This thesis has been submitted in fulfilment of the requirements for a postgraduate degree at the University of Edinburgh.

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Exploring the lived experience of people with dementia and family caregivers in China: an interpretative phenomenological analysis

Xiubin Zhang

Thesis presented in fulfilment of the requirement of the degree of Doctor of Philosophy

The University of Edinburgh

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Declaration

I declare that this thesis is of my own composition, based on my own work, with acknowledgements of other sources, and has not been submitted for any other degree or professional qualification.

Xiubin Zhang

Date: 20/04/2018
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Abstract

Family supported care has dominated Chinese society for thousands of years. Filial piety is an important value of Chinese traditional culture. However, the capacity and availability of family-based care has changed dramatically because of cultural, social, economic and demographic changes. Therefore, in the context of these transitions, more needs to be understood about the meaning of living with and caring for people with dementia in their own homes. Previous studies involving Chinese people with dementia and their family caregivers which focus on their lived experiences are scarce. This study gives a voice to Chinese people with dementia and their family caregivers as active participants in dementia care research. The study aims to gain insight into the lived experiences of people with dementia and their family caregivers, and how they cope with their new roles in China. It specifically explores the meaning of family responsibilities, social relationships and cultural influences from the perspective of different family members and people with dementia.

A qualitative approach has been adopted, using interpretative phenomenological analysis (IPA) in this study. The participants were recruited from in-patient and out-patient lists of one mental health centre in Shandong province, China. The inclusion criteria are people with dementia who have a recorded diagnosis of dementia with the severity of dementia ranging from mild to moderate and have communication capacity to take part in an interview. Family caregivers had to have over 6 months period caring experience to ensure they had sufficient experience to reflect on and comment on. Semi-structured interviews with people with dementia (n=10) and family caregivers (n=14) were conducted in both urban and rural areas of China. The interviews were transcribed and have been analysed using an adaptation of Smith’s (2009) 6 steps of interpretative phenomenological analysis (IPA).

There are four superordinate themes or key themes that have been found from people with dementia and family caregivers’ accounts: (a) ‘negotiating the roles’; (b) ‘the meaning of living with dementia in the social context’; (c) ‘the meaning of responsibility in the cultural context’; (d) ‘the settled life’. These themes have been discussed in relation to family responsibilities and wider social relationships, which have reflected the challenges and dilemmas that the participants faced when caring for people with dementia or living with dementia within a specific social and cultural context.
The study draws on the phenomenology of care-giving and care-receiving to show that both people with dementia and family caregivers struggle with their family responsibility and their roles; they face a series of challenges in coping with the ‘altered’ life of living with dementia at a time when the traditional family support care system is also changing. It highlights the participants’ stress and burden in carrying out family caring responsibility or living with dementia under the current social situation. It indicates that the traditional value of family responsibility has been influenced by sociocultural transitions, which indirectly affect the quality and quantity of care provided by families. It recommends that while there may be continuing support for reciprocal filial piety, a stronger government welfare system is needed in order to support older people and their families in contemporary Chinese society.
Lay summary

Dementia has become a global health problem, reflecting the increase of the older population worldwide. China has one of the fastest growing proportions of older people in the world. It also has the biggest population of people with dementia in the world. In 2012, it was estimated that there were 9.19 million people with dementia in China, which represents over 20% of the dementia population of the world. This enormous dementia population has dramatically increased the family, public health, social and economic burden of care. Many studies that explore the lived experience of people with dementia and their family caregivers have been conducted in Western countries, but rarely in China.

China has a number of unique characteristics regarding ageing and older care services. Firstly, China’s population is ageing at a faster pace than most developed countries. Since China is becoming an ‘old’ society ahead of its economic and social policy preparation, it is facing a huge challenge in serving its older population. Secondly, the socioeconomic transitions and internal economic migration to urban centres have reduced the capacity of the traditional family-based care system and reduced its care workforce in the long-term care sector, especially in rural communities. Thirdly, many older residents having to rely financially on their families since there is insufficient capacity of social welfare support, especially in the long-term care for its older population. Fourthly, whilst the cultural norm of ‘Xiao’ (filial piety) ensures family-based support for older people, it may put great physical, emotional and financial stress on family caregivers. Therefore, a conflict arises between the increased care needs of the ageing population and the expectations of the traditional culture of filial piety. Due to these different characteristics, the Chinese population may have different caregiving and care-receiving experiences from most other countries.

This interpretative phenomenological analysis study aimed to describe the lived experiences of older people with dementia and their family caregivers in China. It focuses on the impacts that changing socio-economy, demography and cultural values have on the perspectives and meanings of living with dementia and caring for a person with dementia. The participants with dementia were recruited from in-patient and out-patient lists of one mental health centre in Shandong province, China. They were diagnosed with mild to moderate dementia by the psychiatrists in the centre and had sufficient communication capacity to take part in an interview. The sample
inclusion criterion of family caregivers was that they had over 6 months period caring experience to ensure that they had sufficient experience to reflect on and comment on. Data was collected by interview with 24 people with dementia and family caregivers. Data analysis followed the six-step process of interpretative phenomenological analysis.

The study found that both people with dementia and family caregivers face great pressure in coping with the ‘altered’ life of living with dementia at a time when the traditional family support care system is also changing. Some pressures related to cultural factors, while others were a direct response to social and spatial resources, changed neighborhood environments, the perceived unavailability of healthcare support services and poor quality of the long-term care facilities. The findings show that participants’ expectations of social support were very limited, the cultural role of filial piety has declined, and the individual families felt that they have no options regarding their caring roles and responsibilities.

One of the most important contributions of this study is the understanding of the meaning of family responsibility for people with dementia and family caregivers in the context of the contemporary socioeconomic and cultural transitions. Another unique contribution to knowledge is to provide insight into the role that the traditional belief of filial piety plays in family-based dementia care, and how it has been utilized by the participants to maintain their family responsibility. The discussions of social and cultural influences on the care services for older people provide insight into the effects of social policy and cultural values on the lived experiences of people with dementia and family caregivers.
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1. Chapter One: Introduction and Background

1.1 Introduction

The aim of this section is to provide background knowledge of the health care system, social support network, pension system and long-term care services in China, in order to show the specific sociocultural context of dementia care services in contemporary China. It also explores the situation, position and challenges of dementia research in China and how the specific sociocultural and political context has influenced the lives of both people with dementia and their family caregivers.

In China, it is a legal obligation for adult children to take care of their older parents (Wu et al., 2005, Qi, 2015). The care of older people has also been viewed as a family’s responsibility for thousands of years as part of the traditional culture of Confucius’s xiao (filial piety). In China, family caregiving accounts for a significant proportion of the care provided for people with dementia (Yu et al., 2016). However, China is currently undergoing a range of sociocultural and demographic changes which have had a significant influence on the capacity and availability of the traditional family support care system. These changes include the 4-2-1 structure of families (four grandparents, two parents and one child) and the increasing trend for migration and urbanization which has decreased the size of the older care workforce, isolated older people and resulted in families assuming less responsibility for the care of their older parents. Dementia care services have been impacted more heavily than care for other diseases due to the fact that dementia care requires more in the way of physical and psychological support (Chen et al., 2013). At the same time as this transition has been taking place in both urban and rural areas, Chinese family caregivers are facing a great challenge in carrying out and coping with their caring responsibility. Moreover, the situation is worse in rural areas as the younger and middle-aged adults from these areas are more likely to move to the cities for jobs (Chen et al., 2013). In addition, the situation of dementia care services is rendered more complex by a lack of the rules and regulations needed for dementia care at a national level, combined with the current financially unsustainable position of social security and long-term care services for older people (Meng et al., 2015).

China has one of the world’s fastest-growing proportions of older people within its population, a huge number of whom are people with dementia. It is estimated that China had 9.19 million people with dementia in 2012, representing over 20% of the
world’s entire dementia population (Chan et al., 2013). This rapid increase in the number of people with dementia has increased the associated familial, public health, social and economic burdens. The estimated total annual cost of dementia care in China rose from $0.9 billion in 1990 to $47.2 billion in 2010 and is expected to reach $114.2 billion in 2030 (Xu et al., 2017). In 2010, it was reported that the cost of informal care accounted for 81.3% of the total estimated costs (Xu et al., 2017). These estimated costs of dementia care were obtained from the existing literature since there is little information available in the form of government statistics related to the cost of dementia care in China (e.g. no figures are available from the national statistics yearbook). However, geographical development is both varied and widely dispersed in China, meaning differences exist in terms of the healthcare support or economic and social support available for the older population according to where they are located geographically (Zimmer et al., 2010). For example, in a quantities study, Xie et al (2014) state that the gap in the use of health services between rich and poor in China is 1.6 times for outpatient care and 3.8 times for inpatient care. Due to the complexity of such regional discrepancies and societal transitions, a background description is very important to support the current study and to help potential audiences understand the study context.

1.2 The change of the traditional family care service

Confucius’s ideal of xiao (filial piety) has been a dominating cultural belief in Chinese society for more than two thousand years. The key elements of filial piety include children’s respect for their parents, obedience of parents, loyalty to parents, the provision of financial support to parents and the duty to look after parents when they are ill or older (Li et al., 2014). Although the traditional concept of filial piety particularly stresses the responsibility of sons in taking care of their aged parents, it also involves much more than the provision of solely physical and financial support. Traditional Chinese families generally live with two or three generations together, and the family members assist one another economically. This type of hierarchical and cohesive family structure has been sustained for centuries (Fend et al., 2014). For many generations, the Confucian tradition of filial piety has been viewed as the core value that forms the basis of the many moral and social conventions that form children’s attitudes and behaviours toward their older relatives (Lew et al., 2011). Moreover, as state orthodoxy, the value of filial piety has always been encouraged by the authorities as a means of reducing the government burden of care for the older population (Pan
et al., 2005). For example, the Criminal Law (1979) states that an adult child could be fined or jailed for up to five years for failing to support their older parents (Palmer, 1995). In 2012, the government’s new law of the Protection of the Rights and Interests of the Elderly redefined children’s obligations to their parents. It requires adult children to support an aged family member by physically taking care of them, financially supporting them and also by providing psychological care (for example, visiting parents regularly if the adult child does not live with them).

The concept of a belief in Confucian filial piety has been a cornerstone in forming the traditional pattern of co-residence and the family support system (Wang, et al, 2008). Filial piety is not only enforced by the authoritarian factors of children paying respect and submission to their parents, it is also supported by a reciprocal factor of interdependence and a relationship of intimacy with the family, thus emphasising mutually supportive exchanges between generations (Yeh, 2003). This is consistent with a majority of the studies that indicate that reciprocal care and respect between generations is recognized as the key aspect of filial piety in Chinese society (Kim and Lee, 2003, Bryant and Lim, 2013). This reciprocal filial piety has a self-reinforcing element in the form of a good family relationship (Yeh, 2003), life satisfaction and social competence (Leung et al., 2010). Therefore, the promotion of reciprocal filial piety is not only a cultural embodiment of virtue, but more importantly it promotes a mutual relationship between adult children and their older parents, thereby stabilizing the family support care for older people and contributing to people’s well-being, as well as reducing the family caregivers’ perception of burden (Lai, 2010).

Influenced by economic development and social mobility, many researchers have long argued over the issues and debates surrounding caring for older people which have focused on the concept of filial piety (Lai, 2010, Stuifbergen and Van Delden, 2011, Leung et al., 2010, Knight and Sayegh, 2010). Some researchers have referred to filial piety as an obligation or duty which is associated with burden (Sayegh and Knight, 2011), while others appreciate it as a motivation and satisfaction (Yeh et al., 2013). Over the past three decades, cultural norms associated with filial piety have been eroded through the processes of social transition and Westernization (Dong et al., 2012, Li et al., 2014). The trend for social mobility has led to a progressive reduction in the level of co-residence among older and younger family members in China (Zhang et al., 2014b), and family-supported care was generally a difficult situation before care institutions became available in the society. People have
become more individualized than in the past, and the nuclear family has emerged as the dominant family structure in modern China (Qi, 2015). Family dynamics have changed as more women have become educated and entered the workforce, which in turn has further decreased the traditional social convention of women being dominant in domestic tasks, such as cooking and looking after the children and seniors. Consequently, the pattern of traditional family care cannot be practised because of the mobility and unavailability of children that has resulted from the context of social, demographic and economic changes (Zhan, 2004). This was echoed by another study, which stated that modernization has led to a decline in the value of filial piety and that the breakdown of co-residence has reduced the opportunities for acts of filial piety (Cheung and Kwan, 2009). One study in Hong Kong found that older people who do not live with their children are more likely to be insecure with regard to whether or not their needs can be supported by their children. According to the respondents in the study, their physical care and financial support needs had not been fully met (Ng et al., 2002).

Traditional patterns of caring for parents have weakened because of the changing nature of the family structure and changing patterns of co-residence in China. Despite the many facts that are stimulating the changing of the family support care system, many researchers have indicated that reductions in family size, along with social and economic development, form the basis of the currently changing family structure (Zhang and Goza, 2006, Cheng and Chan, 2006). This, along with improving life expectancy, has led to a dramatic increase in the proportion of the older population in China, in turn creating a new form of family structure. This new form of family structure is referred to as the 4-2-1 family structure (Hesketh et al., 2005). Moreover, the government’s open policy (moving from a planned economy to a more market-based economy) has served to stimulate industrialization and urbanization, leading to the creation of more job opportunities in urban areas. More and more adults of working age are moving out of the family home in search of jobs. This situation is more pronounced in rural areas, as the younger and stronger go away to seek work, leaving the older and weaker at home. As a result of the migration of working-age adults and reduced family size, China is increasingly seeing the phenomenon of the ‘empty nest’ (children leaving home for university or a job, with only the parents at home). It is reported that currently, the rate of ‘empty nest’ families in Beijing is 35%, and this is expected to rise to 90% by 2030 (Xie et al., 2010).
Although the practice of filial piety has evolved and been reshaped, its core principles continue to exist in people’s consciousness in Chinese culture (Sung, 2001, Mao and Chi, 2011, Li et al., 2014). Qi (2015, p.153) states that Chinese family obligation ‘is sustained by the continuing inter-generational interdependency of family members’, in which a circle-type interdependent family relationship exists from parent to adult children and conjugal family (Li et al., 2014). The author agrees that although certain behaviours and expectations have changed under the social transitions, filial piety will continue to remain the dominant philosophy of sustaining the family obligation until such time as a culturally appropriate care support system for older people emerges (Qi, 2015). Therefore, it is very important to understand the dynamic change of filial piety beyond the social context in order to practically embed the concept of filial responsibility within family-based dementia care services.

### 1.3 Health care system and health insurance in China

The health care system in China has undergone rapid and profound change since 1949. It thus seems helpful to review it and to better outline the social landscape of how the health care system works in China and how it affects dementia care services. Since the birth of the People's Republic of China, health facilities have been owned and governed by the new government. Under this system, health care costs for the majority of rural residents were met through a system of universal insurance by the Rural Cooperative Medical System (RCMS) (Liu, 2004, Barber and Yao, 2010), while the Government Medical Insurance System is in place for people who work for the government and university students (Barber and Yao, 2011). There was currently no form of private commercial insurance. Following the free-market reforms of 1982, rural households lost their health insurance, which led to the RCMS moving from universal coverage to covering only 7% of rural households in 1999 (Barber and Yao, 2010). Most hospitals became market-based health care services, with the sale of medicines and health services in pursuit of profit becoming hospitals’ main purpose (Yip et al., 2010). For example, physicians were permitted to work in their free time to earn extra income and patients were allowed to choose higher-costing medicines and medical equipment (Blumenthal and Hsiao, 2015). At this point, most of the population were left without any health insurance coverage, with the exception of people who worked in the government or industrial sectors. This left a total of 51% of urban residents and 93% of rural residents without any medical insurance in 1999 (Blumenthal and Hsiao, 2015). This pursuit of profit-driven health services has resulted in increased medicine
and health services costs, which has in turn led to many rural residents being unable to access basic health care and also generated an additional financial burden for many families. Such residents incur high levels of out-of-pocket expenditure (i.e. medical expenses paid for by individual patients and not reimbursed through insurance), which has resulted in 35% of urban households and 43% of rural households being unable to afford access to health care services (Hu et al., 2008). As Barber and Yao (2010) state, given the country’s geographical differences in access to health care, quality and health investments, the gaps between regions have continued to widen, with rural residents finding it ever more difficult to afford basic health care.

In order to break the chain of poverty caused by diseases and the diseases that make poverty worse, and in a bid to improve health conditions for rural residents, the Chinese government implemented the New Cooperative Medical Scheme (NCMS) for the rural population in 2003 (Yip and Hsiao, 2008), focusing on the medical expenses incurred as a result of certain catastrophic diseases (Sun et al., 2009). In urban areas, the majority of residents are covered by two types of health insurance programmes (Hu et al., 2008). One is the urban employee-based health insurance, which mainly includes people who work in the government and industrial sectors. This working-based health insurance covers employees’ medical expenditure through reimbursement or with a fixed amount of money per month to cover basic health services, and it was established by the Chinese State Council in 1998 (Liu, 2004). In order to deliver universal access to health care services, the Urban Cooperative Medical Scheme was launched in 2007 to cover the remaining urban residents, including unemployed urban residents, children, students, the elderly and disabled (Yu et al., 2010). It mainly provides coverage for the cost of hospitalization in high-cost medical conditions and out-patient services for certain common chronic diseases. By the end of 2008, it covered 60.4% of the target population (Yu et al., 2010). In addition, the Medical Assistance (MA) Program was launched in 2003 to provide supplementary financial support for the poorest (Yu et al., 2010).

The NCMS comprises co-payments by the participants, local authorities and the central government and covered up to 94% of rural residents in 2009 (Barber and Yao, 2010). It works across three levels of health care services, village clinics, township hospitals and city hospitals, with residents able to claim back a different percentage of their medical expenditure according to the level of care service they receive. Village
clinics are responsible for primary care, and taking care of the overall minor health problems in the residents’ coverage area has the highest level of reimbursement of up to 65%. Township hospitals ¹ deal with minor operations and disease. Reimbursement in this category is around 50% to 60%, with some differences between regions (Barber and Yao, 2010). City hospitals deal primarily with in-patients with serious disease diagnoses and treatment. Having now operated for longer than 13 years, the effects of the scheme are now evident. Coverage by the NCMS had expanded to cover 85% of all rural areas by 2007 and had reached almost all of the rural regions in 2010 (Bai and Wu, 2014). The programme’s design was critical in enabling it to work with people’s health care problems in rural areas (Liang and Langenbrunner, 2013). It has improved equitable access to primary care for the rural population (Liu et al., 2010). However, as this programme was focused ‘with health-system coverage and catastrophic medical spending as major indicators’ (Liu et al, 2015, p1914), people with dementia have barely benefited from the programme since diseases associated with ageing are more likely to be underdiagnosed and undertreated in rural areas (Dai et al., 2011). Despite this, however, this type of health insurance has greatly strengthened primary care and public health (Barber and Yao, 2010, Lin et al., 2010), but it does not play an important role in helping with the long-term care costs of the older population, especially people with dementia in rural areas (Zhang et al., 2014c, Liu et al.,2015).

These three main health insurance schemes are administered and operated differently depending on the area and are targeted only to short-term clinical care. Comparing the urban and rural health insurance systems, the two systems vary in terms of their benefit packages and funding sources, with rural residents having more restricted access to health care services than urban residents as the NCMS provides less in the way of funds and covers fewer drugs, especially for out-patient services which benefit less (Meng et al., 2015). For example, rural participants have to pay an 80% premium contribution while urban residents pay only 25%, and reimbursement

¹ In China, hospitals are organized in a three-tier system according to their ability to provide medical care, medical education and conduct medical research. Based on this, township hospitals serve as the primary health care institutions with less than 100 beds and provide preventive care, minimal health care and rehabilitation services. Available at http://baike.baidu.com/view/1429004.htm?func=retitle (A Hierarchical Approach to Hospital Management).
can be up to 95% (Liu, 2004). The result of this is that some rural participants lack the willingness to participate in the NCMS, in addition to some low-income families being unable to afford it (Zhang et al., 2014c). Moreover, owing to a lack of staff and the low level of staff qualification, along with primary care services in rural areas lacking a gatekeeping function, primary care is underutilized in China (Wu and Lam, 2016). In another study, Hu et al (2008) indicate that low life expectancy and inequality of healthcare in rural areas is reflected by the fact that improvements are required to primary-level health services in rural areas. As such, the promotion of quality primary-level care in rural areas requires qualified staff, sufficient physical resources and data on local residents who have chronic diseases (Barber and Yao, 2010; Barber and Yao, 2010). However, neither of the insurance systems cover the cost of long-term care, especially for the population with dementia (You and Kobayashi, 2011).

Long and colleagues indicate that the out-of-pocket payments made by the urban population stand at 36%, while the corresponding figure for the rural population is 50% (Long et al., 2013). Blumenthal and Hsiao state that ‘the 2003 reforms proved insufficient to ameliorate China’s deep-seated health care problems’ (Blumenthal and Hsiao, 2015, p.1283). Geographic economic disparities have thus generated disparities in regional financing and benefits in the health care services amongst residents (Barber and Yao, 2010). Overall, this fragmented health insurance situation has led to a state of health inequality between urban and rural residents and an unsuitable health care system in China (Hu et al., 2008, Meng et al., 2015). Owing to the weaknesses that have become apparent within this fragmented health care system, the National 13th Five-year Plan of Healthcare Development (2016–2020) aims to deepen health care reform by consolidating the current rural and urban health insurance schemes in order to reduce the inequitable access among health insurance schemes in terms of the fund levels and benefit packages provided (Meng et al., 2015), in addition to further strengthening the three-tiered (see footnote 1) health care service system (The state council of China, 2017). The plan emphasises the promotion of primary-level health care in terms of resource equality and qualified staff training. Meng et al (2015, p. 1490) assert that ‘systemic strategies and policies that include consolidation of social health insurance schemes are needed to achieve universal health coverage in China’. The effects of this united health insurance model will hopefully be seen in the near future.
1.4 Long-term care services in China

In response to the changing structure and expectations of families in China, as outlined above, the long-term care system has gradually changed from a family-supporting system to a multi-dimensional care approach (Yu et al., 2016). Faced with these trends of demographic shifts and socio-economic changes, the Chinese government advocated three tiers of service for geriatric care in its National 12th Five-Year Plan: home-based care, community-supported and institutional supplemented care (Wong et al., 2015).

Despite the decline in the traditional family care system, it remains the main form of care provision for the Chinese older population (Yu et al., 2016). Generally, a spouse or children are more likely to be the main care providers for their family members. However, with such individuals having less in the way of availability and capacity for providing care, families may instead choose to hire a live-in caregiver to look after their family members, especially in urban areas (Wu et al., 2016). According to the Chinese norm, a private live-in caregiver is referred to as a ‘bao mu’, with untrained, middle or old-aged female migrant workers most likely to make up this type of workforce (Wu et al., 2005). Wu et al (2016) found that 93% of private caregivers had received no training from their recruitment agencies, meaning that the caregiving provided to the care receiver is unskilled and uncertified. Despite this, it is still very difficult to recruit a private caregiver as there is a lack of such care staff working in the field of older people’s care. According to Wu et al (2005), low salaries, low social status, heavy labour, lack of respect and ‘losing face’ are the main reasons for people not choosing to work as a live-in caregiver. In addition, it is generally not affordable for families to hire a live-in caregiver, especially for rural residents (Wong and Leung, 2012). The average cost of hiring a live-in ‘bao mu’ is about RMB 3,000 per month (£320), which is equal to an average salary in a mid-sized city. A survey study carried out in Beijing showed that around 45% of people with dementia pay for care in urban areas compared to the 1% of people who pay for care in rural areas (Wu et al., 2009). According to a more recent study, this trend has shown only minimal change, with only 5.9% of residents in rural areas using formal care services in contrast to 36.9% of urban residents (Ford et al., 2013). Therefore, despite the many challenges facing the traditional family care system, it remains the dominant form of support for long-term care services.
In China, as filial piety places the responsibility of caring for older people on families, formal care and support for the older population, especially for those with dementia, is undeveloped (Wang et al., 2015, Liu et al., 2017). Consequently, informal care and support is provided by family members and is widely used as the result of the underdevelopment of community-based care services and nursing care homes (Xiao et al., 2014). Community-based care has been developed only in some urban areas in China and is integrated with institutional care services. In a certain sense, community-based care services act to supplement the lack of adequate affordable care institutions for the older people and the decline in traditional family care support. They are funded by multiple sources and provide a range of care services for people who live in their own homes (Xu and Chow, 2011); for example, services for respite, meals or in-home services are all different options (Wu et al., 2005). By using such community-based services, older people are able to live at home on their own, or with their children, grandchildren or other relatives, which is a solution that many believe suits China’s rapidly ageing population at the same time as respecting its cultural traditions. However, this type of community-based care is non-existent in the rural areas.

