending 200 or 300 hundred yuan (per day) (£23-£35) in the hospital…' [Jin, caring for her husband].*

As dementia is not curable, it is commonly viewed as a medical futility by the public and health professionals. The phase 'no point in spending…' in the quote from Jin above, described an implied statement of nihilism and waiting to die in China. It disclosed the professionals' attitudes toward people with dementia and demonstrates how they view dementia as a terminal illness. This misunderstanding not only causes frustration, despair and poor family-doctor-relationships, but also exacerbated the social stigma toward people with dementia. It affected people with dementia's personal confidence, putting the person at risk of hopelessness and desperation.

Discussion

This study sought to describe the experiences of people with dementia and their family caregivers and any tensions that arose between the cultural expectations of care within families and the contemporary situation for people in a rapidly developing society. The findings show that participants experienced very few support services from both the local community and at a national level and that support services did not meet their perceived needs. There was not only a lack of relevant service and psychological support from healthcare professionals for people with dementia who are being cared for in their own homes and their family caregivers, but there was also a lack of financial and political support from the government. For example, the theme 'lack of support services' indicates the despair and need in accessing support and the low expectation of receiving support services. Among these issues, the main problems are the care costs and the lack of relevant service support. The sense that 'nobody cares' appears in the participants' descriptions. Consequently, the sense of not being supported by health professionals, the local community or the government not only creates a sense of disconnection and exclusion, but also has negative effects on people with dementia and family caregivers' health and wellbeing (Chien et al., 2011; Kaufman, Kosberg, Leeper, & Tang, 2010; Leung, Orrell, & Orgeta, 2015; Lilly, Robinson, Holtzman, & Bottorff, 2012; Takai et al., 2009; Truzzi et al., 2012). This suggests that economic support, service support and psychological support are needed in order to enhance the quality of family support care services and to meet the care needs of this group of the population in China.

In the study, the thought of parents living in a care home was mostly associated with perceptions of low quality in long-term care facilities and the traditional negative view of ‘only a childless person stays at care homes’. Furthermore, the issue of the capacity and quality of care in care homes have limited them when accepting people with dementia due to there being no healthcare professional’s oversight (Feng et al., 2011). In order to reduce the burden of the family support care services, there is need for qualified healthcare professionals to staff long-term care facilities.

In the current study, both participants with dementia and family caregivers perceived stigmatisation from family, community and health professionals. For example, some of the participants with dementia indicated that stigma and discrimination had left them feeling isolated, lonely and helpless. In the theme ‘social attitude and social stigma’, participant Yin experienced anger and frustration as his family didn’t take his words into account. Participants with dementia discussed their feeling of being looked down on by the community while family caregivers refuse to take the person they look after outside because they fear ‘losing face’. This social attitude has created the feeling of disconnection and estrangement for people with dementia and their family caregivers (Clarke & Bailey, 2016). It is consistent with previous studies, which identified that stigma affects the lives of people with dementia and the families living with them and may delay engagement with services at all levels (Cheng et al., 2011; Clement et al., 2015; Milne, 2011).

One finding in relation to the social experience of stigma is the stigmatization from the healthcare professionals. Several participants disclosed that they have been told there is no need to get further treatment from the health professionals after they had been diagnosed, or they were unable to receive information or support from the health professionals. The participants experienced fear and despair about their future because their doctors refused to give them any medical services. Previous literature has also studied stigma associated with health professionals or services, but these studies emphasised diagnosis labelling and discrimination (Cahill et al., 2008; Gove, Downs, Vernooij-Dassen, & Small, 2016; Moore & Cahill, 2013). In the current study, people with dementia, their families and the public incorrectly believed that treatment is not useful. This notion has brought helplessness, fear and hopelessness for the person with dementia and their family, and may reduce people with dementia's access to resources and opportunities for treatment and related social services. This suggests that increasing levels of dementia awareness in China have important implications for people seeking support and for the provision of training for the recognition and management of dementia in dementia care services. As family and relatives are an important support network in China, public awareness campaigns need to challenge misconceptions, stigma and discrimination towards dementia.

Limitations of the research

We wish to highlight three key limitations of this research:

(1) The research took place in just one part of China (in Shandong Province) and therefore does not necessarily represent the experiences of people living with dementia across the whole of China. In addition, the nature of an IPA study is to investigate deep and detailed personal perspectives and to understand how people make sense of their lived experience by listening and analysing the accounts of a particular population. Therefore, there is no claim that findings from this current study can be generalised to other economic and political regions or other ethnical groups. Further studies on the subjective factors of the lived experience of people with dementia and family caregivers in other geographic areas across China and from different socio-economic backgrounds are needed to ascertain whether their experiences differ from the experiences of people with dementia and their family caregivers in this study.

(2) The sample included heterogeneity, not least since some participants lived in urban areas and some in rural areas. In China, the rural population have a very much smaller disposable income than the urban population, and some of the features of the data and its analysis reflect this economic divide.

(3) IPA research brings particular challenges when working as a research team since each team member brings a difference set of experiences and assumptions to the hermeneutic cycle of analysis. This was a particular challenge in this study, with one team member (XZ) having a very close awareness of the culture in which participants lived their lives but this being very unfamiliar to other team members (CC and SR) – we aimed to use these different positions of reflexivity to generate key questions amongst ourselves and of the data, taking at times the position of the naïve outsider.

Conclusion

The study adds a new dimension to our understanding about the tensions and challenges that exist in family support dementia care in China. For the rural population in Shandong Province, in particular, the study indicates that the lack of understanding of dementia, financial burden, social stigma and related support services are the main problems for people with dementia and family caregivers. The participants' accounts of their experiences emphasise the importance of developing a supportive, equally accessible dementia care service in a country with the largest dementia population globally.

Implications for practice

The study adds knowledge about dementia care in China. It highlights the tension that may be identified by people with dementia and their family caregivers between social and cultural understandings of dementia and care expectations, and the availability and cultural acceptability of support services under the current healthcare system in China. It indicates that, for the study participants and possibly more widely, the lack of understanding of dementia, financial burden, social stigma and related support services are the main problems for people with dementia and family caregivers. It suggests that to maintain the sustainability of family support dementia care services in China, providing relevant dementia services and resources to support both people with dementia and family caregivers is very important, in parallel with public health education to raise awareness of dementia and the benefits of health and social care intervention.

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