There are two types of institutional care services, one of which is government-sponsored care homes. Traditionally, these care homes have accepted only older people with no children and income and who have lost the ability to work. More recently, however, especially in urban facilities, some government-sponsored care homes have begun pursuing profit in order to survive in the economy. For example, government-sponsored institutions in Shanghai have begun admitting a wider range of old people who are willing and able to pay (Wu et al., 2005). In rural areas, however, most government-funded care homes continue to operate in the traditional way. Another type of care institution is profit-based private care homes. These types of home rarely have clinical staff, tend to be poorly equipped and the care staff that do work in them are mostly rural unskilled workers (Wu et al., 2016, Yip et al., 2012). The homes are relatively cheap but the quality of care is low, especially in rural and poor regions. In some cities, certain private care homes provide medical staff and luxury accommodation for their older residents, but the cost of these homes is very high, with only wealthy people being able to afford to use them (Yip et al., 2012). In order to promote long-term care services, both central and local government have offered ongoing per-bed subsidies for non-government care institutions. For example, a study investigated seven private care homes in Nanjing and found that 2% of these care
homes’ daily operating costs were derived from government funding, with the remaining 98% of expenditure coming from private pay (Feng et al., 2012). Geographically, the local authorities have also provided a degree of support to their local private care homes, with the amount of funding likely to be determined according to the number of beds they have. In Nanjing, the local government provides per-bed financial inducements for newly constructed private care homes, with RMB 2,000 to RMB 4,000 (£230–£460) as a foundation, in addition to an ongoing operating subsidy of RMB 80 (£9) per bed per year (Feng et al., 2012).

The disparities in care approaches mean that problems persist with long-term care services for the older Chinese population, because of the gaps of pension and family incomes (Sun et al., 2014). Care services for the older people are worse in rural areas due to the fact that 31% of the rural population cannot afford medical services (Li et al., 2014). Chen et al (2016) found that people with dementia were less likely to receive care if they lived in rural as opposed to urban areas. Faced with these above problems, in order to promote the responsibility of families to care for older people, the new law of Protection of the Rights and Interests of the Elderly (2013) has not only enforced individuals’ responsibility for taking care of older parents, but also proposed that basic standards of living and basic medical care are ensured for the older population who have no pension through the pension mechanism and health care scheme. Meanwhile, the National 13th Five-year Plan (2016-2020) has further emphasised the importance of developing the home dominated, community supported and institution supplemented care for older people in China (Fang et al., 2015). In fact, the political implications and the reformed health insurance have improved both health care services in the areas of prevention and primary care and positively provided the public population with affordable and equitable access to basic health care (Yip et al., 2012). However, the level of health care insurance coverage in terms of financial protection and service packages remains small, especially with regard to the coverage of expenditure for age-related chronic diseases and the cost of long-term care in such group population (Liu et al, 2008, Li et al, 2014). Therefore, in the China Country Assessment Report of Ageing and Health, WHO states that ‘there is a pressing need to develop accessible, affordable, effective and age and gender appropriate health services for all Chinese people’ (WHO, 2015, p.30).
1.5 Pension system in China

The first pension system was established in 1951 and only included staff who worked for the government and people who worked in state-owned enterprises (Feng et al., 2011a). This system remained up to the 1980s, at which time China began to introduce a market economy. This employer-sponsored pension became unsustainable as many state-owned enterprises, especially those in industrial sectors, either broke down or transformed into private business, as influenced by the reform of the market economy. In response to this change, pension reform was enacted in July 1997 by the State Councils (Feng et al., 2011). The New Pension Scheme for Urban Workers (NPSUW) was formed through joint contributions from employers and employees in which the contribution rate comprised 11% of an individual’s wage and a further 3–8% employer contribution (Wang, 2006). The mandatory retirement age is 60 for males, 55 for female managers and 50 for female workers. A total of 70.7% of urban workers (not including urban residents who work in private businesses, the self-employed and migration workers) were covered by this employer-sponsored pension scheme, with the remainder left with other types of social insurance or family support (Shao and Xu, 2001). This has greatly improved the status of security in old age for those living in urban areas. In 2011, the government introduced the Urban Resident Pension Scheme (URPS) for urban residents who were either unemployed or otherwise ineligible for the NPSUW (Queisser et al., 2016).

However, the above pension schemes never considered rural residents since the government took the view that the rural population have their own resources in the form of land. This had the effect of forcing most of the older rural population to rely on family support, since once they lose their physical ability to work on the land, they have no means of making money. Only childless and disabled older rural residents are supported by the government through the five guarantees2. This relative lack of social security coverage for the rural population has further promoted the rural-urban economic disparity. Along with the societal and economic changes over the course of the past few decades that have contributed to a weakening of the traditional family

2 Five Guarantees: The Chinese Government guarantees food, clothing, medical care, housing and burial expenses for people over 60 years old who are childless and have lost the ability to earn a living.
support system, the economic gap between rural and urban areas has widened and led to a regional imbalance in social and economic development. In order to balance social and economic development and reduce the poverty rate of the rural population, the Chinese government realized the need for a social security system for rural residents.

In 1992, the first rural social old age insurance system in counties was introduced by the Ministry of Civil Affairs, but this soon stagnated and left 85% of rural elderly residents reliant on family support by 2000 (Wang, 2006). With the underdevelopment of the old age security system in rural areas, the Chinese government began piloting a New Rural Cooperative Pension Scheme (NRCPS) in various relatively developed rural regions in 2007, prior to beginning a country-wide roll-out in 2009 (Peng, 2011). This new rural pension scheme has two components; a basic pension component\(^3\) financed by the local and central government, and contributions from individuals. It has four characteristics: a guaranteed basic benefit, wide coverage, flexibility from region to region and sustainability. It also represented the first ever direct contribution to a rural pension scheme by the Chinese government (Shen and Williamson, 2010).

However, because of discrepancies in the local government’s contributions, this new rural pension scheme has led to differences in regional coverage. As an example, it was reported that over 80% of rural residents living in the suburbs of Beijing were participating in the new rural pension scheme by the end of 2008 (Yuan, 2008). The author indicates that this high level of participation is due to the high living standards in Beijing’s suburbs and the higher level of financial contribution from the local government, meaning that an older person is able to receive RMB 280 (£30) in pension per month. However, most rural areas in China are much poorer than Beijing’s suburbs and as such receive lower subsidies from local governments, meaning that the pension scheme provides only a very low level of pension benefit to most rural participants (Shen and Williamson, 2010). The average amount paid to older people in rural areas is 65 to 85 yuan (£7–£9) per month (Chen and Turner, 2015), and while this amount does go some way to improving the financial situation

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\(^3\) The basic pension component financed by local and central government is a central government contribution of 55 Yuan per month (£6.50) to the basic pension component and the local government with a flexible amount of supporting.
of the older population with no pension, it does not cover the minimal cost of living in a rural area (Calvo et al., 2016).

This NRCPS has significant social and political meaning since it was the first country-wide pension system for rural residents to provide some measure of help to the rural older population. However, due to the low pension level, low coverage and the low level of personal payment ability in many poorer regions, the system may not be of much help as China has major regional disparities with respect to income and level of economic development (Shen and Williamson, 2010). China’s social insurance system for old people has been criticized by Cai and Cheng as ‘segmented, regionally imbalanced, fiscally inefficient and socially and economically unsustainable’ (Cai and Cheng, 2014, p.636). Due to this, in April 2014, the State Council combined the NRCPS and URPS to create the Basic National Resident Pension Scheme (BNRPS) (Queisser et al., 2016), which aims to cover the whole population by 2020 (Cai and Cheng, 2014).

1.6 Dementia care and social support in China

One study has shown that health insurance schemes have led not only to an increase in the number of urban residents seeking medical advice at city health facilities, but also to an increase in the number of rural residents accessing primary care (Zhang et al., 2014a). However, this rise did not apply to people with dementia living in rural areas, since most village clinics or local community health centres in China do not have qualified mental health staff and screening facilities (Hsiao et al., 2016). The types of medication used to treat dementia are relatively expensive, with a majority of them not covered by the health insurance schemes (Wu et al., 2016, Hsiao et al., 2016). In their study, Wu and colleagues investigated one township hospital and found there to be no specialist health professionals working in the area of diagnosis and treatment of neuropsychiatric disorders, and no dementia-related medication in the hospital. Therefore, people with dementia who live in rural areas are more likely to be unrecognized and undiagnosed (Yu et al., 2016). Although the health reform undertaken placed an increased emphasis on primary care to manage chronic diseases, including dementia care services, the outcome has been minimal and it is difficult for people with mental problems to access mental health care. Liu et al (2013) indicate that even though some dementia medications have become available and are partially covered by health insurance, neither those people with dementia included in the study nor their families were willing to seek medical services as long-term
dementia care services are not covered by the health insurance schemes (Wu et al., 2016). In fact, the majority of rural patients with mental illnesses receive no psychiatric care at all (Chen et al., 2013, Wu et al., 2011).

Awareness of dementia among the general population is poor. For example, a survey study (Li et al., 2011) in Shanghai (one of the most economically developed cities in China) found that the general public lacked knowledge of dementia, with the results showing that 45% of family members and caregivers treated dementia as a normal process of ageing and did not consider there to be any benefit of medical care for people already suffering from dementia. Dementia awareness is also extremely low among older people and the less educated. Stigma around the studied participants is common, more than half of the participants said that they would feel ashamed if their family members had dementia (Li et al., 2011). Another cross-cultural study among Chinese, African Americans and Latinos found that the Chinese population held the greatest stigmatization of people with dementia (Mahoney et al., 2005). For patients with dementia, early diagnosis, treatment and intervention are important in order to identify ways to improve their quality of life as well as to anticipate and manage the future societal costs (Wimo et al., 2013). However, only scant attention has been paid to people with dementia as a group in social activity by the general population, politicians and researchers, especially in rural areas in China. The rates of dementia diagnosis and treatment are lower than those seen in many Western countries. A survey of family caregivers in four of China’s biggest cities – Beijing, Xi’an, Shanghai and Chengdu – found that only 26.9% of people with cognitive symptoms had received a formal diagnosis of dementia, and of those who had received a formal diagnosis, only 2% were taking medication (Zhang et al., 2006). Many studies have strongly raised the need to improve public awareness about dementia (Wu et al., 2011, Chen et al., 2013, Yang et al., 2016), especially in middle- and low-income countries with a low level of dementia care services in primary health care.

Health providers’ knowledge and skills in the diagnosis and management of dementia are low in long-term care institutions in China. To illustrate this, the majority of long-term care institutions have no qualified doctors and nurses, and most of their care staff are migratory workers with low levels of education (Liao, 2014). These institutions are able to provide only basic physical care activities and lack the skills and knowledge required to manage the behavioural and psychological symptoms of dementia. In addition, they do not provide dementia care related training to their staff.
As a consequence, many long-term care institutions simply refuse to admit anyone with dementia or, at least, those with advanced dementia (Wu et al., 2011, Wong and Leung, 2012, Liao, 2014). For example, a study in the city of Chengdu found that, among the ten long-term institutions investigated, more than half refused admission to people with advanced dementia (Wu et al., 2016), while no formal medical assessment was undertaken of care receivers prior to them being admitted. In the case of residents already living in the institutions who went on to develop cognitive symptoms of dementia, the institutions did not provide psychological care and rehabilitative care for them. The families were more likely to leave decisions related to their relatives’ care to the institutions (Wu et al., 2016).

According to Dai et al (2013), even in large urban hospitals, medical staff lack knowledge of cognitive impairment and more than half of the health care professionals were not familiar with the standards and criteria of dementia. In community health centre settings, where primary care is provided for urban residents, the physician’s responsibility is skewed in favour of managing chronic diseases such as hypertension and diabetes (Dai et al., 2013). Another study stated that high rates of undetected dementia (93.1%) were related to low levels of education, income and residence, while there is an even higher rate of undetected dementia in rural areas (Chen et al., 2013). Therefore, dementia care services have been largely ignored in primary care in both rural and urban areas. This may partially explain the under-recognition and under-diagnosis of dementia in China. Therefore, it is important to train primary care physicians to recognize early symptoms, carry out early screening and perform diagnosis.

China rapidly entered its era of an ageing population at the same time as the majority of its people continued to have a low standard of living. The majority of middle- and low-income Chinese families cannot afford to hire a private carer, even if they themselves are unavailable to look after their family members. In this situation, family caregivers may only be available to provide a basic level of life care (such as bathing, cooking, dressing, etc.) for the person they are looking after. While some rich families may be able to afford to hire a live-in carer, most paid caregivers lack the relevant skills and knowledge of dementia care due to the lack of education programmes and social support services in China (Chen et al., 2017). The caregivers employed in care institutions are usually low-skilled rural migratory workers, who, while able to address the physical needs of people with dementia, lack specialist training in managing its
behavioural and psychological symptoms (Wu et al., 2016, Wang et al., 2014). Due to professionals lack of knowledge of dementia, there is a high likelihood of psychological care being either ignored or unavailable in both informal home-based care and formal health care service settings (Chen et al., 2016, Wang et al., 2014).

Despite dementia care having been prioritised in the National 13th Five-year plan for Healthcare Development, there is no dementia care-related national plan or strategy available in China, and there are no official statistics for the number of people with dementia. The figures for dementia prevalence that do exist are mostly from Chan and colleagues' systematic review paper (Chan et al., 2013). In light of these factors, the National 13th Five-year Plan for Healthcare Development aims to develop an integrated mental health service system, to include training more qualified mental health specialists, promoting public awareness, reducing social stigma and developing community- and family-level support networks (The State Council of the PRC, 2017). As such, tackling the problem of ageing and dementia care in China remains a long-term challenge. Overall, Chen et al. identified the following four main challenges of dementia care in China (Chen et al., 2016):

- An undeveloped dementia service system
- Inadequate knowledge about dementia among medical professionals and caregivers
- Poor awareness of dementia among the public
- High cost of dementia care.
1.7 Dementia research in China

Dr Simon Ridley, Head of Research at Alzheimer’s Research UK, wrote that:

‘We know that dementia is a global problem and it is important to understand more about the risk factors and barriers to diagnosis across different countries. Investigating the social, economic and cultural factors influencing attitudes and access to dementia diagnosis can help shape strategies that could benefit multiple countries across the world. We must ensure long-term investment for dementia research if we are to improve the lives of millions living with this condition worldwide.’ (King’s College London, 2013).

Traditionally, research and political attention in China has often been focused on diseases with high mortality rates, for example, cardiovascular diseases and cancer (Fang et al., 2015). With rapid population ageing and the increasing number of people with dementia, dementia has been set as a priority in mental health services in the National 13th Five-year Plan by the Chinese government. The research related to the dementia field has expanded in the past three decades, especially in the more developed eastern regions of China. There is a growing volume of research in China and international partnership studies in various areas of dementia— for example, there are studies on genetics, psychopathology, neurophysiology and drug treatment which are all based in China (Chiu and Zhang, 2000, Song and Wang, 2010). The 10/66 dementia research group, in particular, has published dementia related cross-cultural articles among Chinese, Indian and other populations from low- and middle-income countries (Prince et al., 2012, Prince et al., 2007).

There have been several epidemiological studies concerning China since the 1990s. The estimated prevalence between studies and within regions is heterogeneous and varied (Prince et al., 2013). The official demographic statistics of dementia in China lacks information, such as informatics reporting the number of people with dementia not being available in the national statistics yearbook and in the China Association for Alzheimer’s Disease website. The World Health Organization has adopted the data from Chan et al’s (2013) study, with the estimated number of people with dementia in China being 9.18 million in 2010. A recent population-based study found that 7.7% of the over 60s population had dementia in northern rural China (Jia et al., 2014), and that figure is as high as 13% in the Zhejiang province (Yang et al., 2016). In addition,
the World Alzheimer Report (2015, p.27) by Alzheimer’s Disease International (ADI) identified limitations in previous systematic reviews of the prevalence of dementia in China stating that only 5% of multistage designs were applied correctly and only 15% of studies used a comprehensive diagnostic assessment (ADI, 2015).

Song and Wang (2010) argue that, in comparison to Europe, North America, and the more developed Asia–Pacific countries, the number of population-based dementia research in China is less extensive. The authors indicate that China ‘has no specialized research institutions, paltry special research funds with a lack of scale and stable research teams, long-term research, and prevention and control plan’ on basic dementia research (Song and Wang, 2010, p5). One qualitative study about barriers to the recruitment of Chinese participants into dementia research may explain the reasons why the amount of dementia research is less in China (Hinton et al., 2000). The study identified four barriers which stop Chinese people from participating in dementia related research: difficulty in identifying people with dementia; viewing research participation as potentially harmful; dementia as a social stigma; and perceiving research to have no direct benefit to participants (Hinton et al., 2000).

Research concerning the factors that influence dementia causality are extensive, from genetics, lifestyles and environments to education and sex. Yang et al’s (2016) recent study found that age, low education level, less social relationships, smoking or drinking and a history of diabetes and stroke is associated with dementia, but tea consumption was associated with a low prevalence of dementia. To allow the diversity of demographics, race, culture and economy found in different regions to be taken into account. China needs a large number of epidemiological studies in different regions (Fang et al., 2015). Basic research focusing on dementia pathology has recently expanded (Zhou, 2010). Traditional Chinese medicines in treating dementia have attracted considerable attention and research-based evidence on Chinese medicines has expanded in the past 10 years (Ho et al., 2011, Liu et al., 2014). For example, Liu et al (2014) found that the traditional Chinese herb, *huperzine A* improved the memory and learning ability of people with Alzheimer’s Disease.

As premature mortality is given more attention than living with disability in most of the developing countries, the current level of dementia research and its implications of social and political impact in these countries is insufficient (Prince et al., 2007). Liao (2014) indicated that the Chinese government has increased funding in dementia research since 1990s, however, more money went to the areas of biomedical
research, rather than to the field of care, services and public health (Chui et al, 2000, Liao, 2014). Xiao et al (2016) indicate that literature about ‘nursing technical procedures’ has increased during 1997 to 2012, but the research on the ‘clinical experiences’ of nursing staff has been reduced. The authors also indicate that the amount of previous studies among older people associated with mental disorder in rural settings is extremely low (Xiao et al, 2016). Just as Liao points out that even though China has achieved progress with dementia care in recent decades, it is still in its initial stage (Liao, 2014). The author suggests that more mental health nurses should be encouraged to participate in dementia care research (Liao, 2014).

Currently, medications for treating dementia have become available and are regionally varied in being covered by health insurances. Meanwhile, many dementia associated non-governmental and academic organizations have been established in China such as China’s association for Alzheimer’s Disease, Alzheimer’s Disease Chinese, Chinese Geriatrics Society and other local groups and organizations. They perform a variety of services in order to improve public awareness, and to bring the government’s attention towards dementia research and inform the policy makers. International collaboration in research and knowledge exchange has also increased through these organizations. With China’s prevalence of dementia and unsustainable health system, clinical and social research is urgently needed to inform the government and health services to implement evidence-based regulations, treatment, interventions and care.

1.8 The starting point of the PhD study

The origin for this research emerged from concern about the missing voice of people with dementia and their family caregivers in China.

My wish to undertake a PhD in dementia research arose when I worked with Barchester Healthcare Ltd in England, where I witnessed first-hand how social and cultural discrepancy can lead to the different provision of dementia care services for people with dementia. Having spent six years working and interacting with people with dementia at the Memory Lane Unit, I gained insights into the lived experiences of people with dementia in the UK. I learnt about their suffering as their cognitive and functional ability declined, their demands and their support needs in order for them to continue living a normal life. I learnt about the rights of the residents to choose their own food, clothes and make decisions related to their care. I also learned about the
good social network and the types of formal and informal support available to dementia patients, in addition to seeing how the Gold Standards Framework (NHS, 2010) of caring for a person with dementia in the advanced stage or end-of-life stage works. I witnessed the bad family relationships that can exist within family support networks, whereby someone with dementia may only see their family on the first day of their admission to the care home and then just prior to them passing away. I was also inspired by the ‘Prime Minister’s challenge on dementia 2020’ initiative, which aims to make the UK ‘the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and the best place in the world to undertake research into dementia and other neurodegenerative diseases’ (Prime Minister’s challenge on dementia 2020, 2012). I was also astonished by the Scottish Dementia Working Group, in which a group of people with dementia are involved in research, academic collaboration, fundraising and various other events aimed at giving a voice to people with dementia and finding ways to improve services and attitudes. Whatever ‘bad’ or ‘good’ care I viewed during the period of working in the UK, it inspired me to undertake research in the area of dementia care. I want to know more about what works well or not in a cultural context.

When thinking about my latest working experience as a senior carer and a team leader, I vividly recall my feeling as a member of the care staff and the services we provided for people with dementia. I worked as part of a multidisciplinary team that included GPs, nurses, care staff, physiotherapists, occupational therapists, podiatrists and volunteers. Our professional and dedicated team of specialists offered services aimed at continually improving the quality of life of the people in our care. We provided support to people with a range of different perspectives of dementia, to enable them to continue living their own lifestyle for as long as possible and to maintain their needs within an inclusive and respectful environment. During this working period, my own experiences included feeding a resident who was spitting food or using a hoist to get a resident into a bath in a limited space or even cleaning up a resident with incontinence. Through this, I can relate to the lived experience of the care staff, the pressure imposed on them by their workload, their sorrow when a patient dies, their happiness at seeing a smile on residents’ faces, their pain and their life.

The provision of support and respite for families was also a key aspect of our services, which was just as important as supporting the person with dementia themselves. As a senior carer, I had more responsibility than other care staff as I not only needed to
monitor and arrange the whole unit’s care activities when on duty, I also had a greater responsibility with regard to communicating with families. I began to understand the relatives’ fear and frustration after they knew that their loved one had been diagnosed with dementia, their stress and pressure at the time when trying to understand and manage the behavioural problems of the person with dementia and their expectations regarding the kind of support they could receive from the health professionals. These working experiences within a distinct cultural context gave me a basis from which to explore how culture has influenced the lived experience of Chinese people with dementia and their caregivers’ experiences, in order to further my PhD study.

Tracing back to the beginning, I began working as a registered adult nurse in 1993 at a local hospital in China. In the practice, I was sometimes in contact with older people with dementia and looked after them. The experience was both interesting and challenging, but it also left me with a sense of frustration concerning my own ability to understand and support patients, especially witnessing what I considered to be bad care in the clinical setting, whereby people with dementia were never viewed as independent persons; as such, there was no choice for them. All medical-related decisions were made by family members or doctors according to what they considered to be best for the patients. I also frequently heard doctors telling relatives: ‘there is no need for further medical treatment as it is just a waste of money…’, which brought a sense of despair and helplessness to the patients and their families. Comparing the different cultural perceptions of health care services stimulated me to think about the meaning of independence and respect in health care services in different cultural settings.

In communities, I often heard about and saw many people with dementia being cared for by their family, and many stories about how they were treated by others. I also heard about the challenges and difficulties faced by family caregivers, their stress, hopeless and their stories of resilience. In China, due to the fact that health care services are paid for by the patient, once a person with dementia is discharged from hospital, they have hardly any contact with health care professionals. This means there is hardly any post-diagnosis support from health professionals available for people with dementia who are cared for at home. Since a majority of people with dementia are cared for at home by their families without any informal social support or formal health support, I often wonder what the meaning of living with dementia or
caring for a person with dementia is for them, and also about what they really need to make life meaningful.

Through my work on care homes in the UK and working in the hospital in China, I became aware of wider debates within dementia care about the need to continue living a normal life or the extended services that they need to maintain their quality of life. Considering that ‘people with dementia are the experts through the lived experience’ (Swaffer, 2014; p. 710), the lack of voices of Chinese people with dementia and their family caregivers led me to consider undertaking research in this area. Researchers have acknowledged that the performance and behaviours of people with dementia are not only determined by neuropathological changes but are also influenced by how society has supported and treated them (Davis, 2004, Bartlett and O'Connor, 2007, O'Connor, 2007). This indicates the importance of understanding the subjective experience of people with dementia in the specific social and cultural context. My increased awareness of the wider issues concerning their life that face the vast majority of people with dementia and their family caregivers at home inspired me to embark on a research career as I think it may potentially yield greater impact within both the practical and political spheres.

1.9 The nature of the study

This is an interpretative phenomenological analysis (IPA) study. The reason for employing IPA as a methodological approach is because it attempts to examine how people think about a phenomenon or make sense of their lived experiences (Smith, 2009). This meets with the purpose of the study to obtain subjective accounts. Larkin et al (2006) indicate two aims of an IPA study: firstly, to understand the participant’s lifeworld by getting their views as ‘close’ as possible in an initial stage of psychologically informed description; secondly, to develop a further interpretative analysis through positioning the initial description into a wider social and cultural context. After considering all the factors, IPA was selected as the most appropriate approach to achieve the aims of this study.

The study aims to gain insight into the lived experiences of people with dementia and their family caregivers, and how they cope with their new roles in contemporary China. A purposive sample comprising people with dementia and family caregivers was recruited from one mental health centre in Shandong Province, China, to explore their experience of living with or caring for others with dementia. Individual interviews were
used to discuss how the participants felt about their experience of caregiving and care-receiving, how this impacted their daily lives and how they coped with it.

It has been recognised that enhancing public awareness and understanding can reduce the stigma associated with dementia and enable people with dementia and their caregivers to access support (WHO, 2012). Kitwood (1997b) indicated that validating the subjective experiences of people with dementia would make the person an active actor rather than passive participant in their lives. Validating their experience will allow them to have a meaningful life and relationship with others. Although the subjective accounts of people with dementia have gained more research attention in Western literature since the 1990s, there are rarely any such accounts in China. This study responds to the lack of the voice of Chinese people with dementia and their family caregivers in social, political and research activities. I hope that this study will be able to contribute to the knowledge gap of Chinese people with dementia and their family caregivers' lived experience and give them a voice to talk about their lives, preferences and needs.

In the study, the participants with dementia and their family caregivers shared their experiences of living with dementia and caring for people with dementia. Specifically, on the topic of roles and responsibilities, they shared their understanding of family responsibilities within families and society, and the factors affecting their ability to maintain their responsibilities. The study highlighted the participants' burden and challenges within the family-based care system under the current social situation and identified that both people with dementia and family caregivers face great pressure in coping with their roles and responsibilities. This indicates that the traditional value of family responsibility has been influenced by sociocultural transitions that indirectly affect the quality and quantity of care provided by families. The study recommends that while there may be continuing support for family-based care, a stronger government welfare system is needed in order to support older people and their families in contemporary Chinese society.

1.10 The structure of the thesis

The detail of the proposed study will be discussed in the subsequent chapters and is structured as follows.

Chapter one provides the background of the study by describing the specific health care system, pension system, long-term care and dementia care services context in
China. It shows that dementia care services in China are based on a geographically discrepant and unsustainable health care system. In this chapter, I also reflect on my personal career journey as a health professional working in different settings both in the UK and China, and how these experiences have motivated me to conduct my PhD study in the field of dementia care.

Chapter two draws on a broad literature review base to explain the concept of dementia and the meaning of personhood and its relationship with dementia. I review the different perceptions of dementia, how these impact in practice and how these shapes the personal experiences of living with or caring for people with dementia. Focusing on the personal experience, I explore the impacts of living with and caring for people with dementia. I also review the development of dementia research in China as the study focuses on participants of Chinese origin. I consider the language used in dementia practice and the related social stigma in different cultural settings. I end the chapter by identifying the knowledge gaps and research question.

Chapter three covers the whole presentation of the research design, the theoretical framework of the research and the rationale of the research methods, including the sampling strategies, ethical considerations, data collection and data analysis.

Chapter four presents the main findings, which include the following: (1) Negotiating the role; (2) The meaning of living with dementia in the social context; (3) The meaning of responsibility in the cultural context; and (4) Coping with the ‘altered’ life. These four themes are discussed in relation to family responsibilities and wider social relationships, which reveal the challenges and dilemmas that the participants face when living with or caring for someone with dementia. These themes highlight the meanings of the responsibility over the period of living with dementia among individuals and its dynamic change under the influences of social and cultural transitions.

Chapter five discusses the numerous key issues of the findings, which themselves draw on the two areas of social space and cultural influence. The issues comprise the meaning of ‘home’ and ‘ageing’; the physical and social environment; interdependent family relationships; social exclusion and inclusion; filial piety as obligation or affection; reciprocal filial piety versus authoritarian filial piety; and filial piety as a coping strategy. It considers how specific social and cultural roles work and impact on personal life,
especially for people with dementia. Meanwhile, the critique of the research and the reflections of the study are also provided in this chapter.

Chapter six, as the final chapter, focuses on the conclusion and recommendations. It draws out the study’s contribution to knowledge by highlighting the key finding of the challenges and dilemmas that the participants face when caring for people with dementia or living with dementia in their own home in contemporary China. One of the most important contributions of the study is the addition of an understanding of the meaning of family responsibility for people with dementia and family caregivers under the contemporary social and cultural transitions. Another unique contribution to knowledge is the provision of an insight into the role played by the traditional belief of filial piety in family-based dementia care and how this has been utilised by the participants in maintaining their family responsibility. Finally, the findings show that the socio-economic, political and cultural environment plays an important role in shaping family responsibility in family-based care in China. The study illuminates the significance of social and cultural contexts in the lives of people with dementia and family caregivers, and indicates how these new insights into the experience of Chinese people with dementia and their family caregivers can inform the current knowledge base. Recommendations for policy-making to create an understanding social and physical environment, along with support for family-based care, are considered. Utilising cultural values in practice and developing social support services for people with dementia and their family caregivers is also discussed. Suggestions for relevant future research are also given at the end of this chapter.
2. Chapter Two: Literature Review

2.1 Introduction

The aim of the literature review was to understand the broader context and to examine the related empirical research on dementia care, especially care role and care responsibility underlying the social-cultural and economic impacts, identifying gaps in the knowledge base and providing the rationale for this study. Its purpose is to explore how these perceptions shape the meaning of caring responsibility, how the family relationships and connections with wider society has been affected and the meaning of caregiving and care receiving for people with dementia and their family caregivers. The chapter focuses on the following key areas of the review: the process of care giving and caring receiving, personhood and person-centred care in dementia service; the subjective experience of people with dementia and family caregivers; and the social and cultural impacts on dementia care. This literature review has presented a context for the study and provided the rational for doing this research.

The literature review drew on a broad literature base and included any material which might have provided insights relevant to the overall study aim of understanding the lived experience in the context of family care services. The databases such as Google Scholar, MEDLINE, CINAHL, PsycINFO and Applied Social Science Index and Abstracts were used. The key words ‘dement’ or ‘Alzheimer’; ‘lived experience’ or ‘life changes event’; ‘dementia care’ and ‘family caregiver’; ‘caring role or caring responsibility’ and ‘caregiving and care-receiving’ were used in the searches. The searches included publications in both English and Chinese. The Chinese database of Wanfang and the China National Knowledge Infrastructure have also been searched. Initial searches were set with the year 2000 onwards but this was not rigid and relevant papers that were older than this were included. All articles that comprehensively informed aspects of the lived experiences with dementia were searched. Grey literature of some key organization’s websites, conferences or government reports and previous PhD students’ papers (such as theses and dissertations) were also searched for and informed the literature review.

The synthesis of the literature in this chapter firstly, spotlights the different concepts of dementia in wider society, research and healthcare settings, and its implications of the different concepts which are embedded in socio-cultural and political factors. Secondly, it considers the term and meaning of personhood, person-centred care and
relationship-centred care in practice. Thirdly, it examines the definition and process of care and the meanings of caregiving and care-receiving for caregivers and care receivers. Fourthly, it reviews the subjective experiences of living with dementia and caring for a person with dementia and its social and political significance. Fifthly, it examines the empirical research in the area of dementia care in China. It also considers the stigma and discrimination of dementia which is embodied in a social and cultural context. Finally, it concludes the importance of giving voices to people with dementia and their family caregivers in order to understand their life world.

2.2 A social context of dementia

Dementia is an umbrella term for several brain diseases and disorders, which affect an individual’s memory and other cognitive functions and gradually lessens one’s ability to be independent (WHO, 2017), so it has an extensive personal impact as well as on family members and society. Dementia is one of the most common diseases and a major cause of disability and mortality amongst older people. Managing behaviours and maintaining daily activities to meet the needs of care-recipients can be very challenging for caregivers (Chan et al., 2010). Physical, emotional and economic pressures can cause great stress to families and caregivers; therefore support is required from the health, social, financial and legal systems.

Along with the increasing demographics of the older population worldwide, dementia has become a huge global problem. Currently, the WHO estimates that there are 47 million people who have dementia worldwide and there are approximately 10 million new cases every year (WHO, 2017). The prevalence of dementia is increasing as the population ages. The rate of dementia in over 65 years old is about five to eight percent and the proportion for over 80 years old is over 20%. Dementia has significant social and economic implications in terms of formal healthcare, informal care and social care cost. It estimates the total worldwide cost of dementia is 818 billion US dollar, and it will be increasing to a trillion by 2018 (Wimo et al., 2015). In a 2014 Alzheimer’s Society report in Dementia UK, the average annual cost of per person with dementia in the UK is £32,250. In total, it costs £26 billion a year (Alzheimer’s Society, 2014). In the United States, the yearly cost of dementia care per person was $56,290 in 2010, and the total financial cost of dementia care was estimated between $157 billion and $215 billion nationally (Hurd et al., 2013).
Most importantly, dementia is overwhelming for people with dementia and for their caregivers in terms of dealing with daily activities and cognitive problems. It has the potential to destroy one's cognitive abilities and life skills, which can directly affect both the lives of people with dementia and those who care for them. Whilst the focus of work on risk factors, diagnostic processes, treatments and rehabilitation in dementia are essential, the understanding of their lived experiences is critical in providing support to maintain a meaningful and high quality of life for them. The importance of how people with dementia can be supported to live as ‘normal’ as possible after their diagnosis, in terms of their physical health as well as their psychological well-being, is also recognised (Alzheimer’s Society, 2013c). It is in regard to the latter that the focus of this study, that is, the social, cultural and economic impacts on the subjective experience of living with and caring for dementia. In the context of caring for people with dementia who live at their own homes, more needs to be understood about how caring responsibility can be supported and sustained by social environment within the community.

People with dementia are one of the most marginalised and excluded groups in society (Milne, 2011, Wilkinson, 2002b) as well as people who looked after them. People with dementia struggle to maintain social connections after diagnosis and can ultimately experience social exclusion (Bowlby et al., 2010). Social exclusion is categorised by housing, education, income, employment, social support and even neighbourhood deprivation by some researchers (Keady et al., 2012, Milligan, 2003, Milligan and Thomas, 2016). In the context of social isolation and discrimination, people with dementia and family caregivers can become disconnected and lonely. As Morgan et al suggest: ‘In most definitions of social exclusion, social relationships and networks are a central component, a key requirement for a fully participative and inclusive life’ (Morgan et al., 2007, p.479).

2.3 The concepts of dementia

Dementia has been viewed in different ways by professionals and the lay population, and these differing views of dementia contribute to our understanding of the illness. For example, based on Kitwood’s idea (Kitwood, 1997b), Marshall suggests that the ‘disability’ of a person with dementia should be understood within the society by how they have been treated by others, not only to focus on the cognitive impairment per se (Marshall, 2004). A cross-sectional study has categorised three models of caregiver’s conception of dementia: the biomedical model, the folk model and the
mixed model (Hinton et al., 2005). The authors state that, in the biomedical model, caregivers refer to dementia as a brain disorder and they use biomedical terms, such as ‘cognitive impairment’ and ‘Alzheimer’s disease’ in an explanation of dementia. In the folk model, the caregivers believe that the mental-related changes of the person are a ‘normal’ process of ageing; family members or friends more often use the words ‘forgetful’, ‘crazy’, ‘confused’ to describe the person’s behaviours. Hinton et al. reported (2005) that the mixed model was the most common model believed by caregivers, they explain the illness as normal ageing or psychosocial stress, but address it by using biomedical labels. These arguments have led me to consider the questions ‘what is dementia?’ and ‘what are the implications of its meaning to people’s experience of living with dementia or their family caregivers?’ First, I will choose some common notions of dementia from the previous literature and discuss them in more detail in the following section.

2.3.1 Medical perspective of dementia

The biomedical model of dementia heavily influences the understanding of people with dementia in the medical world of dementia diagnosis, treatment and intervention. Such as, dementia has been defined as ‘a syndrome in which multiple-domain cognitive impairment, generally including memory impairment, is sufficiently severe to significantly affect everyday function’ (Quinn, 2014, p.10). In this biomedical model of dementia, Lyman (1989) classifies three characteristics of dementia: dementia is a condition of cognitive impairment; dementia is a brain deterioration which causes intellectual skill and functional skill problems; dementia is diagnosed by a combination of biomedical assessments and clinical functioning. As the progressive nature of dementia deteriorates a person’s cognitive and functional skills, it also heavily influences a person’s ability to be independent and the ability to perform daily activities. It states that dementia is an umbrella term for a variety of brain diseases including Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, fronto-temporal dementia, etc. The most common type of dementia is Alzheimer’s disease as it represents 60-70% of all types of dementia. The symptoms of Alzheimer’s disease include the deterioration of memory, language and other intellectual abilities; it is a terminal illness which lasts for a period of 7 to 15 years (Quinn, 2014).

The diagnosis of Alzheimer’s disease requires a combination of brain imaging, screening for co-morbid conditions, history and cognitive testing, in conjunction with the Mini-Mental State Examination (MMSE) (Bayles and Tomoeda, 2013). There are
two main classification for the diagnosis of dementia used in the UK: The Internal Classification of Diseases, 10th edition (ICD-10) (WHO, 2010) and the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (National Institute for Health and Care Excellent, 2017). Traditionally, within the medical paradigm treatment of dementia was limited to managing the associated symptoms, namely psychiatric and behavioural disorders, with the use of antipsychotic medication, anti-depressants or anxiolytic medication (Orgeta et al., 2011). A subtype diagnosis of dementia is important in the implantation of clinical interventions and treatment. Quinn (p.7) points out that ‘specific features of the history, examination, and investigations can assist in the differential diagnosis of dementia’ (Quinn, 2014). For example, dementias caused by some hormonal imbalances or vitamin deficiencies are reversible or antipsychotic medications can be used in some types of Lewy body dementia in controlling serious behavioural problems. Scotland’s National Dementia Strategy acknowledges that early diagnosis is the foundation to provide support and improve the quality of care for people living with dementia and their families (Scottish Government, 2017). Support could come from a variety of professionals including psychiatrists, geriatricians, psychologists, specialist nurses and the voluntary sector according to the complexity of dementia. Overall, it is useful to think about dementia from a medical perspective about treatment and post diagnosis support.

2.3.2 Dementia and normal ageing

It is common that older people often experience forgetfulness or other cognitive problems. These signs may mislead people in understanding the distinction between dementia and normal ageing. It is a controversial issue in identifying whether mild cognitive impairment (MCI) is the condition of pre-dementia or is the cognitive changes of normal ageing because ‘ageing itself has been viewed as a cause of inevitable decline and defect’ (Sabat, 2001, p.21). There is some support for the argument that dementia is the process of ‘normal’ ageing (Kaufman, 2006), due to some symptoms of bio-pathological and cognitive behavioural changes associated with normal ageing having some kind of similarity with dementia itself (Huppert et al., 1994, O'Reilly et al., 2013). Huppert and Brayne (1994) indicate that viewing dementia as an ageing problem can lead to two different interpretations: one is the confusion of the aetiology of dementia or solely cognitive changes in normal ageing; another one is the belief of dementia as the process of ageing and in that, dementia and normal ageing forms a continuum. They also believe that how the relationship between
dementia and ageing is interpreted has great influence on the implication of dementia prevention, treatment, care services delivery and social policy.

Despite cognitive impairments emerging in normal ageing, O’Reilly et al (2013) claim that the level of fundamental damage of cognitive components, pathology examination and the pattern of impairment are different from dementia. They suggest that distinguishing between the cognitive functioning changes occurring in dementia and normal aging not only has implications in early prevention and reduces incorrect treatment, but also avoids unnecessary distress by being labelled as ‘dementia’. In my opinion, viewing dementia as a normal process of ageing reinforces the idea that dementia is not something that we as a society can do anything to prevent, and this could prevent potential help for people with dementia and their caregivers. Neglecting the impact of dementia on individuals and families may lead to unpredictable health services and refusal to see dementia as a disease which would contribute to the suffering of people with dementia.

2.3.3 Dementia and delirium

Dementia and delirium are the two most common neuropsychiatric syndromes and normally affects older people with long-term health conditions (Meagher et al., 2010). Sometimes the symptoms of dementia are very similar to those of delirium as both of them can cause memory loss, impaired thinking and understanding, and behaviour changes (Meagher et al., 2010). According to the ICD-10 Classification of Mental and Behavioural Disorders of the diagnostic criteria, delirium is an acute organic brain syndrome with reversible disorder on attention and cognition, whilst dementia is a syndrome of brain diseases which cause cognitive impairment progressively and is irreversible over a long period of time. Delirium can be further characterised as rapid, unpredictable shifts from hypo-activity to hyper-activity or mixed (Vasilevskis et al., 2012). The diagnosis procedure of delirium is similar to dementia, but the treatment is distinct. Witlox et al identify that delirium will increase the risk of dementia when an acute change in mental status occurs (Witlox et al., 2010). Therefore, preventing and managing the problems of delirium can prevent the poor outcome of complications and prognosis, and can avoid additional cost and suffering for the patient and caregiver.

Fick et al state that delirium in a patient with pre-existing dementia is a common problem that may have serious complications and poor prognostic implications (Fick
et al., 2013). Furthermore, Witlox et al (2010) identify that the risk of mortality, institutionalization, and dementia amongst the older population are associated with the poor long-term outcomes of delirium. The prevalence of delirium with people with dementia who are over 65 years older can reach from 22% to 89% in both hospital settings and community setting. The authors found that delirium increases hospitalization, morbidity and mortality, which causes health care services a big burden in terms of expenditures. Witlox et al (2010) also noted that in many instances, behavioural disturbances of people with dementia may be due to underlying delirium, and medications may exacerbate or further mask the problem without distinguishing between them (Meagher et al., 2010). Delay in diagnosis may contribute to the poor outcomes associated with delirium superimposed on dementia. With our aging population, the problem of delirium superimposed on dementia is likely to increase in the future and underscores the need to better understand this important clinical issue for the older population. Fick et al (2013) suggest that distinguishing delirium from dementia has a significant medical implication.

2.3.4 Dementia and social disability

While the medical model of dementia puts the emphasis on the pathology of brain tissue, the social model of dementia is based on social model of disability. Unlike the medical model viewing dementia as a condition of illness which is beyond help and cure, the social model emphasizes understanding dementia within the society, and how the relationships between the person with dementia and others influence the disabilities of the person (Milligan and Thomas, 2016). The social model of disability believes a person with dementia would be defined as a ‘disabled person’, but the disabilities they experience are associated with the role of other people within the society. The social model has moved ‘dementia’ to ‘the person’, it leads people to focus on the personhood in delivering dementia care (Kitwood, 1993, Kitwood, 1997a, Kitwood, 1997b). Kitwood and Bredin argue that dementia is an ‘overwhelming tendency to make the brain, rather than the personhood of the dementia sufferer its central focus of attention’ (Kitwood and Bredin, 1992, p.270). It suggests that people with dementia should be treated and cared for in the social context, where they are embodied. This conception of dementia is more focused on explaining dementia as a ‘disability’ which reflects a set of interpersonal processing dynamics between people with dementia and others, rather than the medical model which focuses dementia as the consequence of neurodegenerative processes or loss of neurological functioning.
In addition, Gilliard et al (2005) state several beneficial points of the social model: a focus on remaining abilities instead of losses; listening to the personal experience of dementia; the influence of the social and built environment in enabling or disabling people with dementia; and a recognition of the way in which people with dementia are discriminated against and marginalized (Gilliard et al., 2005).

Thomas indicates two types of social disability according to her emphasis and aims (Thomas, 2004). The first domain of disability study considers that disability is the result of social oppression which is mainly based on Finkelstein’s working of ‘It is society that disables us and disabled people are an oppressed social group’ (Finkelstein, 2001, p.2). It draws attention away from the ‘impairment’ itself and aims to assist people with disability to fight for full equality and social inclusion. However, despite Finkelstein’s work having significant application in social treatment, it has ignored the impacts of the impairments on the individual. The second domain of disability study believes that disability is mainly caused by both impairment itself and social oppression, which principled from Shakespeare and Watson (Shakespeare and Watson, 2001). It believes that impairment and social context are equally restricting the activity of a disabled person where they shaped each other. And it views people with dementia within the society context and connected to the culture, language and social-economy which people are positioned in. It intends to inform policy makers and professionals in the disability services rather than directly to challenge oppression. The contribution of Shakespeare and Watson's social disability model has made a new empowered theory and belief for disabled people, in which their life can be changed.

Bartlett and O’Conner (2010) indicate that the social disability model has challenged the medical model of dementia which purely viewed people with dementia as passive care recipients of welfare, rather than treating them as individuals with this particular disability as an active social actor. From this point, Bartlett and O’Conner suggest a new form of thinking about people with dementia as an active citizen. Similarly, Shakespeare and Watson (2001) argue that the social model of disability has put the strategy of removing social barriers as a policy priority, rather than only viewing it as body deficits. Bartlett (2014) thinks that to ensure effective citizenship, people with dementia’s rights must be recognized and their voices must be involved into the communities and social world. She states that the studies which focus on the citizenship of people with dementia are under-represented in disability studies and
more research is needed in this area. An effective social citizenship allows people with dementia to grow as its own scope and to be free from stigma and discrimination (Bartlett, 2014). This requires a friendly social environment to empower them and to let them fully participate in the social life. For example, in the UK, a national innovation of Dementia Friendly Communities Programme has been developed by the Alzheimer’s Society as part of the Prime Minister’s Challenge on Dementia to ensure people with dementia feel understood, valued and are able to contribute to their community (Alzheimer's Society, 2013a).

Comparing with medical disability, social disability views disabled people as related to others in the social world rather than only viewing it as neurological changes. Thus, while the second domain of social disability seems more appropriate in delivering care services as it considers the experience of illness and recognises the significance of ‘personhood’, social disability also mandates a focus on understanding dementia care as a product of social disadvantage and social oppression, its implication on social and medical treatment seems more ‘fit’ with a holistic conception of dementia care. From here, I will turn to look at what is a person and the impact of a diagnosis of dementia on perceptions of being a person.

2.4 Personhood and person-centred care

As dementia destroys a person’s cognitive skills and functional skills in daily activity, how a person with dementia is viewed and treated has important implications in care services. There are many debates regarding the term ‘person’ and ‘personhood’ in people with dementia. Kitwood (1997b, p.8) defines that personhood ‘is a standing or status bestowed on one human being, by others, in the context of relationship and social being.’ He believed that person-centred care can maintain personhood through relationships with others and recognises the needs for comfort, occupation, attachment, identity and inclusion. Kitwood was the first person to bring the words ‘person-centred care’ into dementia care. He challenged the dominance of the traditional biomedical care model and highlighted the importance of the person with dementia rather than the disease itself. The person-centred care model has a positive influence on the dementia experience through maintaining personhood and focus in understanding dementia by encouraging a thorough understanding of the individual’s subjective experiences, interactional environment and social cultural context which the individual is involved with (O’Connor et al., 2007). Brooker summaries Kitwood’s work and expresses person-centred care as VIPS (valuing individual, recognizing
uniqueness, understanding the perspective and supporting needs). He emphasises the value of the individual and providing individualised care by putting these values into practice (Brooker, 2007). Person-centred care has focused dementia care on a person’s psychological response and social life, rather than limiting the care services to a person’s neuropathological changes, in which understanding the subjective experience of dementia is the cornerstone for providing a better care for people with dementia (Downs, 2010).

Sabat (2001), also in response to the understanding of the predicaments of selfhood with people with Alzheimer’s disease, identifies three types of selves. Self-1 is a personal identity which is expressed in the first-person pronouns ‘I’, ‘me’ and ‘mine’. It is manifested through each person as a unique being in the world, it is found that Self-1 is intact in people with dementia, even in their advanced stages. Self-2 is related to the attributes of an individual’s physical and psychological characteristics, for example, a boy with black eyes is his physical attribute and his feeling sad by being rejected from his friends is his psychological attribute. Such attributes are connected to a person’s past and present experiences and their beliefs of the attributes, but these attributes could change over a person’s lifetime. Therefore, a person can still be part of Self-2 even when his or her cognitive functions has declined. Self-3 is constructed by others and society, in which Sabat (2001) believes that Self-3 is far more vulnerable than Self-1 and Self-2 because it can be weakened, strengthened or undermined by others. Therefore, maintaining Self-3 requires others’ cooperation. Thus, Self-3 is very important for people with dementia as it is associated with how others treat and recognise them, and it is shaped by inter-personal relationships with others and social contexts as a whole (Sabat, 2001).

Kitwood highlighted ‘personhood’ as the biggest priority in the concept of person-centred care which has changed the paradigm of stigmatisation and marginalisation of dementia. However, Kitwood’s (1997b) person-centred care version has been criticized for failing to capture the interdependency and reciprocity which underlies caring relationships (Nolan et al., 2002). To argue the deficits of Kitwood’s ‘person-centred care’, McCormack et al believe that person-centred care in nursing practice has excessively tended to emphasize on individuality and autonomy and it becomes confused with consumerism whereas over emphasising personal choice and independence would be ignoring interdependence and interactions with others (McCormack et al., 2012). From the care provider’s point of view, Davis states that
the emphasis on enduring personhood in people with dementia has negative impacts for those who are caring for them (Davis, 2004). He suggests that caregivers or families may feel guilty if they feel that the relationship with the person no longer exists and they may think that they have responsibility for the dissolution of the person’s personhood. Davis also points out that the family carers should be allowed to recognise the loss of personhood during the deteriorating process of dementia and that they should be given the legitimacy to recognise and to mourn the loss of the person who no longer is the person they once were. He suggests that ‘what is most important is that the devastation in relationships that crumble during the dementia process is better understood’ (Davis, 2004, p.377).

To debate with ‘what a person is’ in dementia care, Hughes (p. 277) declares that ‘the person is situated in a rich texture of contexts of culture, time and place, in a narrative history which has a past and future and which interconnects with the narrative of others’ (Hughes, 2011). Hughes’ idea opens up the notions of what is a person and provides a paradigm to understand personal subjective experiences by understanding the embodiment of relationship with others. Just as Nolan et al note that ‘meaningful triadic relationships are based on mutual appreciation of each other’s knowledge, recognition of its equal worth, and its sharing in a symbolic way to enhance and facilitate joint understanding’ (Nolan et al., 2002, p.204). It means that mutual relationships and social interactions between people with dementia and others will be ignored if the care services only underpin ‘the person first’. In addition, others researchers argue that Kitwood’s understanding of the negative psychological impacts on a person with dementia was based on their subjective experience; this ignored the effects of the wider social context upon people’s experience of dementia (Bartlett and O’Connor, 2010, Bartlett and O’Connor, 2007) and also oversimplifies the social interactions in the context of dementia care services (Adams and Gardiner, 2005).

Based on Kitwood’s person-centred care, McCormack and McCance have developed a framework for person-centred nursing (McCormack and McCance, 2006). However, in practice, the authors think that the person-centred care would be difficult to progress if it only considers ‘the person’ from a single position in the care services, without pay attention to evidence of best practices grounded in the concept of personhood (McCormack et al., 2012). Therefore, McCormack and McCance suggest that the model of person-centred care should put the individual in
society/community, where personhood can be embodied through social interdependency and interconnected relationships (MacDonald, 2002). In a recent book: ‘Person-Centred Practice in Nursing and Health Care: Theory and Practice’, McCormack and McCance (2017) took into account person-centred nursing framework in health and social care settings, in which they suggested that the model of person-centred care should be situated in contextual factors such as organizational culture or care environment to support person-centeredness in everyday practice. Furthermore, Clark (2002) similarly contends that meaningful care and services to older people should ‘situate’ an older person's individual needs within a rich matrix of relationships and socio-cultural beliefs. In order to create a better care model, Nolan et al proposed a Senses Framework underpinning the model of relationship-centred care to capture the important dimensions of interdependent relationships in the care setting (Nolan et al., 2006). The Senses Framework (see box 1) suggests the following to create a sensible care environment for all with six evidence-based senses:

**Box 1 the Senses Framework**

| A. | Security – to feel safe. |
| B. | Belonging – to feel part of things. |
| C. | Continuity – to experience links and connections. |
| D. | Purpose – to have a goal(s) to aspire to. |
| E. | Achievement – to make progress towards these goals. |
| F. | Significance – to feel that you matter as a person. |

(Nolan et al., 2006)

The concept of personhood has considered a person's best interests in the first place. However, if the principle of providing care services is only considered from the dimension of the person's best interest, it may ignore other people's best interests, therefore, the practicality of personhood should be taken into account in multiple dimensions of all people who associate with care services. A good care service or model needs to consider all related persons and emphasising on a specific model of dementia care (without an adequate understanding of how it is shaped by wider social, cultural and political factors) must be avoided.

**2.5 Confucian concept of selfhood and identity**

Ikels based on the Confucian concept of self, argues that the meaning of ‘self’ has influenced dementia care in a Chinese society (Ikels, 2002). The author viewed self
in two dimensions, one is as ‘a unique being or individual’ and ‘a true nature of the self’ which separates people from each other (p.245). Another self is the extension of the self which ‘recognizes that all human beings are consist of the same essence’ (p. 245) and all human being are each other. According to Confucian concepts, self is relational-based, in which each individual has a specific role in relating to others (Ho, 1995). Therefore, in Eastern culture, an individual self and identity is conditioned to social relationships, social requirements and obligations (Ho, 1995). This self is defined as being embedded in relationships with others, which is referred to as ‘relational self’ by Ho and ‘extension self’ by Ikels (2002). In which, one’s roles and identity has been affected by specific relationships with others (Herr, 2003). According to Confucianism, family relationship is hierarchically organized by father–son, husband–wife and elder brother–younger brother, in which the more responsible family members are morally superior to the others while the less responsible members need to respect and obey the high ones (Zhang and Zhang, 2007). Here is also where filial piety enters the picture. Therefore, maintaining harmonious social relationships is one important component of maintaining self’s roles and identity.

In Western philosophical thought, cognitive impacts are given priority in dementia care. However, Chinese families and the person with dementia do not seem particularly upset by the possibility of dementia and they do not take the cognitive impacts on the concept of the self as a priority. In Chinese thinking, even a person with dementia’s communication skills and cognitive capacity have changed, but the person is still possess relations and connections with families, friends and others (TSAI, 2009). ‘Thus correct performance of social roles serves both as the means of developing the self and as a demonstration that the self is still there’ (Ikels, 2002, p.249). Therefore, from Confucian’s value to consider, even though a person has had dementia, the ‘extension self’ is still exist. For these above reasons, Ikels (2002) states that ‘the earliest stages of dementia, cognitive decline, are less salient and less significant for contemporary older Chinese and their family members than the later stages of personality change that disrupt the correct performance of social roles’ (Ikels, 2002, p.249). Zhang and Zhang (2007) argued that one of the core principles of family relationship in Confucius’ thinking is that family members must love each other and live in harmony. This thought by Confucius is one of the core components of filial piety, emphasizing to ‘never do to others what you would not like them to do to you’. Confucius’ thinking believes that harmonious ideas such as an individual's physical and mental harmony, family harmony and social harmony have the potential to solve
the contradictions between the individual body and mind, family, society, and country as well as between man and nature (Wang and Ma, 2008). Therefore, Ikels (2002) believes that continuing to pay respect and love to parents who have dementia is reflecting one’s moral character of the Confucianism, and viewing them from the dimension of ‘relational-self’ is a better way of putting dementia care into practice.

2.6 Caregiving and care-receiving

Dementia has great impact on the daily life of the person who is living with dementia due to its nature of progression. Dementia caregiving has been long viewed as a task which puts a negative personal, social and health influence on care-givers, this maybe be especially true for people who look after their family members at home with less health professional and social support. Schulz et al (1995) and Schoenmakers et al (2010) indicated that the caregiver’s psychological and physical morbidity is associated with people with dementia’s behavioural problems, especially psychiatric health effects. Schulz and colleagues also state that the degree of effects are related to personal income, self-rated perceived stress, life satisfaction and self-esteem while Schoenmakers et al indicate that caregiver’s characteristics are responsible for the onset of depression (Schulz et al., 1995, Schoenmakers et al., 2010). Consistent with these studies, Ory et al (1999) state that psychological and physical health outcomes between dementia and non-dementia caregivers are distinct, because caregiving to people with dementia is more time consuming, more demanding and needs more responsibility.

However, recent literature is starting to emphasise the positive effects of caregiving in developing a positive aspect of the caregiving framework to support caregivers, in which Carbonneau et al believe that ‘these aspects may contribute to maintain caregivers’ involvement by buffering the impact of caregiving stress and burden on the caregiver’s mental and physical health’ (Carbonneau et al., 2010, p.328). The authors state that understanding these positive effects is essential for developing positive aspects of caregiving framework to prevent caregiver burden and to reduce negative factors in caring procedure. Furthermore, Schulz et al suggest that understanding caregiving can provide a guideline in designing caregiving associated interventions and appropriate help for caregivers (Schulz et al., 2004). Another study indicates that understanding the meaning of caregiving is the way to understanding the living experience of caregivers and care receivers (Ward-Griffin et al., 2007). Tronto notes that ‘care about requires listening to articulated needs, recognizing
unspoken needs, distinguishing among and deciding which need to care about’ (Tronto, 2001, p.62). This indicates that care intervention needs attentiveness, understanding, competency and knowledge of the context of care process. Understanding the dynamics of caregiving and care receiving is very important because it can assess whether the care process of ‘caregiving’ and ‘care receiving’ is accurate. If the care context is misunderstood, incompetent care can occur. Therefore, it is very important for us to access the meaning of the lived experience of people with dementia as it helps to understand the relationships between caregiving and care receiving. In the following section, I will explore the concept of caregiving and care receiving by understand how people perceive the meaning of caregiving and care receiving from the existing literature.

2.6.1 Defining care and caring process

Drawn from Aristotelian ideas, Tronto (p.104) said: ‘in order to delineate the realm of care, it might be useful to resort to an Aristotelian idea of nested ends: though care can produce pleasure and creative activities can be undertaken with an end toward caring, we can recognize care when a practice is aimed at maintaining, continuing, or repairing the word’ (Tronto, 1993). Arguing with this, Tronto states that the pursuit of pleasure, creative activity, production and destruction only happened with no-life subjects and should not normally be considered in the process or activity of care in human life. Central to human life, care is a practice of combining thought and action together, in which ‘good care’ is component attentiveness, responsibility, competence and responsiveness (Tronto, 1993, p.127). In order to give an explicated explanation of ‘what is care’ and ‘why we care about caring’, Tronto (1993) analysed four phrases of care: ‘caring about’, ‘taking care of’, ‘care-giving’ and ‘care-receiving’ to picture the meaning of caring in human life. In the process of caring, she believes that the relationship of these four components is mutual and interdependently. According to Tronto, ‘caring about’ refers to awareness of the needs of care for individuals and making an assessment to ensure to meet the needs. Tronto suggests that recognition of the need should be based on the cultural, individual, social and political spheres. ‘Taking care of’ is about identifying need and the decision-making of how to respond to it. It is more focused on the responsibility of meeting the needs, rather than simply focused on the needs. ‘Care-giving’ is actually the actions of meeting the needs for care. Whilst ‘care-receiving’ is the responding of care received and checking whether the care-giving meet the needs. These four phases show an ideal integrated
framework of caring process and explained how care is applied in practice. Due to the current study focused on exploring the lived experience of family responsibility of people with dementia and family caregivers, analysing the empirical framework helps to understand the relationships between caregivers and care recipients.

In Confucianism’s notion, the most significant moral component of care ethics is to maintain caring relationships as it not only sharpens the person’s identity, but also more importantly, it is about the moral goals (Herr, 2003). As the process of caring is more about the intimate family relations (the parent-child relation, sibling’s relation and intergenerational relation) in Chinese family of Confucian philosophy, to reach the moral goals requires the one caring to be attentive and responsive to the one cared for and to consider things from the priority of the one cared for. Even though it somehow may leave negative impacts to the one caring. On this point, care-receiver needs are superior to care-givers needs. So the meaning of care in Confucianism’s concept is slightly different from the Western world’s concept as Confucianism family relationship is contented in hierarchical relations. However, the process of caring in human life requires social, psychological and emotional support, wherever in the world care has taken place.

In reality, caregivers and care-receivers may have different ideas about caregiving in the process of caring. So there is always conflict among these four phases and conflicts between caregivers’ needs and care-receivers’ needs. Therefore, in practice, we need to balance and prioritize each of these phases and identify the real needs of the care-receivers while balancing the caregivers’ needs. In addition, the meaning of ‘good care’ may vary from individuals as the meaning of ‘good care’ is shaped by moral and political concepts (Tronto, 1993). On this point, cultural and social context should be considered when delivering care services. When proposing to apply Tronto’s framework into the dementia care design, we must not only consider caregivers and care-receivers in the practice, but it also important to consider the social and cultural concept of ‘what is care’ and ‘caring’.

2.6.2 Understanding caregiving

Defining caregiving is a complex task. Pearlin et al (p.583) argues: ‘that caregiving and caring acts are intrinsic to any close relationship and can refer to actions which may be found in a variety of relationships or roles such as parent-child or husband-wife’ (Pearlin et al., 1990). From this acknowledgement, it seems that the authors
understood caregiving as an action between caregiver and care-receiver, in which the intimate relationship is the main support element of caregiving. According to Tronto (1993), the process of caregiving is a fundamental human act of an intersubjective process in which the care-receiver’s needs can be identified through observation and communication with the caregiver. Different from Toronto’s (1993) simplified norm of ‘caregiving – the direct meeting of needs of care’. In Shultz’s perception, caregiving not only requires personal input with time, energy and money, it also has a physical and psychological impact on the person who takes the caring role (Schulz and Martire, 2004). The dominant conceptual model for caregiving assumes that the onset and progression of chronic illness and functional decline is stressful for both care-receiver and caregiver and, as such, can be studied within the framework or conceptual model of stress.

A report in ‘Dementia: a Public Health Priority’ by WHO identifies three levels of impacts of caregiving for people with dementia (WHO, 2012). It includes psychological impact which is mainly presented in the caregivers’ depression and anxiety; physical health effects of poor health; well-being and quality of life; economic impacts of living; healthcare and related costs which are caused by the full and long occupation of caring activities which force caregivers to suspend or stop working (WHO, 2012). National Institute for Health and Care Excellence (NICE) Guidelines state that support should be available to people who suffers psychological distress or negative impacts due to caring for people with dementia (NICE, 2007). Hence, it is important to consider the impact of the condition not only on the people affected but also on their families, especially the people who are providing direct care.

Theoretically, the literature is more likely to present caregiving of people with dementia in a negative way, despite many studies identifying aspects of caregiving can be positive, especially in terms of mutual relationship and reciprocity between caregiver and care receiver (Sung, 1995, Yeh, 2003, Wiles, 2011). Considering the sense of reciprocity between care-receivers and caregivers, we may need to further consider the capacity both of giving and receiving. Identifying the positive dimension of caregiving can enhance caregivers’ reasonability as well as quality, which skews the perceptions of the living experience on both caregivers and care-receivers and contributes to innovative support programs on the positive effects (Carbonneau et al., 2010, Li and Loke, 2013).
2.6.3 Understanding care-receiving

Tronto and Fisher define care-receiving as ‘the response to caregiving by those toward whom care is directed’ (Fisher and Tronto, 1990, p.43). Here, it seems that the authors have considered the relationship and interaction in the definition of care-receiving. The authors also indicate that the care-receivers have more intimate knowledge about what they need. Despite being aware of this knowledge, in practice, the authors admit that care-receivers may have little control in terms of their needs to be defined in the caring process. Based on this theory, Tronto (1993) further emphasises the important of understanding care-receiving in the process of caring because it is the only way to know whether the needs have been met. However, in reality, this need has often been limited by resources available to them. Tronto indicates that the ideal process of caring is unrealistic but can be negotiated by understanding the picture of ‘what good caring’ will be. For example, removing the social construction that those who need care are viewed as helpless. She also illustrated two characteristics of care-receiving: needs always conflict due to the different stakeholders; and needs are defined and limited by the unbalanced power relationship between caregivers and care-receivers. Therefore, in practice, understanding the perception of needs and analysing care-receiving can help us to better understand the personal subjective experience and provide a useful guide for thinking about how we give good care to people who are in need.

It is estimated that two thirds of people with dementia live in the community and are cared for by their families or friends (Brodaty and Donkin, 2009) and, for many of these individuals, formal and informal support is essential to aid independent living. The authors state that the majority of older people with chronic health conditions, including neurodegenerative disorders have been cared for by their family members in the first place, and among chronic disease conditions, dementia has a valid effect on disability and needs for care. Therefore, understanding the subjective experience of living with dementia is significant in dementia care and intervention. Whilst some arguments about receiving help and assistance from others may deprive a person with dementia’s independence and autonomy (Fine and Glendinning, 2005), there are also meaningful findings associated with reciprocity (Peacock et al., 2010, Borley et al., 2016). In other words, holding too positive or too negative attitude towards the lived experience of people with dementia, would risk devaluing their lived experience (Steeman et al., 2007). Relating to the issue of care-receiving, I will review
the impact of dementia on people with dementia and the meaning of living with dementia in the following sections.

2.7 The lived experience of people with dementia and family caregivers

The main purpose of the current study is to hear what people have to say about their experiences of living with and caring for dementia, therefore, accessing the subjective accounts of life experience in the previous research is a central part of the study. There has been increasing interest since the 1980s in the involvement of people with dementia in research and valuing the opinion of people with dementia in many Western countries (Goldsmith, 1996, Kitwood, 1997a, Wilkinson, 2002a, McKeown et al., 2010, Allen et al., 2017). Brooker indicates that ‘the starting point for helping someone is trying to understand the world as they see it’ (Brooker, 2007, p.64). Following this, Braun et al suggest that the viewpoint of both people with dementia and their caregivers must be considered in order to better understand the stress of caregiving and to provide the support that they need (Braun et al., 2009). In fact, only by understanding the perspectives and subjective experiences of people with dementia and their caregivers, can quality care services be established. Related to this, I now consider the topic of accessing the subjective accounts of people with dementia and family caregivers in a general sense as relevant to the current study. The following sections will review the lived experience of people with dementia and family caregivers from the existing literature.

2.7.1 The impact of dementia on people with dementia

In comparison with the studies of the perspectives of dementia caregivers, there are far fewer studies on the perspectives of people with dementia. However, the voice of people with dementia in studies has been growing since the 1980s and focusing on the caring relationship will not only lead to a better comprehension of caregiver stress, but also helps to develop effective therapeutic interventions to enhance caregivers and care recipients’ well-being (Braun et al., 2009).

While physical and psychological effects on caregivers are the most commonly mentioned caregiving experiences, ‘loss’ of control is a dominant issue for people with dementia (Aggarwal et al., 2003, Phinney and Chesla, 2003, Roach and Drummond, 2014, Read et al., 2016, Page and Keady, 2010). One systematic literature review study reviewed 50 existing articles (De Boer et al., 2007), and found that more than
half of these articles identified loss in the dementia experiences. According to these studies, the feeling of loss refers to many aspects, such as loss of self-esteem, self-value and self-identity, loss of function skills in daily life, loss of independence in daily activities, loss of capacity in decision making and loss of the sense of being in the world etc. For example, a person can lose the ability to drive because the person cannot remember how to drive, often this is linked to deterioration in functional skills due to memory loss. Mok et al (2007) indicate that some protective behaviours of people with dementia may come from intimacy loss in the changes of relationships with others. An interpretive phenomenological analysis revealed three themes of experiences of dementia symptoms: being lost, being slow and being blank (Phinney and Chesla, 2003). The authors claim that being slow is a person’s reaction to their daily activities slowing down or being stopped. In being lost, the world is no longer the same world as it was, people who are experiencing dementia feel that it is difficult to cope with the illness. People often lose the sense of mission of why they do or do not involve with something. Being blank relates to the person with dementia withdrawing from the world due to their ability to understand and involve into the world.

Furthermore, Aggarwal et al (2003) point out that such negative feelings may cause low self-esteem and low self-value. They also suggest that caregivers or family members should try to understand what people with dementia are experiencing in order to understand their behaviours.

Struggling to cope with the changed life is another significant topic among people with dementia (Górska et al., 2017). Mazaheri et al (2013) identify several causes of struggling, for example, the loss of the ability to count makes people with dementia struggle when handling money. They also claim that the illness causes changes in the body and lost connections with the social world which make people with dementia feel that it is difficult to remain in their former life routine and to be involved in social activities (Mazaheri et al., 2013). The perception of social connection is also related to sociocultural and political influences, in which the social and cultural environments lead to people becoming estranged or being unable to provide support to each other (Burns et al., 2011, Shang and Wu, 2011, Davis et al., 2009). Care-recipients are sometimes worried that they become the burden of the caregivers, losing the role in the family or losing their personality (Read et al., 2016). Some emotional reactions such as fear, anger and frustration are also reported in people with dementia which are associated with loss, coping or uncertainty about the future, in which people with
dementia are unable to articulate what they need for their care in the future (Read et al., 2016).

Steeman et al (2007) suggest that caregivers or family may change their approach by considering that some behaviours of people with dementia were possible coping strategies rather than the result of their behavioural deficits. This might help carers to better manage the behavioural problems of people with dementia. The authors also claim that interventions based on the perspectives of the person with dementia might relieve part of their suffering (Steeman et al., 2007). From my working experience with people with dementia, I completely agree with Steeman’s idea, some things can appear to be different if we look at it from different angles and think about it in a different context. For example, a person with dementia walks into other person’s room may is the purpose of looking for a toileting rather than invasion other’s privacy. Just as, Phinney and Chesla (2003, p.284) claim that ‘a symptom is not an inner experience unavailable to the outside observer until it is revealed through language, but rather it is a lived experience whose meaning is both in the language used to articulate the breakdown and in the breakdown of embodied habits and practices’. Brooker (2007) states that understanding what people with dementia are experiencing has psychological validity and therapeutic potential. Therefore, understanding what people with dementia are experiencing has significant implications in planning care services and delivering care services to them.

2.7.2 The impacts of caregiving on family caregivers

Many studies have reported that caring for people with dementia has the potential to cause many negative experiences, such as frustration, anger, disappointment, guilt etc (de Witt and Ploeg, 2016, Williams, 2010, De Witt et al., 2009, Massimo et al., 2013). Caregiving is associated with many unique demands and multiple challenges. Acknowledgement of how these may impact on the well-being of caregivers has been recognised for several decades, with Adelman et al (2014, p.1054) using the phrase ‘invisible patients’ to refer to the caregivers of older people with chronic diseases. When discussing the impact of caregiving, researchers have made reference to ‘burden’, ‘strain’ and ‘stress’, with the terms typically encompassing physical, psychological, social and financial effects or status (Mahoney et al., 2005, Adelman et al., 2014, Zarit et al., 1986). In the literature, these terms have been used interchangeably thus creating difficulties when trying to establish a shared understanding of the specific effects of caregiving. In recent decades, research has
attempted to explore more specific effects linked to informal caregiving with an increase in psychological distress or negative impact on psychological well-being, as informal caregivers are less likely get support. Despite the difficulty during caregiving, there were still many family caregivers who found positive aspects through caring for their family member who have dementia (Duggleby et al., 2009, Che et al., 2006, Andrén and Elmståhl, 2005). Such as in Butcher et al's (2001) secondary data analysis study with 103 family caregivers, they not only found the negative impacts of caregiving for family caregivers, they also identified the meanings and joy created through caring. This review will first look at the negative impact of caregiving in four aspects: physical burden, psychological burden, social burden and financial burden.

Stress and depression are the most emotional effects during caregiving which have identified by many researchers (Adelman et al., 2014, Feast et al., 2017, Burns and Rabins, 2000). Dealing with the care-recipient’s behaviour can lead to depression and frustration in the caregivers. For example, in Quinn's study, one caregiver admitted that she just could not help losing her temper when she was carrying out the daily caring duties (Quinn et al., 2008). Lots of family caregivers claimed that they were stressed and frustrated when dealing with the patient's behaviour problems and coping with the changed relationships. Apart from this, family caregivers often claimed that they had ‘lost’ their loved one or disliked the distance appearing in the formerly close relationship (Butcher et al., 2001, Gillies, 2012, Shim et al., 2012, Quinn et al., 2015). Personal grief and loss is one of the most frequently cited difficulties expressed by spouse caregivers (O'Shaughnessy et al., 2010, Ford et al., 2013). The unknown and ongoing nature of the disease with uncertainty about the future also causes worries for both caregivers and care-recipients. Caregivers were worried that they might not be able to manage caregiving in the future or be depressed that they cannot stop the development of the disease (Quinn et al., 2008). Alarmingly, one study even found that some caregivers even feared that they may develop the disease by witnessing the decline of a loved one (Navab et al., 2012). Caregivers can feel helplessness and sadness which is caused by an inability to provide the care that meets the needs of their loved ones or an inability do anything to change the ‘bad’ situation (Willoughby and Keating, 1991).

As well as impacting on psychological well-being, it reported that caregiving has been linked to poor physical health with increased risk of cardiac heart disease,
hypertension and other health conditions (Hiel et al., 2015, Haley et al., 2010). Two major literature reviews have been carried out examining the health consequences of caregiving. Schulz et al (1995) reviewed over 40 studies that explored caregiver health status and found caregivers reported higher numbers of chronic illnesses, more ill-health symptoms and taking more prescription medications than non-carer populations. Apart from the nature of physical tiredness because of the heavy duties of caring for people with dementia, another comparative review paper by Shim et al (2012), found caregivers of people with dementia are more likely to suffer more health problems than those caring for frail elders without dementia, especially spouse caregivers who have more physical negative experiences with dementia care than other informal caregivers. This is because most of the spousal caregivers are in older age themselves and they often have a variety of chronic diseases as well (Brodaty and Donkin, 2009).

The theme of isolation and social disconnection were found in some studies (Moyle et al., 2011, Nay et al., 2015, Keady et al., 2012, Daly et al., 2013). One study reported that both caregivers and care-recipients had feelings of being trapped and loss of contact with friends or neighbour due to the heavy duties of caring or because of the immobility of the illness (De Witt et al., 2009). Stigma or social embarrassment were also found in the studies (Nay et al., 2015). It reported that social embarrassment was caused by the cognitive decline or behaviour problems of the person with dementia which could stop caregivers or care-recipients participate in social activities and social events (Innes et al., 2016). Many caregivers and care-recipients complain of a lack of social support and little information or resources available from healthcare professionals. For example, the study reported that some physicians lack awareness of the first signs of dementia and so make a late initial diagnosis, which as a result could cause delayed support from other family members or formal healthcare providers (Hughes, 2011). Consistent with this, Quinn et al (2008) report that caregivers who tended to downplay their caring responsibility due to the reason of lacking the information from the physician.

The financial burden for people with dementia and their caregivers was found more often appearing in the studies from low income countries. For example, a study of Chinese people with dementia in Hong Kong reported that the financial burden could cause vulnerability for both caregivers and care-recipients (Mok et al., 2007). Mazaheri et al also state that some participants (people with dementia) felt hopeless
for the future because of lack of insurance and health support services for older people in Iran (Mazaheri et al., 2013). This finding is consistent with Prince’s findings, who found much greater economic stress for family caregivers and people with dementia in low income countries compared to the more developed countries (Prince et al, 2004). The report ‘Dementia: a public priority’ states that family caregivers account with financial burden more likely because they had to stop working for a period of time or to quit their job in order to provide care for their family with dementia’ (WHO, 2012).

As much of the literature tends to focus on the ‘negative’ consequences of caregiving. More recent studies of family caregivers indicate that caregiving can be experienced as positive (Carbonneau et al., 2010, Peacock et al., 2010, Borley et al., 2016). Kramer (1997, p.218) indicates that ‘a lack of attention to the positive dimension of caregiving seriously skews perceptions of the caregiving experience and limits our ability to enhance theory of caregiver adaptation’. Therefore, it is important to document that family caregivers involved in providing informal care take pride in their role, and perceive many positives.

Netto et al (2009) studied the gains of caring for a person with dementia, which were: personal growth, gains in relationships and higher-level gains. For example, some caregivers claim that through the hardships of the caring procedure, they become stronger and this experience makes them cherish more what they have in the moment Netto et al (2009). Che et al (2006) identified that the difficulty and hardships of caring for people with dementia could inspire caregivers’ self-awareness, and this self-awareness gives caregivers ‘self-empowerment’ to cope with the daily caregiving. Finding the meaning of caring and keeping hope have been also indicated as the useful strategies for coping with caregiving in everyday life for caregivers. Wolverson et al (2010) reported that participants treat hope as the possibility of a positive future to help them through the difficult times, which is consistent with Duggleby’s study (Duggleby et al., 2009). Simpson claimed that caregiving was a dynamic process to reconcile caregivers themselves, this process helps caregivers to adjust themselves to the role of caregiving (Simpson, 2010).

Researchers have found some positive points in the rebuilt relationship between caregivers and care-recipients (Butcher et al., 2001, Netto et al., 2009). For example, in Butcher’s study, one of the participants said: ‘Now we are in that stage between, where we are able to enjoy each other to a large extent’ (Butcher et al., 2001, p.49).
Many caregivers claimed that caregiving brings family members closer through constant contact (Netto et al, 2009, De Witt et al, 2009). This maybe because daily caring duties creates more time for caregivers and care-recipients to be together, to share companions of each other. Feeling appreciated by the care-recipient is another source to help the caregivers to cope with caregiving and bring the relationship closer together (Gillies, 2001). Shim et al (2011) suggested that the dynamic was a source to create positive experiences for caregivers. This is consistent with some studies of Canadian-Chinese family caregivers which identify filial piety as a protective and motivating factor in reducing stress and caregiving burden for family caregivers by appraising their caring role (Lai, 2010).

Through caring for people with dementia, some caregivers claimed that they not only gained the knowledge of the illness itself, they also gained the skills to deal with the disease due to undertaking the caring tasks and responsibilities. Netto et al reported that the skills of how to make the best decision for their loved ones and the skills of problem-solving were common topics discussed by caregivers (Netto et al., 2009). Moreover, the caring experiences for family caregivers also improved their personal skills such as: the skills of how to communicate with people with communication difficulty and the skills of managing the chaos in daily life, were also present in the literature (Peacock et al., 2010). This positive outcome of personal grown, can be a meaningful strategy in challenging long-term caregiving process (Davis and Morgan, 2008).

2.7.3 Impact discrepancy in different cultural settings

The review found that the life experiences of people with dementia and their family caregivers in the Western countries have been intensively studied, but rarely studied in the Asian countries. Traditional cultures may have cultivated the caregiving experience differently from one population to another. Therefore, the feelings, opinions and expectations of caregivers may differ as the research population come from different social, cultural and economic contexts. For example, Navab et al (2012), a qualitative study with 8 family caregivers, indicated that Iranian caregivers may blame themselves and feel guilt or negligence when their family members get ill because family values and social expectations expect them to look after their older parents well. Iranians also think their loved ones getting ill is a punishment for their sins in the past (Navab et al., 2012). In a Hispanic caregivers’ study, the author indicated that familism and loyalty to family are strong factors in influencing caring
roles (Simpson, 2010). In China, strong traditions of filial piety demand that the Chinese respect their elders and take responsibility to care for them when they get old; and this may put great physical, emotional and financial stress on family caregivers. As a result, these pressures may modify the caregiving experience differently from other ethnic groups. Therefore, culture values such as those above may create different impacts on the lived experience of people with dementia and also put pressure and stress on caregivers in certain areas.

Gender is another impact factor which should be considered in the study of lived experience of dementia caregiving. Gender impact may be associated to culture and social factors. For example, the values of ‘marianismo’ were discussed in the Hispanics’ caregivers’ study by Borrayo and colleagues, where women were normally expected to be family caregivers because in their cultural value women should be self-sacrificing and take the responsibility of caring for their unwell family members (Borrayo et al., 2007). In China, traditional cultural values often expect daughters-in-law to look after their older parents-in-law. For example, study identified that social and cultural expectations expose Chinese caregivers to extra stress (Sayegh and Knight, 2011). They also indicate that cultural values have a strong link in differences between the experiences of care-giving which can be in either a positive or negative way. For example, the cultural themes of stigma may make family members refuse to admit their loved one has dementia and draw themselves away from seeking support from outside. Oppositely, filial piety and family obligation would put emphasis on the person in caring for their loved one (Lai, 2010). Therefore, stigma, shame and filial piety of cultural values must be considered when studying populations from diverse backgrounds. It is also important to encourage families to value such culture and to support female caregivers by using appropriate intervention programmes. Alongside this, it is important to provide some educational programs to equip caregivers with knowledge of the disease, the impact of stress on their own health and the strategies to cope with caregiving.

Many researchers found peer group support and understanding were very important to getting through hardships of the caring process for caregivers (O’Shaughnessy et al., 2010, Williams, 2010). Williams also claimed that appropriate health interventions or supporting activities may promote or enhance relationships between caregivers, care-recipients, the rest of the family members and other social relationships as well (Williams, 2010). However, this review found that not only were many participants
receiving inadequate assistance and emotional support from outside (the other family members and/or professional healthcare), but they also lacked the knowledge of the illness and the skills to manage the disease, especially in developing countries. Mazaheri et al indicated that the caregivers who lack the understanding and skills are more likely to have tense care relationships (Mazaheri et al., 2013). It is also one of the reasons which causes late diagnoses (Hughes et al., 2009). In one study, most of the people with dementia were not aware of their diagnosis and explained their experiences as part of getting older or the forgetfulness of ageing (Hughes et al., 2009). Evidence was found that social support services are not only a relief for caregivers, but also bring the sense of belonging to them (Winslow, 2003). Therefore, it is very important that dementia support groups or training programmes are available in local communities to aid this population.

The allocation of health resources and health services also play significant parts in the impact of experiences in dementia care. Some caregivers may be concerned by the cost of diagnosis, intervention or treatment of health services. Consequently, this financial burden may become a barrier to the early diagnosis for patients and extend emotional stress to caregivers. Unlike the free healthcare system in the UK, China has a financially unsustainable healthcare system. Some people without pension or financial support from family would find it difficult to access the health services, and as a result they would be suffering more from the illness. Consequently, their dementia experience would be different from people who can access the health services or social support. Therefore, dementia caring associated health resources should be allocated to this population and local health services should be available to them. Health policy developments are required to make sure this has been executed. In addition, as the difference of caregivers on their perceptions of the quality of the past and present relationship, their ability to find the meaning of caregiving, their situation of social status, economic condition and educational level etc would be impacted by these factors.

2.8 Hearing the voices of people with dementia and family caregivers

Kitwood (1997b) indicated that validating the subjective experiences of people with dementia would make the person ‘more alive, more connected and more real’ (p.91). Undoubtedly, their subjective experiences may have associated to their past exclusion from the processes of engagement. According to Epp, validating the
personal experience can be facilitated through response to people with dementia empathetically and understanding their feelings and emotions (Epp, 2003). Regarding how to access the subjective of people with dementia, Kitwood (1997b) suggests several ways to gain access to the personal world of the uniqueness of each person: access to the account of writing by the person with dementia; listen to what they’ve said about some specific issues or topics; listen and imagine what they would say in everyday life; learn the meanings of their behaviours and actions through observing them or by using ‘poetic imagination’ or ‘role play’. For example, using ‘role play’ can possibly gain the own stock of ‘dementia-experience’, in which the role player has some similar experience of living with dementia. A possible example of ‘poetic imagination’ can be linked with Genova’s book of ‘Still Alice’, the author had a cognitive psychological linguistic professional background, who used imagination write a novel about Alice’s lived experience with early onset Alzheimer’s disease (Genova, 2014). The novel reflects how Alice battles with a shifting sense of losing, leaving, forgetting and finding the meaning of life through displaying her life beyond her career, family daily life and her relationships. This novel has combined the author’s professional and personal knowledge, which has a considerable research value in making sense of the subjective of experience of people with dementia.

The number of personal accounts which are now written or presented directly by people with dementia has increased in the recent two decades. It is now recognised that the personal account of those with dementia can be accessed, especially with capturing feelings (Kitwood, 1997a, Wilkinson, 2002b). The Scottish Dementia Working Group (SDWG) is made up of people with dementia who have shared their experiences with others through presenting in conferences, research collaboration with universities and other organisations, organizing dementia related events to raise dementia awareness and providing training to the general population, which has gained successful impact on the national and international scope. Furthermore, Terry Pratchett, an English author of fantasy novels, has shared his experiences in a two-part documentary series on BBC 2 and discussed Alzheimer’s and how it had affected his life through a spectrum of media (BBC2, 2017). A recent BBC Panorama: Living with Dementia: Chris’s Story, has revealed the family’s life of living with dementia (BBC, 2016). The documentary showed how the whole family: Chris himself, his wife Jayne and their daughter Kate are fighting, coping and continuing with their lives. It gives a remarkable insight into what life is like behind closed doors and people with dementia and family caregivers’ world. Other people with dementia have also been
using a variety of techniques or media tools, such as publications, blogs, diaries or ‘YouTube’ to share their living experience and communicate with the social world. For example, ‘My Story: Alzheimer’s from Inside Out’ by Richard Taylor, who has presented his experiences of a worldwide tour (Taylor, 2007). There are many blogs from these presentations that are available on his web. These allow the health professionals, general public and policy makers to gain insight into the dementia world.

Current examples of written accounts suggest that increasingly more people with dementia are sharing their experiences, hopes, feelings and fears using modern technology and the media, which have validated the understanding about people with dementia. National Dementia Strategy (Scottish Government, 2010), addresses that people with dementia and their carers should play a main role in research related to dementia prevention, treatment and care. It also refers to the ‘rights to accessible information and support, to participate in decisions that affect them, to live as independently as possible with access to community facilities, to full participation in planning care and to be assisted to be involved in policy-making’ (p.16). Just like Nazarko (p. 224) says: ‘the quality of life that the person with dementia experiences as the journey progresses is dependent on the ability of others to enable the person to function to capacity’ (Nazarko, 2015). And again, Swaffer (2014) says: ‘no longer can this expertise be ignored as people with dementia are the experts through the lived experience, and not including them in research not only further stigmatizes them, but hinders the validity of the research’ (p.710). Empowering people with dementia with knowledge regarding their life, preference, needs and validating their experience will allow them to have a meaningful life and relationship with others. Involving people with dementia into research is not only improving the validity of the research, but also increasing the self-value and involvement for people with dementia (Stevenson and Taylor, 2017).

The subjective accounts of people with dementia has gained more research attention in the Western literature, however, these types of studies of people with dementia and family caregivers in China are rare. The literature search identified three peer-reviewed publications in the Chinese National Knowledge Infrastructure and one in the Wanfang database when using the key search terms ‘dementia,’ ‘family caregivers’ and ‘experience’. Two of the four publications in Chinese were literature review papers which summarised the impacts of care giving to the family caregivers; one study was about psychological resilience and factors that affected family caregivers; the last
study was related to the nursing education and interventions to family caregivers. None of the studies involved people with dementia. Liao et al (2014) indicate that the amount of Chinese publications relevant to studies in nursing research related to dementia care in China is insufficient (Xiao et al., 2016). In a longitudinal study, Xiao et al (2016) found that previous studies which estimated the dementia rate in China have been low. These empirical studies evidence that there is a lack in the voice of people with dementia and family caregivers in China. Song and Wang (2010) state that the experience of people with dementia not only imposes an economic burden, but also a decline in the quality of life. It is, therefore, very important to provide evidence-based understanding and support to them. Since one in five people with dementia in the world live in China, it is critically important to understand people with dementia and their family caregiver’s feelings, ideas and thoughts which will help healthcare staff and possibly politicians to know the difficulties and challenges that people with dementia and family caregivers have experienced in their life, living with or caring for people with dementia. For example, a number of researchers have identified that involving people with dementia in research can contribute to constructing services more appropriately (Wilkinson, 2002a; Hubbard et al., 2003; Swaffer, 2014; Stevenson and Taylor, 2017). Smith (2007) has recommended how interviewing can gain an understanding of dementia, and the focus of the research reported in this thesis on the specific experience of caring responsibility aims to contribute to the wider picture of the lived experience of people with dementia and their family caregivers in China.

2.9 Summary

This section of the literature review has reflected the different perspectives on the nature of dementia and its implications on practice. It also provides good evidence in reviewing the impacts of caregiving and care receiving on people with dementia and family caregivers. In preparation to hearing what the participants have to say about their lived experiences, I have considered several key concepts of the study: how the nature of dementia can be understood; the physical, psychological and social responses to caring responsibility; the relationships between dementia and caring responsibility; and the subjective experiences of people with dementia and family caregivers. It is noted that local context has significant impact on the perception of individual’s subjective experience. I will base the current study from a perspective of acceptance that it is important to understand the individual experience of dementia
but more important to understand the actor’s situation on the context and who the person is on the experience of dementia and dementia care. There is much to learn about how the social and physical environment influences the personal accounts of people living with and caring for with dementia.

A lack of understanding the correlation between the macro of political strategies on dementia care and the micro of individual needs in real life, which is embodied in the wider range of social disability, may influence the understanding of an individual's journey through dementia. Caregiving and care receiving are such fundamental and critical components of this journey and is worth investigating. In the studies reviewed, the significance of life events and physical, psychological and physical appraisals to personal responses of the events appear that personal accounts improve the understanding of the subjective experience of caring responsibility in dementia care. This literature review reinforces the proposition that a theoretical understanding of dementia cannot be separated from understanding the person who is experiencing it, in the context of their world as the personal account means ‘different things to different people in different contexts’ (Brooker, 2015, p.11). Previous reviews indicate that research in dementia care which are associated with personal accounts is insufficient, especially with people from low and middle-income countries (Wilkinson, 2002). That is also one of reasons why this PhD study was designed; to explore what Chinese people with dementia and family caregivers perceive about the topic of caring responsibility and the meaning of what caregiving and care receiving for them.
3. Chapter Three: Methodology and Method

3.1 Introduction

This chapter will explain how I have approached my research and discuss the appropriate methodological approach to investigate the research questions, the rationale for the choices and the method used for answering the research questions. Reaching a decision about research methodology requires careful consideration of what the study is trying to achieve and finding the best way to answer the research questions. The current study employed a qualitative approach by using interpretative phenomenological analysis (Smith, 2009). The chapter explains the selection of research methodology and the process of participants recruitment, data collection and data analysis. The necessary ethical principles with involving people with dementia in the research which related to information consent, capacity of decision-making and confidentiality are also discussed in the chapter. Reflexivity on the research methodology, ethical consideration and the limitations of the study approach selection have also been stated.

3.2 Research aims and research questions

3.2.1 Research aims

The study aims to gain insight into the lived experiences of people with dementia and their family caregivers, and how they cope with their new roles in China. It specifically explores the meaning of family responsibilities, social relationships and cultural influences under a changing socio-economy, demography and culture society. The negative and positive impacts of the participants’ lived experiences will be explored, their ability to cope with dementia and their expectations from family and health and social care support. Additionally, any variations between their expectations and their experiences of the healthcare system in dementia services will be sought.

3.2.2 Research questions

The main question is ‘How do people with dementia and their family caregivers in China feel about the experience of living with dementia?’ The secondary questions are developed from the main question:

- What does live with dementia mean to them?
- What are the impacts of living with dementia?
• What does ‘Xiao’ (Filial piety) mean to them?
• How do they cope with living with dementia?
• What are their expectations and experiences of the healthcare system and social support?

3.3 Phenomenological approach

The purpose of my study is to investigate the lived experiences of people with dementia and their family caregivers in China, and specifically to develop a deep understanding of the impact of a specific Chinese context and culture on their perceptions of caring responsibility. This points to a phenomenological inquiry, which aims to investigate as closely as possible the psychological meaning of the experienced phenomenon of the participants (Smith, 2009).

3.3.1 Rational for the approach selection

Phenomenological inquiry was developed from the philosophical theory of Heidegger’s hermeneutics and its process is interpretative (Speziale et al., 2011, Smith, 2009). According to Creswell (2013), the basic purpose of phenomenological study is to investigate the very nature of the participants’ who have experienced a specific phenomenon, in which the researcher intended to identify the common meaning of this phenomenon. Over the process, a rich contextual phenomenological analysis is required to capture a faithful phenomenon and a composite description of these common meanings of the experiences of all of the participants. Speziale et al (2011) manifest that phenomenological inquiry is a suitable approach to investigate phenomenon in nursing practice due to its nature of interpretation and explication. In this current study, a phenomenological approach has been used through the process of interpretation of the descriptions of the participants’ subjective experiences of living with or caring for dementia to reveal what the nature of their experience is and the meaning of what they experienced (Creswell, 2013).

Another reason to take a phenomenological approach is that it enables people with dementia to be included. The absence of a ‘voice’ from people with dementia has been recognised and there is a growing trend to include the voices of people with mild and moderate dementia in research (Wilkinson, 2002b, Innes, 2009). Phenomenology helps understand a participant’s experience and determine the meaning of the experience, this may contribute to the design, development and evaluation of health care services as well as informing policy and practice (Norlyk and Harder, 2010). It is recognised that the subjective experience of those with mild and moderate dementia
can be accessed, particularly when studies focus on gaining feelings rather than gaining facts (Hughes et al., 2006). Finlay highlights the strengths of phenomenology in a way that illuminates the lived experience of people with dementia and their family caregivers: 'The special contribution and strength of phenomenology is the way it can capture the richness, poignancy, resonance and ambiguity of lived experience, allowing readers to see the worlds of others in new and deeper ways.' (Finlay, 2009, p.474). Giorgi and Giorgi (2008) think that phenomenological psychology research aims 'to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place.' (p.28). Therefore, the phenomenological approach seems appropriate to reach the aims of this study. From my experience of working with patients, talking and listening to them is the best way to understand their needs. As the phenomenological approach provides the value of understanding personal psychological experience during research, it meets the purpose of what the study seeks for. On the other hand, my practical working experience with people with dementia can enhance my skills in accessing and interviewing people with dementia and to understand and interpret what they have experienced during their life. However, familiarity with working with people with dementia and familiarity with China may mean that I am so used to something that I don’t notice it.

In considering how best to develop this research, I thought about a number of possibilities of qualitative research approaches in the beginning. For example, Grounded Theory is one that has been frequently used by qualitative researchers. It is a method that allows the researcher to move from data to theory and was designed to open up a space for the development of new, contextualized theory (Charmaz, 2014). Grounded Theory provides a better understanding of the structure of the participant’s experiences by studying the social psychological process. Data gathering, and analysis are designed to allow concepts and categories to emerge from the data. Therefore, Grounded Theory is more suitable when identifying social processes and providing a better understanding of the structure of participants’ experiences. As Grounded Theory aims to develop a theoretical analysis of the collected data through systematic procedures (Charmaz, 2014), in which the new theory is generated by exploring contextualized experiences and remains in an explanatory level (Dorothy., 2010), but this is not the purpose of my study. My study aims to gain deep and detailed perspectives of particular experiences or events of individuals, so Grounded Theory is not the most appropriate approach to this sort of
enquiry as it focuses on identifying causal and intervening factors, as well as the context of a particular health issue (Lewis, 2015). Discourse analysis was also considered as an alternative methodological approach that has gained popularity as a qualitative approach in psychology research. However, discourse analysis aims to construct a framework by revealing the social psychological characteristic of a person. It is focused on understanding the social objects that are constructed by language (Willig, 2008), rather than the individual’s language which is constructed by the social context (Smith, 2009). Therefore, discourse analysis is not suitable when investigating a detailed, in depth personal experience. Interpretative phenomenology is used to explain and describe human phenomenon through an interpretive approach. As the choice of research approach should be determined by the research aim and question, to ‘fit with’ this, interpretative phenomenological analysis (IPA) was chosen as the recognised framework for the current study. IPA is suited to studying the detailed experiences of individuals and how individuals make sense of their personal experience and social world. The theoretical underpinning of IPA is discussed in the following.

Phenomenological methods in dementia research

Researchers and healthcare professionals are increasingly interested in gaining access to the subjective accounts of people with dementia (Harman and Clare, 2006, Clare, 2002a, Quinn et al., 2008, Clare et al., 2005a). A small number of researchers have adopted a phenomenological approach to studies which have involved the personal accounts and subjective experiences of people with dementia (Clare, 2002b, Clare et al., 2008, Tuohy et al., 2013). Phenomenological methods allow the researcher to develop an understanding of the experiential world of a person with dementia. Clare et al (2005a) suggest that the phenomenological methods ‘...allow for the involvement of the person with dementia as a collaborator in the research process, rather than as a ‘subject’ to be studied, and create the potential for the person with dementia to be engaged in co-constructing a model of the subjective experience of dementia' (p.406) and this is an important principle which will be addressed in this current study.

Phenomenological approaches used in dementia research can be evidenced in the literature. For example, Clare et al’s (2005a) phenomenological model of awareness was developed from the personal subjective experience of living with dementia in early stages and continuity coping over time in an IPA study. It indicates that a
phenomenological approach allows exploration of the meaning of phenomenon in its social and psychological context to understand this phenomenon on the fluctuating and dynamic construction, rather than view it as a fixed attribute. Phinney et al adopted an interpretative analysis to explore the meaning of activity for people with dementia and its implication for a practical model (Phinney et al., 2002). Ashworth highlights that to understand the actions and talk of a person with dementia, the lifeworld, such as identity, sociality, embodiment, spatiality, temporality, project and discourse should be considered (Ashworth, 2006). Ashworth’s research explains how to see a person with dementia as a person first and foremost rather than focusing on someone’s functional ability. This has significant implications for phenomenological research and is applicable in the current study. For example, I try to understand the participants’ experience within the social and cultural context and I also using the participants’ own words or synonyms to construct the themes when doing data analysis.

In capturing the 'lifeworld' of the participants, the current study recognises people with dementia as active, responsive agents, and continually seeking a meaningful life in their experiences (Sabat, 2001). The study tries to understand their experiences from the real-life perspectives by avoiding any presumption and pre-experience (Smith, 2009). To do this, reflexivity is considered a key part of the process of the study. The hermeneutic circle was used to gain the detailed, in-depth subjective account of the participants and to understand the dynamic relation of them making sense of their experience. With its characteristic of description and interpretation, IPA is the best-fit phenomenological approach for my study.

Limitations of the methodology

Although phenomenology has become a dominant philosophy that guides knowledge generation in nursing research (Norlyk and Harder, 2010), like many research methodologies, IPA has some limitations. As explained in the above, I give a clear rationale for semi-structured interviews as a data collection method, primarily in order to be more supportive of the participants with dementia, and because of the method's potential to generate rich data. However, the method of interviewing used for data collection only focuses on clarifying the meaning of the world beliefs, but not of actions (Arksey and Knight, 1999).
In addition to the limitations of qualitative methodology which I have mentioned above, for example, the preconceptions of researchers, there are several limitations in the sampling of this study. Firstly, there are inconsistencies between homogeneity and heterogeneity. As discussed above, homogeneity of sampling is required in IPA study, however, history and personal culture can influence one’s understanding of concepts. Heterogeneity will be unavoidable in a group of the population, such as educational level, socio-economic status and gender. These characteristics of participant variability may influence how they view the meaning of their experiences. Furthermore, heterogeneity also exists in the length of the illness and care-giving and the severity of dementia as the participants may have experienced more sufferings or be more adapted with their situations. These features could lead to differential personal perspectives from the participants.

The study recruited participants from a specific geographical area so the findings cannot be generalized and applied to people from other ethnic groups or people from different social contexts without consideration of the relationship between the study context and other contexts. For example, people who live in Hong Kong and Taiwan will view their experience of social support differently from people in mainland China, because the dementia care strategy and the healthcare system in these two cities are different from mainland China. Moreover, the disparity of health insurance and the pension system in urban and rural residents are different, people may view their lived experience differently because of the geographic and social-economic disparity if they reside in different regions in China. In addition, the method of interview has also limited the opportunity for people who lack communication skills or lost oral ability. Therefore, the study is lacking the knowledge of these group of population.

Lastly, to be consistent with the sampling strategy and theoretical representation of an IPA study, this study recruited a smaller sized sample, therefore the findings do not represent the whole population of Chinese people with dementia and family caregivers. However, this is not the aim of the study, one of the aims of this study is focusing on gaining specific subjective experience on a specific context. In this case, IPA is useful in exploring the meaning of living with dementia and the meaning of care-giving and care-receiving.
3.3.2 Theoretical perspective of IPA

IPA has been developed as a distinctive approach to conducting qualitative research in psychology, offering a theoretical foundation and a detailed procedural guide. Smith (2009) state that IPA aims to examine ‘how people make sense of their major life experiences’. The process of IPA research involves a ‘double hermeneutic’, and it explains that as: the participants make sense of their experience, the researcher makes sense of what is said by the participants, this interpretative process forms a dual hermeneutic. IPA as a qualitative research approach has been best known in psychology and is being increasingly applied in psychology research (Smith, 2011a, Tuohy et al., 2013). More recently, this approach has been used to explore the subjective experience of dementia patients (Clare et al., 2005b, Clare et al., 2008, Wawrziczny et al., 2016, Wolverson et al., 2010), thus it has been established as a suitable method for this participant population and research area.

IPA commits to the examination of how people make sense of their major life experiences (Smith, 2009). 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 is particularly concerned with the experience of important events or significant changes in a person’s life (Smith, 2009). It explores in depth what the experience is and what sense a person makes of the experience. Therefore, using IPA is an appropriate framework for this research because it provides a way of understanding the subjective experience of people with dementia. It focuses on drawing on the researcher’s own interactions with the participants and using that as an interpretative resource – getting insights into the lived experience of the participants. It helps the researcher to understand the participants’ lived experience.

Larkin et al (2006) indicate two aims of an IPA study: Firstly, understanding the participant’s lifeworld by getting the participant’s views as ‘close’ as possible in an initial stage of psychologically informed description. Secondly, developing a further interpretative analysis through positioning the initial description in a wider social, cultural context. Larkin et al manifested some potential prompts of an IPA study in the process of providing extracts over the study and stated the functions of IPA through interpretation of the event and getting insight into the participant’s lifeworld. They indicate that IPA deploys the cultural resources, expresses some unconscious conflicts and desires of the participant, and displays the unique social relationship of
the participant with others (Larkin et al., 2006). Each of these possibilities offers the researcher entry to the participant’s lifeworld through their orientation towards the world. Brocki and Wearden state that IPA intends to explore the personal view of the world from an insider’s perspective of the phenomenon, rather than the formulation of objective accounts (Brocki and Wearden, 2006). IPA is concerned with exploration of the participants’ experiences, perceptions, views and understandings, which fits with what the current study seeks.

In this section, I will discuss the philosophical underpinnings of phenomenology and the implications of this for the nature of knowledge. I will critique phenomenology, hermeneutics and idiography (these are three key standpoints which are mainly connected to IPA), and the theoretical perspective of the research, before exploring the implications for the research methods.

Phenomenology is both a philosophy and a qualitative research approach whose goal is to explore and describe particular phenomenon (Speziale et al., 2011). The discipline of phenomenology is to study how we experience from the first-person point of view. It has been applied mainly in two streams: descriptive phenomenology and interpretative phenomenology (Tuohy et al., 2013, Speziale et al., 2011). Phenomenology as a philosophy can be tracked back to Edmund H. Husserl’s work in the twentieth century and then has been further developed by Martin Heidegger, Merleau-Ponty, Jean-Paul Sartre et al. For Husserl, phenomenology aims to examine human experience and focuses on its perception (Smith et al, 2009, p.16). Husserl’s phenomenological inquiry is a form of descriptive phenomenology and it is derived from the individual’s consciousness of their experiences. Husserl tried to understand personal experience by ‘bracketing’ the objective existence consumption of the world. Social scientists influenced by this branch of phenomenology seek to gain access to people’s common-sense and to interpret their actions and their thinking from their point of view (Bryman, 2012).

Based on Husserl’s work, Heidegger’s phenomenology is more focused on an interpretive way of understanding the personal perspective. Heidegger developed the concept of Dasein as ‘being-in-the-world’ to understand human beings through analysis the activity of existing. He indicates that ‘being-in-the-world’ should be understood not only as a spatial object, but also needed to be connected with the sense of belonging. For example, the meaningful perceived world of a person with dementia is not purely a living body in the spatial place, but also the connections,
relationships and familiarity with the place. Therefore, because the nature of the human being is ‘being-in-the-world’, it means that when we interpret the meaning of things or activities, we need to consider the contextual relationships to things in the world (Smith, 2016). Therefore, a person’s subjective world is not purely his/her primary mental feeling, but also the meaning of this subjective experience that is pertinent to the real-life context needs to be considered (Larkin et al., 2006). Heidegger’s philosophy of person-in-context tells us that we cannot impose meaning in only the subjective sphere as ‘we are a fundamental part of a meaningful world’, but we need to understand meaning “as a function of our involvements with that world’ (Larkin, 2006, p.106). This fit to the purpose of the current study to understanding the participants’ subjective experience in the Chinese cultural context. Heidegger’s phenomenology is more concerned about examining the things that have emerged from underneath. Heidegger’s phenomenology has changed scientists’ understanding of meanings from Husserl’s epistemological level to seek further understanding of meanings to its ontological level through looking at ‘what is’.

In addition, Merleau-ponty’s ‘phenomenology of perception’ which is based on Martin Heidegger’s ‘being-in-the-world’, indicates that the perceived world with meaning lays on our bodies’ mode of existence in that situation. It suggests that one’s thought and awareness can be shown from one’s body movements and body position toward the world. As the body is the part of the ‘life world’ of a person, it cannot be separated from one’s perception (Smith, 2016). Therefore, Merleau-ponty’s philosophy of one’s body ‘being-toward-to-world’ is significant to understand one’s living world. Merleau-ponty also argues that the body’s relationship with space is significant in reflection to the original intention. It highlighted the role of the body in human experience (Smith, 2016). Therefore, both Heidegger and Merleau-Ponty’s phenomenology had important implications in understanding life experiences, especially when a person with dementia becomes more reliant on using their bodies to create relationships with others and the social world.

Whereas Husserl et al present the discipline of phenomenology as the study of ‘phenomenon’, in which human existence is the site for the revealing of being, in the Chinese tradition, human existence is a unity of one’s body and one’s mind. Each person’s self-awareness was based upon a holistic understanding of the world, which was structured as an interactive relationship between humanity and nature (Cheng, 2000). This can be answered from Confucius’ conception of selfhood and identity,
wherein individual identity was defined by the group of population which one belongs (Ho, 1995). This is, ‘self and others are conjointly differentiated from the phenomenal world to form the self-in-relation-with-others’ (Ho, 1995, p.117). It means that the individual is not a separate being, but a part of a whole. Therefore, in Confucianism, individual behaviour is relational dominant and can be self-cultivated through the process of one’s own striving and society’s impact on them. Hence, cultural accomplishment is significant in understanding an individual’s being, family and social context. From this point of view, cultural sensitivity and cultural awareness is an important component of the interpretation of the subjective accounts of the participants in China.

It is clear that even though human experiences of the world can be different, there is a consensus about a human’s mental functions of feeling, such as joy, happiness and sorrow. However, human experiences of the world are not just to be understood by its functional points, it is more about how we assess and understand these functions in their context, because the body is infused with consciousness (Smith, 2016). This is how different traditions generate great differences in their conceptions of the human individual.

IPA attempts to understand the first-person perspective from a third person position (Larkin, 2006). It is acknowledged that the process of analysis involves a ‘double hermeneutic’ in that the participants make sense of their experiences in the first instance; and then, through the interpretative exercise, the researcher makes sense of what is happening to the participants by interpreting their perspectives (Smith, 2009). This study focuses on people with dementia and their family caregivers’ subjective accounts, specifically my interpretations of their experiences. These processes form a substantial component of the original data and interpreted themes. Within such processes of interpretation, the findings would be influenced by each participant’s understanding about their own experiences and the researcher prior knowledge and experience. Therefore, I acknowledge that my undertaking of this study is likely to be influenced by my professional and personal experience. In recognising the influence of my own lived experiences upon the interpretations, this suggests to me that I not only need to understand the participants’ experiences, I also need to understand my own experiences in relation to the culture, the values and the language in which the participants are involved in. Only through looking at the context that the individual is embodied in, can the meaning of the individual’s experience be
understood. I also need to keep in consideration the influence of my roles on the study, such as my identity over the process of the study, for example, whether or when I identified myself of being a PhD researcher or being a Chinese woman and a daughter.

The ‘hermeneutic circle’ is one of the most important ideas of hermeneutic theory and it forms a dynamic relationship in the research process. Hugh et al (2006, p.183) point out that the ‘hermeneutic circle is the process of interpretation that can lead to a refinement of our preconceptions’. This process explains the rationale of the hermeneutic circle and concurs with Heidegger and Merleau-ponty’s philosophy, it is concerned with the dynamic relationship between the part and the whole. It manifests a person as an individual, but also that the person is being embodied in the contexts which surround him/her. It is known as ‘hermeneutic phenomenology’. The aim of interpretative phenomenology is doing a hermeneutic process to describe, understand and interpret participants' experiences (Tuohy et al., 2013).

Another hermeneutic circle that needs to be considered is the dynamic relationship between researcher and participant in IPA research, in which the researcher needs to bracket his/her own pre-knowledge and experience and understand the participant's experience by stepping himself/herself into the participant's shoes (to look at the participants experiences from their perspective) (Smith, 2007). It means the researcher moves from a point where he/she is perceived from his/ her own experience to the point where the participant is focused (to view things from the participant’s view point) to uncover their experience. It requires the researcher to continual round the circle back to where he/she started the study. It is the fundamental theory of interpretation and the theoretical underpinning of IPA (Smith, 2009). In the current study, the principle of hermeneutic circle has important implications in investigating the real meaning of the participants' experiences. For example, during the process of analysis, I need to be aware of how my position as a Chinese, female and a mother influences my understanding of filial piety and also how it impacts my relationships with my participants.

IPA is particularly concerned with the experience of important events or significant changes in a person’s life (Smith, 2009). It explores in depth what the experience is and what sense the person makes of the experience. This particular consideration is called idiography by Smith and colleagues because IPA is interested in understanding the detailed experience of an individual and the perspective of the individual in a particular context. To ensure idiography, the researcher is normally recommended to
have a small sample size (Smith, 2004, Smith, 2009), which allows them to conduct detailed analysis of single cases and to examine the similarities and differences within a small sample size. As a result of the detailed single case analysis, it brings a deep understanding of the particular person and their response to the particular experiences. Reid et al (2005) indicate that IPA provides an opportunity for researchers to engage with a research question at an idiographic level and to gain the insights of participants themselves. Therefore, idiography has significant influence in IPA research to explore a detailed and particular investigation of the lifeworld of the individual.

The process of an IPA analysis includes exploring, describing, interpreting and situating the means of the participants’ experiences in the specific context. It means that in IPA research, researchers need to understand participants’ relationship to the social world through interpretation of their lived experiences of particular events. For Merleay-Ponty, meaning was embodied in the participants’ life world, so an interpretation is required from the researcher to interpret the meaning of what participants ‘say’ or ‘do’ in that particular context. In applying this theory to the case of dementia research, I have proposed a semi-structured interview with people with dementia and their family caregivers in producing practical knowledge about their lived experiences, and in the process they may gain new abilities to create knowledge. In this case, the practice setting will take place in the context of traditional Chinese culture and will look particularly at the impact of the culture, value and belief on individual’s ideas. This also requires me to understand the social and cultural context when interpret and determine the meaning of their experience, so that this understanding of knowledge can be applied to practice. The process of the study is not only consistent with hermeneutic theory of phenomenological approach, is also concurs with idiographic theory of the particular experience in the particular context. Therefore, IPA provides an opportunity to investigate people in the context of their everyday lives.

3.4 Study quality

Phenomenology has become an important methodology in nursing research, and the term phenomenology is frequently used in nursing literature (Norlyk and Harder, 2010). However, there are many challenges to adopt phenomenology as a framework for conducting a psychological research as there are no defined rules or standards to restrain elaborate interpretation and to tell how to accomplish a qualitative study
Similarly, there are many controversial issues related to the validation and evaluation of qualitative study (Norlyk and Harder, 2010, Mays and Pope, 2000, Sousa, 2014). In the process of a qualitative study, there are also many other uncertain factors that influence the interpretation of the data. For example, the presumptions, perceptions and the analyser’s own personal perspectives. Therefore, for qualitative research, the conventions and standards to evaluate the quality of the research is difficult to define. According to Smith, a valuable and well written IPA paper should focus on one particular aspect, with strong data to support themes and rigorous interpretation to identify the convergence and divergence of data analysis (Smith, 2011b). In the following section I will talk about how to evaluate the quality of a study, to do this, I draw on Yardley’s (2000) criterion of sensitivity to context, commitment and rigour, transparency and coherence, impact and importance to discuss the quality and validation of the current study.

3.4.1 Sensitivity to context

To ensure the quality and validation of a qualitative research, it needs to always ensure sensitivity to the different perspectives that have been involved in the study and who is related to the study (Yardley, 2000). Research contexts can be comprised by many factors.

Firstly, previous theory, relevant literature and the pre-empirical works are essential for shaping the researcher’s observations and explanations in a qualitative study. For this reason, considering the extensive grounded philosophical approach, the intellectual history of categories and the different perspectives and arguments in the beginning of the investigation, are beneficial for deriving a new insight into the understanding of the meanings of the participants (Yardley, 2000) or add new knowledge to the relevant existing knowledge (Mays and Pope, 2000). For example, in the current study, Yeh’s (2003a) theoretical framework of Dual Filial Piety Model (see chapter 4 discussion) was adapted to further understand and discuss the limitation and the value of reciprocal filial piety and authoritarian filial piety in Chinese society.

Secondly, language, culture and social interaction have played central roles in the meaning and functions of the phenomena/experience of the event, therefore awareness of the social-cultural setting is very important in qualitative research (Yardley, 2000). Therefore, in the current study, I am always aware how urbanization
and industrialization influence the social-cultural meaning and the concept of caring responsibility for people with dementia and their family caregivers. For instance, migration and social mobility caused unavailability and less capacity of children’s responsibility for their older parents and how this phenomenon has changed the meaning and concept of the traditional belief of filial piety.

Thirdly the social context of relationships between researcher and participants influence the researcher on how to enter into the participant lifeworld and share understanding with the participants. Because of the nature of participant’s involvement in a qualitative study, the relationship between the researcher and the participants may have potential to cause exploitation and raise some ethical issues. Therefore, from study design to data analysis, each stage of the study needs to be considered carefully and sensitively. As a qualitative approach is not only considering the ‘inside’ feelings and opinions of what the participants’ have said and their actions, it is also considering the relative identities and understanding of the participants that provide the framework for the investigation. For this reason, linguistic and dialogue sensitivity are very important in controlling the meanings and functions of interpretation. Finally, researchers’ characteristics, such as their personal role, position and pre-experience influence the balance of power in the process of studying. For example, during the process of the current study, I was aware that the participants knew that the research was carried out as part of my doctoral thesis, and it is possible this may have contributed to a perceived power imbalance with the researcher perceiving this as having expert knowledge in this field. I also aware that my long period of time of working and living in another culturally different country (the UK) could have led me to raise some cultural inappropriate questions. To avoid these, during the process of the data collection and analysis, context sensitivity was always being considered and reflectivity was used to avoid any interpretative bias.

3.4.2 Commitment and Rigour

The commitment of the quality of a qualitative research encompassed a prolonged contemplative topic, the competent and skilled methods and the immersing of data in the study (Yardley, 2000). In the current study, a comprehensive literature review in the area of dementia care has been carried out. I have also previously worked in a memory lane unit in the UK where the main job responsibility was involved with making post-diagnosis care plans for the person diagnosed with dementia and delivering care activities for them which also includes engagement with the wider
family. This provides an insight about the real-world life of people with dementia and their family caregivers for me (albeit in a different country), which supports me to interpret the participants’ subjective experience. An extensive reading on the research methods was carried out and the underpinning of IPA study was also investigated. I also attended a training course of working with others on the field of qualitative research to discuss and reflect on the issues and challenges encountered during data collection. And I have also taken part in IPA workshop training sessions which provided the opportunity to consider IPA related issues. Additionally, I attended two seminars of NVivo training: ‘Basic introduction in coding and analysis’ and ‘NVivo beyond the Basics: Queries with Nodes’. To further enhance commitment, I listened the interview recordings and read the transcriptions several times to become fully immersed in the data, this also helped to do the reflection.

In a qualitative study, rigour refers to the completeness of the data in which systematic collection, a comprehensive analysis and transparent interpretation are drawn from (Spencer et al., 2003, Yardley, 2000). Rigour was enhanced in this study providing the full information needed for in-depth analysis within a limited study period. Multiple coding also enhanced rigour of the study in which the interpretation addresses all the variation and complexity of the data (Yardley, 2000). In addition, my two PhD supervisors have reviewed and checked the emerging codes to ensure the accuracy of the coding frame and identify the discordant interpretation between the research team. The study also looked at the findings from different sources (from people with dementia and family caregivers) to raise rigour of analysis. Finally, checking back over the themes that emerged from the transcriptions to ensure that themes were generated from the data itself was done.

3.4.3 Transparency and Coherence

According to Yardley (2000), transparency was enhanced by providing a detailed description of how the data was collected and analysed by providing the textual data in which the readers can discern the correctness and accuracy of the analysis. In addition, transparency refers to the study report being able to provide an open presentation of all related research process, such as the detailed research procedures, the recruitment of participants, the methods that were used (Mays & Cope, 2000). It is necessary to include the researcher’s reflexivity of discussion of experience or motivation response undertaken in this study, how this work has been influenced by external factors. For example, I kept a reflective diary throughout each stage of the
study to disclose my emotional responses or some ethical issues during the data collection and the challenges I faced over the data analysis. Some examples of my reflective notes were illustrated (see appendix 9). This has helped me to adjust my emotional fluctuations during data collection and data analysis, to avoid emotional influences and being a natural researcher to judge and interpret participants’ experiences. I have also in the research method section displayed a clear account of how I collected the data, the process of analysis and also provide sufficient original data for the readers to judge whether the supported data were enough to support the interpretation.

Coherence was maintained by the philosophical theoretical framework adopted in the study, the method used and the analysis undertaken fit with the research question (Yardley, 2000). For instance, in the current study, the descriptions used in the study report were coming from the voice of people with dementia and family caregivers, but not the perspectives of health professionals or other relevant population groups. It is consistent with the purpose of the study and appreciably answered the research question. Additionally, the criteria of coherence in a qualitative research is to produce a convincing account in which a reality has been created which has been recognised by the readers as meaningful to them. For example, the analysis of the meaning of caring responsibility for Chinese family caregivers was expressed as ‘she is my mother’, ‘he is my father’, ‘I had to do it’ to reflect how the culture perspective has influenced the participants’ views, in which most of the readers are familiar with these illustrative expressions.

3.4.4 Impact and Importance

Impact and importance are the decisive criterion in all research. Yardley (2000) indicates that the ultimate value of qualitative research is judged by the objective analysis of participant’s subjective accounts, and its application in which knowledge and understanding of one particular area is gained and the findings are applied in practice. The current study highlights the experiences of living with dementia and caring for people with dementia which offers an insight to those health professionals or decision makers who make impacts on lives of people with dementia and their family caregivers. It hopefully has implications for creating more positive and supportive dementia care services.
According to Yardley (2000), theoretical value is the most primary impact of qualitative research which can lead to a new perspective of understanding a phenomenon. Over the past two to three decades, the psychological processes and mechanisms have been explained through understanding the subjective experiences of people with dementia or caregivers (Brodaty and Gresham, 1989, Aggarwal et al., 2003, Harman and Clare, 2006, Aarsland et al., 2007, Brodaty and Donkin, 2009). These theoretical knowledge have been widely applied in practice. For example, Cooper et al cited that emotion-focused coping strategies had significant clinical implications on the development of psychological intervention to reduce anxiety in dementia caregivers (Cooper et al., 2008). In the review of the empirical literature of dementia caregiving, Schulz and Martire indicated that empirical research contributes to practice guidelines and recommendations for healthcare professionals and their application on intervention approaches which improve caregiver burden, depression, and quality of life (Schulz et al., 2004). In the current study, filial piety as a coping strategy was developed through people with dementia and family caregivers making sense of the situation of the current healthcare and social support system and the available healthcare resources for managing the situation. These theoretical understandings of caregiving and caring responsibility have a wider impact when applied to practical issues. It suggests the continuity of Chinese filial piety needs to be supported on a stronger government welfare system.

Apart from the theoretical and practical impacts, Yardley (2000) states that social-cultural impact is another consideration utility of a qualitative study, which change our ways to think or talk about things. For example, the analysis of social ability model of dementia challenges the portrayal of the medical model of dementia that views dementia as a disability which is addressed on individual suffering, rather than looking at dementia as the result of social constraints which can be improved by changing the social environment. In addition, the common conceptual framework formulates our research questions which limits our understanding of various levels of cultural perspectives. At this point, this overall approach to investigate the nature of things may be limited to the understanding of people with dementia or dementia caregiver’s living experiences in different ethnic groups. By the means of this analysis, the social-political ideas can help to promote the relevant principles or regulations on health care services. Qualitative analysis also helps to make more rational, practical decisions through analysing the meanings and functions of cultural perspectives in contexts.
(Yardley, 2000), such as, the interpretation of the meaning of filial piety in a Confucian world.

3.5 Ethical considerations

There are many ethical and practical issues when involving people with dementia in research. When the research involves human subjects, ethical considerations of involving people with dementia in research mainly focuses on: how to gain ethical approval to conduct studies which involve people with dementia; whether the participants with dementia have the capacity to provide informed consent and the capability to be involved in the research and their rights of being involving in research; maximising benefits and minimising any risks of harm (Sherratt et al., 2007, Holland and Kydd, 2015). However, with the characteristics of the progressive cognitive impact in dementia, it is necessary to consider all ethical issues giving rise to dementia because qualitative interviews are likely to have the potential to be exploitative (Clarke, 2006). Considering the literature about lacking involvement of people with dementia in research, I will now focus on this issue and discuss it below.

Involving people with dementia in research has shifted the way dementia is known which has changed the care and research associated with dementia. Thinking people with dementia are unable to participate in research activity can be seen as a reinforcement of the stereotypes of people with dementia being incompetent and excluding people with dementia from the social responsibility of research (Bartlett and Martin, 2002). This stereotyping can prevent people with dementia from being an active person in decisions of their care and reduce the opportunity to be understood, communicated with and retain specific decisions from their viewpoint. However, the capacity to make decisions may only be temporary or in an extensive period as the nature of dementia is progressive and fluctuates which may influence the levels of competency and capacity for people with dementia in decision-making (Hughes and Baldwin, 2006). A person who lacks the capacity to make decisions in certain aspects of their life may still be able to make decisions in other areas (Moye and Marson, 2007). At this point, the person’s comprehension and reasoning may change depending on the specific situation, and over time, so it is important to consider capacity to give informed choice and consent and provide opportunity to participate in a research for people with dementia. It should also consider other factors such as the person's physical and emotional condition of health, the effects of medications, or
even the time of day and places which may affect the individual's capacity to make decisions (Sherratt et al., 2007).

There is an increase in evidence and perspective knowledge in literature which involves people with dementia in research no matter how severe their disabilities are by using different research approaches (Hubbard et al., 2003, McKeown et al., 2010). The challenge for researchers is to develop and expand varied and flexible ways to support people with dementia in research (Hughes and Baldwin, 2006). Scottish Dementia Working Group (SDWG) (2014) reported the following core principles for researchers to conduct a study which involved people with dementia in the research (see box 2).

**Box 2 SDWG’s principles for researchers to conduct a study which involved people with dementia in the research**

<table>
<thead>
<tr>
<th>Box 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Informing the participants and the families with the study and findings which give the feeling of being informed, involved and valued.</td>
</tr>
<tr>
<td>• Research priority is set to improve the lives of people with dementia and the research agendas are set by both people with dementia and researchers.</td>
</tr>
<tr>
<td>• Researchers should hold ‘safety awareness’ on both physical and emotional zones for people with dementia and themselves during the investigation.</td>
</tr>
<tr>
<td>• Researchers should consider language appreciation for people with dementia either in speech or writing.</td>
</tr>
<tr>
<td>• Researchers should have knowledge appreciation about the participants’ information, and be aware of the need for the participants’ physical and emotional well-being.</td>
</tr>
<tr>
<td>• Researchers are expected to be compassionate, respectful, tolerant, patient, and understanding.</td>
</tr>
</tbody>
</table>

(SDWG, 2014)

The messages from the principles about how to involve people with dementia in a research were key for me to recruit my participants and conduct the interviews. It has guided me to review the participants as active, valued actors by ensuring a meaning and ethical involvement.

**3.5.1 Ethical Approval**

Obtaining approval for involving people with dementia in research is a time consuming and challenging experience for researchers. In the UK, National Research Ethics
Service aims to safeguard research participants’ dignity, rights, safety and well-being by protecting and promoting the best interests of the participants. A new updated process of Health Research Authority (HRA) Approval was also issued by the National Health Service (NHS) to protect and promote the interests of patients and the public in health and social care research (NHS, 2017). It states the process of complex and different levels of review and ethical approval for health and social care research. In England and Wales, the Mental Capacity Act (MCA) clarifies the legislation for the participation of people who have the incapacity to consent in care, treatment and research (MCA, 2005). In Scotland, the legal guidance for ethical approval for a research study involving any adult who lacks the capacity to consent, is provided by the Adults with Incapacity (Scotland) Act 2000 (UK Legislation, 2000). The act provides a legislative guideline in the areas of rights and welfare, finances and funds, medical treatment and research for people who have capacity issues. However, the current study has been conducted in China and the detailed ethical considerations that are more likely to be ethically suitable in a Chinese context. This will be discussed in more detail later.

Ethical approval was gained from both the University of Edinburgh Ethics Committee and Shandong Mental Health Centre Ethics Committee before proceeding with the study (see appendix 1a, 1b and appendix 2). As the research approach involves vulnerable adults and families of vulnerable people, during the process of interviewing negative emotions for participants may potentially be provoked as it is likely to touch on sensitive topics such as loss and sadness. In consideration to this, I ensured that all participants understand the potential risks that may emerge in the research and be given the opportunity to ask questions which they are concerned about before they sign the consent form. I also informed that all participants have their right to withdraw at any time.

### 3.5.2 Informed Consent

It is widely supported by legislation and practice that people should be regarded as competent to give informed consent unless evidenced that they are not able to. It should also not presume that people who lack capacity to make decisions in one area of life cannot make individual decisions in others areas (MCA, 2005), which may lead to the discrimination of potential participants and losing the opportunity to understand the needs of the participants (Sherratt et al., 2007). The capacity of many people with dementia to provide and engage in informed consent and discussions are increasingly
recognised by researchers (Wilkinson, 2002), but this is more likely to be approached in an individual way (Sherratt et al., 2007). The fluctuation in abilities and progressive nature of dementia negates the ‘one-off consent’ for people with dementia which places the person with dementia in a less powerful position (McCormack, 2002). It requires researchers to be aware of the difficulties of information retention with people with dementia and recognize the change of the participants’ conditions during the process of the research.

On-going consent is now recognised as an important approach in dementia research as well as other aspects of qualitative research. Dewing (2007) proposed a model of process consent with people with dementia by discussing the five conditions: informed flexibility, sympathetic presence, negotiation, mutuality and transparency, to be incorporated within the process of research. Sherratt et al (2007) further discussed Dewing’s process consent framework to further actively involve people with dementia in research. These five processes are: preparation and background, establishing basis for consent, initial consent, ongoing consent monitoring and feedback and support. Hughes and Baldwin (2006) suggests that a valid consent should be: informed, competent, un-coerced and continuing, but they also think that it is difficult to define ahead of time who should be informed if the person has moderate to severe dementia. They recommend three ways for informed consent (see box 3):

**Box 3 Hughes and Baldwin’s three ways for informed consent**

- The doctor makes the decision
- Negotiation between health professionals, the patients, his/her family, the laws or moral requirement of the context.
- Consumerism-the patient should know all
  (Hughes and Baldwin, 2006)

Following Hughes and Baldwin’s recommendation, the informed consents of the current study were given by using the second method, negotiating with health professionals, the person with dementia and their family members to comply with the law and cultural value in China.

**People with dementia**—The Information sheet (in Mandarin, a dominant language in China) (see appendix 3b) was sent to all potential participants with detailed information of the proposed research along with my contact details which allowed
participants to ask any questions related to the study. Sufficient time was given for people to consider participation (at least 3 days before fieldwork) before confirming their willingness by signing the consent form (see appendix 5b). Verbal consent was also sought throughout the study and discussed with participants before each interview to confirm their informed consent. For people with dementia who have lost the capacity of making-decision, the guardian or a relative of the person with dementia was given written information about the study. Assessing whether people with dementia have the ability to give informed consent is a controversial issue. According to Hubbard et al (p. 64), ‘difficulties in comprehending, making judgements, reasoning, communicating and remembering’ are main elements in considering a person’s capacity of making-decisions (Hubbard et al., 2003). Hughes and Baldwin summarised four principles (see box 4) to decide if a person with dementia lacks the ability to make decision:

**Box 4 Hughes and Baldwin’s four principles to decide if a person with dementia lacks the ability to make decision**

- Unable to understand the information relevant to the decision in question
- Unable to retain the relevant information
- Unable to use or weigh that information as part of the process of making the decision
- Unable to communicate that decision

(Hughes and Baldwin, 2006)

However, the cognitive abilities of people with dementia fluctuate and are progressive because of the nature of the illness, therefore the informed consent was on-going and, it was confirmed across the process of the study. When a potential research participant lacks capacity to provide consent then a legally authorised proxy consent is considered (McKeown et al., 2010). The provisions of the Mental Capacity Act (2005) were followed regarding whether a person lacks capacity.

Involving people with dementia in social research is in its infancy in China. I have searched some main websites and relevant national policy or regulations, such as the
National Occupational Standards for Old-Age Care Workers and the website of China Association for Alzheimer’s disease and the China National Committee on Ageing. Mental Health Act of the People Republic of China which was issued in 2012, it is the first and only law related to mental health on the area of practice and research. The Act doesn’t explicitly mention dementia, neither does it provide any principles to follow in relation to researching people with dementia who are unable to consent. It only says that in a clinical setting, such as regarding treatment or operation, if people unable to consent, the legal guardian has the right to consent and also needs to gain ethical approval from the ethics committee of that institution. Therefore, in practice, family members act as surrogates to make decisions about participating in research for the person with dementia. However, some organisations or institutions may have their own regulations regarding research with people unable to consent. As Shandong Mental Health Centre has no specific regulations in relation to research with people unable to consent and according to the Mental Health Act of the People Republic of China for people who did not have capacity for decision-making, the legal guardian or relative will sign the consent form if there are participants who are unable to consent.

**Family caregivers**--The information sheet (see appendix 4b) with detailed research information was sent to the potential participants, my contact details were provided on the information sheet to allow them to ask any questions relating to the study. For those who decided to take part in the study, written consent was gained from them before conducting the interview.

### 3.5.3 Informed consent among illiterate or less educated older Chinese.

One study indicated that informed consent is where patients are expected to participate in the decision-making process by weighing the benefits against the risks of recommended treatments (Kušec et al., 2006). Therefore, only when a patient is able to fully understand the benefits and risks of one treatment, then a competent decision can be made by this patient. However, Kušec et al (2006) document that there are a number of barriers in the process of decision-making which involve people with low levels of education or are illiterate in understanding the participated project.

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4 Resource from the Ministry of Civil Affairs, (MZ008-2001), Beijing, China
Regarding this, the authors recommended that using the appropriate language to make it easily understood for a less educated target population is very important in the procedure of decision making. Indeed, the information consent was written in a non-academic formulation, using common and simple words. This was significant across the decision-making process to enable the participants to be competent decision makers. Studies evidence that poor literacy skills not only lowers comprehension in understanding the procedure of the clinical care, but also affect the rate of participating within the clinical research (Tamariz et al., 2013). In fact, the authors indicate that the challenges of informed consent comprehension amongst low literacy populations can be accounted for by all stakeholders and across all of the sectors.

National Bureau of Statistics of China (2015) reports that the national literacy rate was 96 percent amongst the population of over 15 years old, which has increased by 30 percent since 1982, when the compulsory 9 years of school education was issued by Chinese constitution. However, regional disparities in literacy rate is still remarkable in China. Regional literacy disparities are strongly linked with economic background. For example, the illiteracy rate in Tibet had been at 37.33 percent compared to about 1.72 percent in Beijing. In Shandong where the current study was conducted, the rate of illiteracy was 6.65 percent. In the current study, the participants characteristic of education level (see table 1 and 2) shows that 8 out of 24 participants in the study were illiterate. In order for these participants to fully comprehend the aims, procedures and the benefits or the potential risks of participating in the study. I read the information consent individually to each of these 8 participants to improve informed consent understanding which was recommended by Tamariz, et al (2013). And then I explained the points which they did not understand or were concerned about by using their words (some words were in a local dialect). I also avoided using any technical terminology in the oral explanation of the information consent and written forms. In doing this, it required me to expect extra time consumption, this may not be suitable with a large sampling study, but it ensured that the decision making was comprehensive. The informed consents of the eight participants who were illiterate were signed either by themselves using a symbol or squiggle or signed by their doctors or family members. Afolabi et al illustrated a multimedia tool to explain study procedures by integrating video, animations and audio narrations in three major Gambian participants, which had significant effect in improving the participants’ comprehension with the informal consent of people with illiteracy (Afolabi et al., 2014).
However, considering the cost and the technical skills needed, this multimedia tool was not realistic for my study. In future studies, there may be a place for exploring a culturally appropriate approach to help low literacy older Chinese’ comprehension of information and consent in research.

3.5.4 Confidentiality

A pseudonym was used for each participant in writing up the research. Identifying information such as quotes used have been anonymised to ensure the participant is not identifiable. Only the research team had access to the original data. The digital data is stored in a password coded computer and all physical files are locked in safe place. All research-related information in this study was in line with the relevant legislation established within the Data Protection Act 1998 (Data Protection Act, 1998). However, it is difficult to guarantee confidentiality for those who are connected with the research sites, such as some clinics or hospital staff, and they may possibly recognise elements within the final account.

3.5.5 Reflection on ethical considerations

When the study involves human subjects, and particularly when there may be concerns about the participants’ capacity of decision-making, the researchers should be prepared to address all the related ethical issues. Ethical decision making is a common process in the fields of health and social care despite the matters of a moral and ethical nature having been viewed as complex and challenging (Hughes and Baldwin 2006). The researchers need to access carefully all of the potential risks to the participating individuals and balance the direct benefits to the individuals (Sherratt et al., 2007). A professional researcher should have the resources and skills to deal with these issues. The current literature on qualitative research participation reflects the broad changes of practice in involving people with dementia. Finding the appropriate ways to promote and facilitate the involvement is beneficial to understanding the needs of people with dementia, and more importantly, to avoid exploiting their rights and not paying respect to them when conducting research. However, the appropriateness of engagement with ethical issues and actively involving people with dementias in research by researchers has always been questioned in the literature (McKeown et al., 2010).

Ethical considerations in qualitative research, especially involving people who lack capacity in making decisions, is an area that will continue to present complexities and
dilemmas from time to time. However, as people with dementia become increasingly involved in research, it is inevitable that the processes of engaging with ethical issues around will be influenced by their engagement. Safeguards to protect vulnerable people and retention of their rights are absolutely essential but we also need to be aware of over-protection which may be a barrier for people with dementia in having the opportunity to participate in research. As researchers, our responsibility is not only to ensure to conduct an appropriate research procedure during some research projects, but also to find ways to involve and care for vulnerable participants; to enable them to actively engage in the study and make a meaningful contribution so that their perspectives of the world are being included and applied to their care and needs. So, I view the current study as a two-way process: a way to seek the answer to the research questions and a way to provide an opportunity for the participant’s experience to be listened to.

Furthermore, any interview questions which may cause an emotional reaction to have been carefully considered and designed before the process of interviewing, and I prepared how to deal with such emotional issues and responses. For example, if the participants appear to have any emotional reactions, such as crying or being distressed, I was prepared to give them time to calm down and allow them to drop out from the interview if they so wish. However, I found that most people who participated in the research had a positive experience and found it helpful that their voices were heard. There was one family caregiver who seemed to need emotional support and the village clinic physician was informed with the consent of the participant, and she was given the contact number of the China Association for Alzheimer’s disease. As Shandong Mental Health Centre is the gatekeeper, I continue to keep in close contact with them and am prepared to respond to any ethical issues that may be raised during the period of data collection, the data analysis and while writing the report.

3.6 Research method

3.6.1 Sampling strategy and inclusion criteria

IPA aims to obtain the specific experiences of an individual or a general account of a group or particular population in a specific context or environment. Therefore, the characteristic of homogeneity in the participants and idiography of the individuals’ subjective experience is required (DiCicco-Bloom and Crabtree, 2006). To commit to these conditions, a purposive sampling strategy is necessary (Smith, 2009). The
characteristics of the participants were homogeneous in their ethnicity, sociocultural context and sharing critical similarities related to the research question, however the social economic status, household income, education, housing and gender varied amongst them. This allows me to define the study group related to the research topic as well as making personal meaningful for the participants. Taking this into account, I need to consider that the selected participants who are interesting with and can provide information regarding the research topic. Purposive sampling is recognised as an appropriate strategy to answer the research questions by studying the experiences of a specific group of specific events or phenomenon (Smith, 2009). Another feature of IPA study is to gain full interpretation of each participant’s account; therefore, it requires a small sample size which allows a detailed and time consuming case-by-case analysis (Smith, 2009). But there is no particular rule of how many participants are needed, so I proposed to recruit 10-12 participants in each group - people with dementia and family caregivers which is based on the volume of the data needed for answering the research questions as well as the availability of the time length, funding, staffing and other resources.

In order to obtain particular insight of the research topic, the characteristics of the lived experiences of the particular event should be shared amongst the participants. One of the most obvious characteristics was that the selected participants must have been diagnosed with dementia or is looking after a person with dementia. With the type of dementia being complex and varied, it is not beneficial if I focused on one particular type of dementia for recruitment and answering the research questions. Therefore, I did not concern myself with the types of dementia when recruiting the participants. As the focus of the study is the Chinese people who are living with or caring for dementia, so others common characteristics of the participants are where they come from, and their experiences of a familiar cultural and social context. In addition, for the dementia group, having the ability to communicate verbally to share their experiences in this particular area is very important. Therefore, a recommended potential participant list from the hospital and clinic staff were initially accessed and obtained before the research information sheet was sent to the patients and their family caregivers. Moreover, another important feature of drawing the purposive sample is the selected participants not only have the potential to share their story of one particular experience, but also bring the aspect of contextual cohesiveness to the sample in terms of their shared perspectives on same culture, health, social care and political systems. Therefore, all the participants have been located in Shandong.
province. According to these above characteristics, I recruited participants who met the inclusion criteria below:

**Family caregiver**

- Participant who provides the main caring for people with dementia if there are more than one caregiver
- The period of caring for a family member with dementia must be over 6 months to ensure that the caregiver has sufficient experience to reflect on and comment on
- Participant must be an adult (over 18 years old)

**People with dementia**

- People with dementia have been formally diagnosed (some may not be informed of their diagnosis)
- People with dementia must be those with a recorded diagnosis of dementia with the severity of dementia ranging from mild to moderate
- People with dementia must be cared for in the communities

### 3.6.2 Choosing a research site

The research site was set in one of the mental health centres in Shandong province, China. This site was chosen because Shandong is the hometown of Confucius where the traditional culture of ‘xiao’ (filial piety) originated from. There is a total of 98.47 million people in Shandong, 13.67% of the whole population are over 65 years old (National Bureau of Statistics of China, 2011). However, according to Alzheimer’s Disease International in China (ADI-China), there are no official statistics of people with dementia and no authorised strategies or regulations in caring for people with dementia and very limited support services for people with dementia and their family caregivers. The mental health centre is one of few authorised institutions for dementia diagnosis and treatment with professional psychiatrists in the province. The centre is used for the treatment of mental illness, older health care combined with the rehabilitation of the three major business characteristics of the three specialist hospitals. The service is divided into psychological counselling, children's psychological development training, epilepsy treatment, neurology, geriatrics sub-specialist, and basic mental health care services in community clinics.
3.6.3 Participant recruitment

The participants were recruited from the mental health centre from both in-patient and out-patient services (hospital and clinics). They had been diagnosed with early or middle stage dementia by the psychiatrists in this health centre. The patients who met the inclusion criteria and were interested in the research were put on the recommended patient lists by the staff and the research information sheet was initially sent out from the centre by the doctors. Those who expressed an interest in taking part were invited to attend a meeting in the centre so that I could introduce myself and give a full explanation of the study and allow questions to be asked. The interview was conducted in the centre or participants’ homes. Since the focus of my study is to explore the impact of traditional culture on a person’s perception of people with dementia and their family caregivers, I therefore only approached those who live in their own homes or their children’s home and self-manage daily activities or were looked after by their family members. IPA focuses on gaining the specific experiences of the specific context and therefore a proposed sampling size was planned that was relatively small, but it must be shown no more new information emerging.

After interviewing eight people with dementia and thirteen family caregivers, there appeared to be no new information in the latter two interviews with people with dementia and one interview with family caregiver. According to Malterud et al’s (2010) work: study aim, sample specificity, use of established framework, quality of dialogue and analysis strategy are the key indicators of adequate sample size for a qualitative study. Consistent with this, the methodology of IPA proposes to obtain an in-depth analysis of narrative details from a few, select participants. Furthermore, the aim of the current study concerns a very specific experience, therefore, the recruitment was focused on participants with specific experiences of living with dementia or family caregivers who look after people with dementia, and had the specific characteristics to achieve the study aim. Malterud et al (2010) note that adequate sample size for qualitative studies can be guided by sufficient information power of the data. Therefore, once sufficient information power has been obtained and the data saturation has shown, the study did not seek further interviews.

The participants were from both urban and rural areas in Shandong province. The participants (see the table 1 and 2) were mixed, with 10 people with dementia and 14 family caregivers, one was a pair with a father and a daughter, and none of the other participants were in a pair in order to increase the opportunity for recruitment. The
participants of the dementia group consisted of 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 and two lived with home carers. In this group, there were six who 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’ group consisted of nine females and five males, whose ages ranged from 39 to 78, there were, five spouses, eight children and one mother. In this group, four participants were retirees, one was a teacher, one was a senior civil servant and two were industrial workers; the other ten family caregivers were either unemployed or farmers. All ten had no pension. All of the participants were of Chinese origin, with the rural participants being more likely to be living in villages and the urban participants were more likely to reside in residential blocks. They represented a range of social, geographical and educational backgrounds.
### Table 1 Characteristics of participants -family caregivers (FC)

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age</th>
<th>Education level</th>
<th>Location</th>
<th>Relationship with people with dementia</th>
<th>Occupation and income</th>
</tr>
</thead>
<tbody>
<tr>
<td>FC1 Guang</td>
<td>60</td>
<td>high school graduate</td>
<td>urban</td>
<td>daughter</td>
<td>retired with pension</td>
</tr>
<tr>
<td>FC2 Xue</td>
<td>42</td>
<td>high school graduate</td>
<td>urban</td>
<td>daughter</td>
<td>unemployed, No-income</td>
</tr>
<tr>
<td>FC3 Ying</td>
<td>73</td>
<td>illiterate</td>
<td>Urban</td>
<td>Wife</td>
<td>unemployed, No-income</td>
</tr>
<tr>
<td>FC4 Liu</td>
<td>65</td>
<td>high school graduate</td>
<td>urban</td>
<td>wife</td>
<td>Retired with pension</td>
</tr>
<tr>
<td>FC5 Ling</td>
<td>59</td>
<td>secondary school graduate</td>
<td>urban</td>
<td>son</td>
<td>retired with very low income</td>
</tr>
<tr>
<td>FC6 Mie</td>
<td>60</td>
<td>master degree</td>
<td>urban</td>
<td>daughter</td>
<td>retired with high pension</td>
</tr>
<tr>
<td>FC7 Wan</td>
<td>73</td>
<td>illiterate</td>
<td>urban</td>
<td>wife</td>
<td>unemployed, no income</td>
</tr>
<tr>
<td>FC8 Huan</td>
<td>76</td>
<td>illiterate</td>
<td>Rural</td>
<td>husband</td>
<td>farmer with very low income</td>
</tr>
<tr>
<td>FC9 Yu</td>
<td>51</td>
<td>primary school graduate</td>
<td>rural</td>
<td>son</td>
<td>farmer with low income</td>
</tr>
<tr>
<td>FC10 Shou</td>
<td>50</td>
<td>secondary school graduate</td>
<td>rural</td>
<td>son</td>
<td>farmer with medium income</td>
</tr>
<tr>
<td>FC11 Xu</td>
<td>64</td>
<td>diploma</td>
<td>rural</td>
<td>son</td>
<td>retired with pension</td>
</tr>
<tr>
<td>FC12 Gui</td>
<td>72</td>
<td>illiterate</td>
<td>rural</td>
<td>mother</td>
<td>farmer very low income</td>
</tr>
<tr>
<td>FC13 Yan</td>
<td>39</td>
<td>diploma</td>
<td>rural</td>
<td>daughter</td>
<td>unemployed average income</td>
</tr>
<tr>
<td>FC14 Jin</td>
<td>78</td>
<td>illiterate</td>
<td>rural</td>
<td>wife</td>
<td>farmer with low income</td>
</tr>
</tbody>
</table>
Table 2 Characteristics of participants - people with dementia (PWD)

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Education level</th>
<th>Type of dementia and medical report of dementia stage</th>
<th>Location</th>
<th>Income</th>
<th>Care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWD1 Wen</td>
<td>male</td>
<td>72</td>
<td>diploma</td>
<td>VaD/mild/urban high income</td>
<td>daughter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD2 Yi</td>
<td>male</td>
<td>85</td>
<td>primary</td>
<td>AD/mild/urban high income</td>
<td>son</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD3 Jing</td>
<td>male</td>
<td>67</td>
<td>high school graduate</td>
<td>AD/mild/urban average income</td>
<td>daughter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD4 Liang</td>
<td>male</td>
<td>78</td>
<td>illiterate</td>
<td>VaD/mild/urban average income</td>
<td>home carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD5 Chuan</td>
<td>female</td>
<td>73</td>
<td>illiterate</td>
<td>VaD/moderate/urban low average income</td>
<td>home carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD6 Yie</td>
<td>female</td>
<td>76</td>
<td>secondary school graduate</td>
<td>AD/mild/urban no income</td>
<td>son</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD7 Yin</td>
<td>male</td>
<td>87</td>
<td>diploma</td>
<td>AD/moderate/urban no income</td>
<td>daughter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD8 Shen</td>
<td>male</td>
<td>72</td>
<td>illiterate</td>
<td>PDD/mild/rural low average income</td>
<td>sons and daughters</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD9 Zong</td>
<td>male</td>
<td>80</td>
<td>secondary school graduate</td>
<td>AD/moderate/rural high income</td>
<td>daughter and son</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PWD10 Shao</td>
<td>male</td>
<td>72</td>
<td>primary</td>
<td>AD/mild/rural low average income</td>
<td>wife</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

3.6.4 Data collection

Semi-structured interview was the data collection method used to conduct this study rather than observation. In comparison with focus group interviews, semi-structured individual interviews provide an opportunity to gain a rich, detailed and personal account of one’s experience (Smith, 2009). On the other hand, focus groups tend to answer questions which will give rise to evaluations and positioning and it is suitable for collecting third-person stories rather than personal experiential narratives (Smith, 2009). Arksey and Knight indicate that ‘qualitative interviews examine the context of thought, feeling and action and can be a way of exploring relationships between
aspects of a situation’ (Arksey and Knight, 1999, p.32). They also state that semi-structured interviews provide an opportunity for the interviewer to seek further explanation or clarify the answers by probing or prompting questions. As discussed in the above, IPA requires a rich, detailed and first-hand data from participants. Therefore, semi-structured interviews are a suitable method to capture people’s perceptions, feelings and understanding in the study. To compare, participant observation offers the opportunity for the researchers to see what the participants are actually ‘doing’ directly, rather than only hearing what they are ‘saying’. However, a person’s feeling and perspective cannot be known by only observing what they have done. Also, relying on observation may cause certain flaws as the participants know they are being observed; their behaviour might be less natural and may not demonstrate how they normally behave (Bryman, 2012).

Interview questions are deduced from the five secondary research questions and aim to answer the main research question. They are organised around a set of questions (see appendix 6a and 7a) which focuses on exploring the meaning of the participants’ experiences, the impacts of the current sociocultural transitions on their life and their coping strategies with the ‘altered’ life. There are also other questions emerging from the conversations. These interview questions were designed with open-ended question to allow the participants to fully express their viewpoints, and this provides an opportunity for new themes to emerge (Turner III, 2010). The interview questions with people with dementia were designed with simple words and short sentences to accommodate and challenges with understanding and communicating. For example, in order to answer the research question ‘What does living with dementia mean to you?’ I asked participants the following questions: How long have you had memory problems? How do you feel since you’ve had these problems? Brooker (2007, p.65), derived from Kitwood (1997), has drawn three points to appreciate the perspective of people with dementia (see box 5):

**Box 5 Brooker’s three points to appreciate the perspective of people with dementia**

- Listening to and reading direct accounts of the experience of people with dementia
- Attending carefully to the actions and words of people with dementia
- Using imagination to understand the experience of dementia
In consideration of Brooker's (2007) suggestions, I have always been careful when listening and responding to participants and note down their meaningful actions such as gestures and other emotional responses during the process of data collection. And in later data analysis, imagination was used to lay myself in that first-person position to interpret and understand the meaning of the participants' subjective experience. The participants were interviewed individually by the researcher and on one occasion. The interviews were conducted in the hospital and in the participants' own houses depending on their preferences. Sixteen interviews were conducted in the hospital while eight at homes. According to DiCicco - Bloom and Crabtree (2006), a safe, familiar and comfortable environment is a critical component to share the individual interviewee's personal experiences and establish rapport. The interviews were conducted in Mandarin (the official language of China) and lasted between 30 and 60 minutes. The interviews were audio recorded by using a digital recorder and which was agreed by the interviewees. Taking into consideration the impact of cognition and communication abilities of person with dementia, the length of interviews with people with dementia was took generally shorter time period than family caregivers – approximate 30 minutes to 1 hour respectively. As it was not always clear how much the participants with dementia knew about their condition, diagnostic terms such as 'dementia' or 'Alzheimer's disease', were avoided in the conversation unless the participants mentioned it themselves. 'Memory loss' or 'forgetting' were instead used in the conversation. Following with the conversations and interviews, half of people with dementia have presented that they know they had dementia, but two of them said: 'this is because I am old'. Most of the family caregivers have used the words 'dementia' or ‘Alzheimer's disease’ during the interview, but most of them have understood the term as ‘forgetting’.

Prior to the interviews, preparation was done regarding what questions to ask in the starting of the interview, how to get the interviewees talking and how to response with the interviewees’ emotional reactions. During the interviews, field notes (see box 6) were used to note any important non-verbal or emotional responses or any specific requirements that needed further actions. In the process of interviewing, one lady with dementia was upset and cried, I suggested a break and offered her a drink. She insisted on continuing with the interview after I gave the opportunity for me to come back to do it later. One family caregiver seemed to need emotional support and the village clinic physician was informed with the consent of the participant, and the
caregiver was given the contact number of the China Association for Alzheimer’s Disease.

Box 6 Samples of Field Note

- I meet Shen in the hospital ward. He lies in bed, motionless, and appears to not want to talk to anybody. My first impression is that Shen seems to be an unhappy and serious man, he hardly smiles and has a sad face. However, he was interested in my study after the doctor introduced me to him. I feel that he expected me to be an expert who can help him. I also feel that he is lonely and wants to chat with somebody. I think these are the possible reasons for him to agree to have an interview with me. He agrees to conduct the interview that afternoon. When the afternoon come, I go back to the ward again, I see Shen walking slowly across the corridor with his cane. He appears to be happy to see me. During the interview, Shen talks a lot and refuses to take any drink which I offer to him when he coughs. He talks a lot about his family situation, especially with his grandson’s illness and how he borrowed money from his daughters because of his grandson's hospital bills. The financial problem faced by him is probably stresses him the most. After 20 minutes of talking, he starts to cough a lot and looks tied even though he still keeps on talking. This interview is completed in less than 30 minutes [Field note, 13.09.2015].

- Used to see Ye stumble along the hospital corridor like an invisible person, who never talked to anybody. She suddenly burst into tears when talking about how her family forbid her from going to the kitchen and how her friends stopped her from attending the morning exercise group. This makes me feel surprised, shocked and a little guilty by causing her to feel sad. Is her crying because of how she has been treated by others because of the isolation and exclusion she has perceived or crying about losing her role in the social relationship? I offer her a drink and a break, but she insisted carrying on talking. Is this because she cherishes the chance to talk about her story or because she just wants somebody to listen to her. How will her emotional response effect later data analysis? [Field note, 04.10.2015].

3.6.5 Data analysis

Interpretative phenomenological analysis was adopted in the study for data analysis. Data analysis in IPA involves moving from the particular to the shared and from phenomenological to interpretative (Smith, 2009). In committing to the idiographic of an IPA study, the data was analysed case by case. After all of the single cases were analysed, an across cases analysis was carried out to obtain a deep level of interpretation from the study. The emerged themes were discussed with my
supervision team. NVivo software was used to manage the transcripts of the records of interviewing and the field notes. The process of analysis followed Smith's (2009) six steps.

To consider the translation challenge of Van Nes et al (2010), they claimed that ‘concepts in one language can be understood differently in another language’ (p. 313). For example, in Mandarin the expression ‘older cow’ is a metaphor that means a person is hard worker, which would be difficult to understand for a native English speaker. I did the first coding of data analysis in Mandarin in order to preserve the originality of content and meaning. Therefore, the data analysis stayed in Mandarin until emergent themes were developed, then I translated the new themes into English. To resolve the issue that my supervisors were not familiar with Mandarin, four example interview descriptions translated into English were shared to show the process of data analysis. In order to keep the accuracy and correctness of the translation, adequate thought and attention to all of the translated data was recommended (Van Nes et al., 2010). In doing so, I frequently went back to the first coding to check the interpretation and keep record of any issues or doubts in case something needed to be further adapted later.

**Step 1: Reading and rereading**

I listened to the recording of the interviews several times before transcribing the data in order to familiarise myself with the data and fully engage with the participants' accounts. After transcribing, the transcriptions were also re-read to ensure the accuracy. Smith (2009) state that re-reading allows the researcher to be involved in an active engagement with data analysis and to shift the generic explanations to the specifics of particular experiences. Repeated listening also helped to pay attention to the aspects of non-verbal response beyond the voice being caught (e.g. crying and laughter). The rereading can help to reduce the level of the analyst's own power effect on the transcript and allows to develop a model of the overall interview structure of the data analysis (Smith, 2009).

**Step 2: Initial noting**

Line by line commenting is required in this stage. This step is to examine semantic content, language and context on an exploratory level. Researchers are required to note anything that they are interested in from what the participants saying. Such interpretative noting helps researchers to understand why participants are concerned
with these specific things. I have hand written detailed notes on the transcripts (see appendix 8a and 8b). For example, asking the questions of why a phenomenon is important and particular to the participants; identifying the aspects of the phenomenon which I am interested in from the accounts. This initial analysis was conducted manually on the right-hand column in my notebook, beside sections which appeared relevant to the participant's experience. Initial notes and comments were recorded free and open, then gradually they were made to be more specific and briefly grouped. Through line by line analysis, notes and comments were grouped or 'coded' to prepare to structure into emerging themes. I illustrated this process in table 3, which contains some original transcripts and the exploratory comments from the interview with one participant, Xue (pseudonym), a family caregiver, talking about her experiences of looking after her father (see table 3).
<table>
<thead>
<tr>
<th>Original transcript</th>
<th>Exploratory comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: What have you gained from looking after your father?</td>
<td>Xue answers the question hesitantly, is she thinking or is the answer difficult for her to say? Using the words such as ‘whatever’, ‘must’, what does Xue want to express? Claims children’s responsibility but seems overwhelmed by it. Confirms the important gain for her, filial piety is the culture value.</td>
</tr>
<tr>
<td>P: Having any gain? …It is my responsibility to look after my parent… After all, he is my father, whatever difficulties I have…I must to look after him. The most important thing for me is the fact that I have played as a role model for my son, he will carry the culture of filial piety as he watches me do it. Err… this is the biggest gain.</td>
<td></td>
</tr>
<tr>
<td>I: Can you tell what you gave up because you had to look after your father?</td>
<td>Definitely answered about her loss or sacrifice of looking after her father. Talking about not being able to attend social activities to physical and emotional effects to show what she has given up. Found it exhausting and life effecting. Emphasizing answer to emphasize the effects are huge for her</td>
</tr>
<tr>
<td>P: I think that I give up a lot, I gave up all of social activity because I had to stay at home. Because of this, I am in a bad mood, there is no physical activity. Along with shortage of sleep. All of these damages my health. From a financial point, I cannot do something which I would like to do because there is no income. My job, life and health are all gone.</td>
<td></td>
</tr>
<tr>
<td>I: If you can have a choice, do you consider sending your father to a nursing institution?</td>
<td>The participant has considered other options for looking after her father, but were unsuccessful because there were no suitable or satisfactory care institutions. Negative description of care institutions. Talking about the problems of care homes. Make clear of her choice.</td>
</tr>
<tr>
<td>P: Yes, I would. I have been looking 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, I don’t want to send my father to there. I want my father to have a good quality of life.</td>
<td></td>
</tr>
</tbody>
</table>
**Step 3: Developing emergent themes**

This step focuses on looking for emergent themes, in order to do this the ‘volume of detail’ of transcript and initial notes needs to be reduced, but the complexity of interrelationships, connections and patterns were retained. I used the exact words and phrases from the participants to head the emerged themes to maintain the focus on their perspectives. This stage involves description and interpretation, and the emergent themes reflect both the participant’s original words and the research's interpretation. Emerging themes captured patterns of meaning within the data and were entered into a right-hand column of the section which were connected to the participants’ accounts. This analytical process served to abstract the individuals’ experience and meanings behind what the individual participants had said and was influenced by the context (see table 4).
Table 4 Developing emergent themes

<table>
<thead>
<tr>
<th>Original transcript</th>
<th>Exploratory comments</th>
<th>Emergent themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>I: What have you gained from looking after your father?</td>
<td>Xue answers the question hesitantly, is she thinking or is the answer difficult for her to say?</td>
<td>Looking after parents is the children’s responsibility</td>
</tr>
<tr>
<td>P: Having any gain? ...It is my responsibility to look after my parent…. After all, he is my father, whatever difficulties I have…I must to look after him. The most important thing for me is the fact that I have played as a role model for my son, he will carry the culture of filial piety as he watches me do it. Err… this is the biggest gain.</td>
<td>Using the words such as ‘whatever’, ‘must’, what does Xue want to express? Claims children's responsibility but seems overwhelmed by it. Confirms the important gain for her, filial piety is the culture value.</td>
<td>It is an obliged job</td>
</tr>
<tr>
<td></td>
<td>Definitely answered about her loss or sacrifice of looking after her father. Talking about not being able to attend social activities to physical and emotional effects to show what she has given up. Found it exhausting and life effecting. Emphasizing answer to emphasize the effects are huge for her</td>
<td>It is a cultural belief</td>
</tr>
<tr>
<td></td>
<td>The participant has considered other options for looking after her father, but were unsuccessful because there were no suitable or satisfactory care institutions. Negative description of care institutions. Talking about the problems of care homes. Make clear of her choice.</td>
<td>Play a role model</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gaining</td>
</tr>
<tr>
<td>I: Can you tell what you gave up because you had to look after your father?</td>
<td></td>
<td>I give up a lot as I had to do it</td>
</tr>
<tr>
<td>P: I think that I give up a lot, I gave up all of social activity because I had to stay at home. Because of this, I am in a bad mood, there is no physical activity. Along with shortage of sleep. All of these damages my health. From a financial point, I cannot do something which I would like to do because there is no income. My job, life and health are all gone.</td>
<td></td>
<td>(physical, emotional, social)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tiredness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of money</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pessimistic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I cannot carry on</td>
</tr>
<tr>
<td>I: If you can have a choice, do you consider sending your father to a nursing institution?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P: Yes, I would. I have been looking 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, I don’t want to send my father to there. I want my father to have a good quality of life.</td>
<td></td>
<td>No alternative choice for me</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative attitude of care institutions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I have responsibility to looking after my father</td>
</tr>
</tbody>
</table>
Step 4: Searching for connections across emergent themes

This process is to abstract and identify patterns between the emergent themes. I reworked the transcript to ensure the accuracy. By doing this, all of the emergent themes were listed in chronological order (the time that they came up) to find connections and patterns within them. It is very important to re-evaluate the themes by coming back to the original text to ensure the consistent use of the same themes. Any themes that didn’t have sufficient data supporting them were discarded in this step. Smith (2009) suggested several specific ways to look for patterns between the themes: such as, abstraction (a new title is developed by clustering and grouping the similar themes to form a super-ordinate theme), subsumption (related themes are linked together under one super-ordinate theme) or contextualization (connecting the related themes to the series of critical events for the participant). Among these different ways, I have used abstraction (see box 7) to organize and group the emergent themes to sub-themes and then super-ordinate themes.

Box 7 Abstraction leading to the development of a super-ordinate theme

<table>
<thead>
<tr>
<th>Negotiating the role</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is my responsibility (Looking after parents is the children's responsibility; it is an obliged job; I give up a lot as I had to do it; no alternative choice for me; I have responsibility to looking after my father)</td>
</tr>
<tr>
<td>I cannot cope (Physical, emotional, social impacts; tireless; I cannot carry on)</td>
</tr>
<tr>
<td>My role and responsibility have been changed (They not let me go to Kitchen, I treat she same as a child)</td>
</tr>
</tbody>
</table>

Table 5 illustrates the super-ordinate themes and themes from one participant (Xue). As the volume of data increased, I utilised NVivo 10 (a qualitative research data management tool) to locate, organise and track the data. This allowed me to retrieve excerpts from the transcripts and enabled a hierarchical structure of identified themes to be created by providing a clear picture of the number of times a particular theme emerged within each case and later across all cases.
Table 5. The super-ordinate themes and themes from one participant.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Page/Line</th>
<th>Key words</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Negotiating the role</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is my responsibility</td>
<td>2. 68</td>
<td>it is my responsibility</td>
</tr>
<tr>
<td>My role and responsibility has been changed</td>
<td>5. 163</td>
<td>I no need to look after him</td>
</tr>
<tr>
<td>I cannot cope</td>
<td>1. 37</td>
<td>cannot solve it</td>
</tr>
<tr>
<td><strong>The meaning of living with dementia in the social context</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I need your support</td>
<td>2. 49</td>
<td>nobody there</td>
</tr>
<tr>
<td>The dilemma of the long-term care services</td>
<td>3.117/5.173</td>
<td>too bad, only me</td>
</tr>
<tr>
<td>I need more money</td>
<td>3. 85</td>
<td>not enough money</td>
</tr>
<tr>
<td><strong>The meaning of responsibility in the cultural context</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I play a role model</td>
<td>2. 71</td>
<td>played as a role model,</td>
</tr>
<tr>
<td>The ways of being filial is different</td>
<td>4. 156</td>
<td>caring is different</td>
</tr>
<tr>
<td>The changing perception and norms of filial piety</td>
<td>4. 144/147</td>
<td>cannot be valued by money</td>
</tr>
<tr>
<td><strong>Coping with the ‘altered’ life</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The settled life</td>
<td>4. 138</td>
<td>a better care and live longer</td>
</tr>
<tr>
<td>Being filial is a coping strategy and other ways of coping</td>
<td>2. 72</td>
<td>he will carry the culture of filial piety as he watches me do it</td>
</tr>
<tr>
<td></td>
<td>1. 27</td>
<td>I will scold my son to relieve my angry</td>
</tr>
</tbody>
</table>

Step 5: Moving to the next case

In committing with the idiography of IPA, the researcher is required to analyse databases case by case and to bracket the ideas and themes from the first data analysis before going to analyse the next case. This is very time consuming, but helps to obtain a detailed and deep analysis which also helps to quickly recognize the new emerged themes in the next case.

Step 6: Looking for patterns across cases

Having analysed all of the cases, strong interpretation is evident in this stage. In order to find patterns across all of the cases, I developed a master table (see table 6) to
present the emerging themes and connections over time as all of the data was collected and began to provide a sense of ‘super-ordinate’ themes and ‘subordinate’ themes (Smith, 2009). A master table allows the research to be clearer and makes it easier to look for connections amongst emerging themes without missing the important information. In practice, it means compiling themes from all of the cases to look for connections and clusters by constructing similar themes. Some of the themes may be dropped at this stage if they do not fit well with the emerging structure or because they have a weak evidential base. Then the final list is comprised of numerous superordinate themes and subthemes. In this process, I extracted the familiar or relevant excerpts from the transcripts and grouped them to illustrate meaning and context. After this, I moved back and forth across the emergent themes to check that the sub-themes were reflected in the transcripts. Then grouped these sub-themes into themes and super-ordinate themes (Smith, 2009) (see figure 1 in the finding chapter).
Table 6 Master table of themes for the group of participants

<table>
<thead>
<tr>
<th>One example of the experience of responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is my responsibility</td>
</tr>
<tr>
<td>FC1 Guang: ‘my sisters and I share the responsibility of looking after her (mother).”</td>
</tr>
<tr>
<td>FC2 Xue: “It is my responsibility to look after my parent…. after all, he is my father.”</td>
</tr>
<tr>
<td>FC4 Liu: “I have no other option…”</td>
</tr>
<tr>
<td>FC5 Song: ‘My younger sister and I all help with the daily activities. She is mainly responsible for washing the dirty clothes while I take care of our father’s personal hygiene and do the most of cooking.”</td>
</tr>
<tr>
<td>FC6 Mei: “Three of us (sisters) take turns to look after our mother.”</td>
</tr>
<tr>
<td>FC8 Huan: “I have no choice, what I care about is the marital relation, this is the reason, I [feel that] I have more responsibility to look after her.”</td>
</tr>
<tr>
<td>FC9 Yu: “I never think about it [sending mother to care home], she is my mother.”</td>
</tr>
<tr>
<td>FC10 Shou: “What is my thought? I have no opinion, she is my mother, what else can I do?”</td>
</tr>
<tr>
<td>FC11 Xu: being filial is the</td>
</tr>
<tr>
<td>FC12 Gui: “what can I do? I need to feed them once I alive.”</td>
</tr>
<tr>
<td>FC13 Yan: “My mum has had a hard life since she was married to my dad. She looked after the whole family and worked hard, like an ox. That is also the reason she got ill at this age, therefore as a daughter I need to take my responsibility and look after her.”</td>
</tr>
<tr>
<td>FC14 Jin: “I (financial) rely on my eldest daughter, as I told above, she paid that 7,000 yuan for my husband hospital cost.”</td>
</tr>
<tr>
<td>PWD2 Yi: “I didn’t take my children responsibility for my parents when I was younger. Now, I cannot do anything about it.”</td>
</tr>
<tr>
<td>PWD5 Chuan: “I have one son…he would buy stuff for me if I needed it.”</td>
</tr>
<tr>
<td>PWD6 Yie: “They all help me, my daughter helps me to wash clothes once she is here and my son helps with cooking.”</td>
</tr>
<tr>
<td>PWD7 Yin: “My son, my daughter-in-law, and most of my daughter-in-laws look after me.”</td>
</tr>
<tr>
<td>PWD9 Zong: “I left some money for my son, for him to spend on his family since he has a low salary.”</td>
</tr>
<tr>
<td>PWD10 Shao: “I …have a son and daughter. They would buy the materials that we need for life.”</td>
</tr>
</tbody>
</table>

3.7 Reflection and reflexivity

3.7.1 Reflection on methodology

Despite there being clear differences between qualitative and quantitative approaches, some researchers think that choosing qualitative or quantitative approaches in studies is more related to how the researcher positions himself/herself within a particular
discipline or research which is popular in its settings, culture or literature than considered purely with methodologies. The choice of which approach to use may also reflect the interests of those conducting or benefitting from the research and the purposes for which the findings will be applied. Despite filial piety being an important social role in Chinese societies, social conditions are changing which lead to redefining the children's responsibility to their older parents. Therefore, it is critical to understand the meaning of the perceptions of this term for most of the services users in order to make the services better. In correspondence to this, a qualitative study has been used for the current study.

The philosophical underpinning of study is the important research guidelines to know how to conduct a research project. It is critical to the quality of the study as it enhances the ability to notice potential research problems that may arise during the process of conducting the research and has the ability to defend the findings to supporters and critics. For the researcher, understanding the philosophical underpinnings of a research project helps to raise good research questions and guide the project to move from one phase to the next by selecting the appropriate tools to answering the research questions. Hathaway (1995) indicates that the appropriateness of methodology selection is more critical than the technical tool used regarding the quality of a research. Meanwhile, choosing a research method may be influenced by universities and other organizations who are affiliated with the research. Decisions about which kind of research method to use may also be effected by the researcher's own experience and preference, the aim of the findings, the population being investigated and the availability of time, money, and other resources (Hathaway, 1995). The aim of the current study is to understand the individual experiences of living with and caring for people with dementia in communities. Phenomenological inquiry was adopted to investigate the perspectives of the participants by using semi-structured interviews.

3.7.2 Reflexivity

In addition, reflexivity is an ongoing self-awareness during the process of research, and it increases the validity of research as it makes the process of research more visible and supports the construction of knowledge within research (Pillow, 2003). Pillow suggests that different historical and personal cultural values can influence researchers in different ways in planning, doing and analysing their study. Therefore, in qualitative research, it is very important to critically analyse how one’s
epistemological and ontological assumptions influence the data analysis and the research as a whole (Mauthner and Doucet, 2003). Within IPA, self-reflexivity is a methodological tool to understand how meanings have been described and interpreted by the researchers. Throughout the process of the study, I always considered how my position influences me from the stage of planning the research to writing up the thesis. For example, I considered how my background as a nurse influences me in designing the research, what I see or hear in the research site, interacting with my participants, and interpreting the data. As a female Chinese researcher, my position will have unavoidably influenced the process of interview and the data analysis. Therefore, it is very important for me to consider how ‘cultural intuition’ influences me in the process of the study (Hogarth, 2010). For example, I have the same ethnic background as my participants. As we share similar beliefs and cultural values, these may help me to integrate easily with the participants and to understand the meanings of their experiences. However, these perceived similarities may also limit me in discussing some topics that I already know from my prior knowledge or the previous literature. For example, I could ask the question of the meaning of filial piety for the person with dementia or their family caregivers, but it is difficult to directly discuss whether the children are being filial to their parents as this is impolite from a cultural perspective. As a result of this, some meanings might be lost because questions have not been touched. Furthermore, I need to critique my assumptions related to cultural stereotypes, such as the ideas of the female role in supporting family members and the stigma of dementia. Such assumptions may lead to some impacts on the process of data analysis. Therefore, I have always critiqued these assumptions and considered how my position has influenced the current study.

In phenomenological inquiry research, particularly when using semi-structured interviews as the method, the researcher becomes the research tool so a reflexive approach which addresses not only what the researcher came to know but how the researcher came to know it is important. Therefore, in the process of the study, I have showed why I was interested in this topic, how my background influenced what I was interested in and what I considered to be important. During the interview, sometimes my emotions were swayed dramatically. I was stressed and frustrated by the situation and despair of the participants. There was one case of interviewing an older mother who looked after her two sons with dementia without any informal and formal support, and her lived experiences has echoed for days and months with me. It took me a long time to get back into my role and to realise the importance of my role as a researcher.
I was shocked by the intensity of the work – there was so much going on. I did find it hard to focus on what was working and it has taken me a long time – it was only after leaving the field that I was really able to grapple with this. I was amazed at the way the participants interacted with me and actively attended the study. It is hard to describe how rewarding that can be. I think a challenge for me in writing was how much of myself to put in the writing, while on one hand I wanted to produce responsible knowledge and show how I had produced it, but on the other hand, I was dealing with highly emotive issues and objective knowledge, especially as the result of having two distinct cultural understandings about dementia. I think I have held back on this and it is something I might be more aware about in the future.

I think I am now much more skilled and confident with qualitative research. I am also much more aware of the problems with a medicalised approach to view people with dementia and alert to the assumptions that a lot of people seem to make and the ways that people with dementia are stigmatised and put into boxes and labelled – things I did unknowingly myself in the past. I am also much more aware of the importance of the social model and the contributions they have made and the importance of not losing that in our attempts to ensure that the health and medical needs of people with dementia are met. I find myself being a much louder advocate for people with dementia as active citizens and an advocate for family caregivers and that the work they do should not be undermined.

3.8 Summary

The chapter above has presented the theoretical framework, methodological approach and method of this study. Interpretative phenomenological analysis has been used in this study. The participants were recruited from list of in-patients and out-patients from one of the mental health centres in Shandong province, China. Semi-structured interviews with people with dementia (n=10) and family caregivers (n=14) were conducted in both urban and rural areas. The interviews were transcribed and have been analysed using an adaptation of Smith’s (2009) 6 steps of interpretative phenomenological analysis (IPA). This chapter has also identified the ethical complexities of using semi-structured interviews with people with dementia during the field work and how I have addressed some practical problems during the field work. I have also illustrated the process of data analysis, and discussed my position within the research and how it has affected this study. The quality, validation
and limitations of the current study has also been discussed in the chapter above. The next chapter will explore the findings of the study.
4. Chapter Four: Findings

4.1 Introduction

IPA has been used for the systematic processes of data collection and data analysis. Data analysis has involved the description and interpretation of the first person accounts of participants with dementia or family caregivers and the researcher’s understanding of the first-person perspective (Larkin, 2006). For a more detailed account of the process of data analysis, please see Chapter 3. The analysis of data in this study is primarily at an individual level, the final emergent themes are grouped from all of the participants (Smith, 2009). The focus of my dialogue with participants is on their perspectives of family responsibility, as experienced by someone with dementia or their family caregivers, in their specific personal context and time. By actively engaging with, and giving careful attention to these personal accounts, my intention is to: (a) Gain a deep understanding of the participants' points of view. (b) Engage in a process of shared meaning making with the participants. (c) Develop a detailed, in-depth and transparent account of the meaning of the data (Smith, 2009).

The study provides an in-depth exploration of the lived experience of family caring responsibility of people with dementia and family caregivers in China in the areas: how they negotiate with their changed roles, how the social and cultural transitions have affected their life, what are their expectations from society and how they applied their own ways to adapt to the 'altered' life. It provides evidence of the influences of the social and cultural context on family responsibilities, coping strategies and quality of life.

This chapter presents the emergent themes from the current study in detail. A diagram (see figure 1) has been used to present the 'super-ordinate themes' and related 'subordinate themes' (Smith, 2009). Then, in the following section, a detailed presentation of the findings under each super-ordinate theme and its related subordinate themes are described. According to Smith (2009), abundant quotes from the participants were needed to demonstrate the description and interpretation of the narratives. Therefore, in this section, I have not focused only on findings about ‘what the meaning of the lived experiences’ is for the participants from an interpretative view of a researcher, but also I have provided lots of original extracts from the participants for the readers themselves to judge the value of the interpretation.
4.2 The diagram of the superordinate themes and related subthemes

<table>
<thead>
<tr>
<th>Negotiating the roles</th>
<th>The meaning of life in the social context</th>
<th>The meaning of responsibility in the cultural context</th>
<th>Coping with the ‘altered’ life</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is my responsibility</td>
<td>My life beyond the social environment</td>
<td>Being filial is cultural continuity</td>
<td>Being filial is a coping strategy and other ways of coping</td>
</tr>
<tr>
<td>My role and responsibility has been changed</td>
<td>I need your support</td>
<td>Different ways of being filial</td>
<td>Death is a way to reduce the burden</td>
</tr>
<tr>
<td>I cannot cope</td>
<td>They don’t believe me</td>
<td>The changing perception and norms of filial piety</td>
<td>The settled life</td>
</tr>
<tr>
<td>I have no plans for the future</td>
<td>I need more money</td>
<td>The dilemma of the long-term care</td>
<td></td>
</tr>
</tbody>
</table>

Figure 1: Superordinate themes and related sub-themes

4.3 Findings

Four superordinate (main) themes have been identified through the participants’ accounts. They are ‘negotiating the roles’, this theme includes the perception of responsibility, the loss, the changed relationships and roles of people with dementia and family caregivers. It highlights the challenges, burden and stress they have perceived through the period of living with or caring for dementia undergoing the social and cultural transitions in China. ‘The meaning of living with dementia in the social context’ highlights how the social and physical environment have affected the meaning of life, have shaped the meaning of family responsibilities and relationships; which is associated with social influence about the sense of responsibility and the distribution of responsibility between individuals and society, the issue of who should be taking the responsibility, and how this influences the participants’ lived experiences. ‘The meaning of responsibility in the cultural context’ illustrates the cultural meaning of being filial, the ways of taking filial responsibility, the difference between filial piety and responsibility and the tendency of the traditional value. ‘Coping with the ‘altered’ life’ captures the participants’ efforts in the development of coping strategies with the
changed life and their sense of the relationship between death and responsibility. These themes are shaped around the status of people with dementia within a family and within the society. They reveal the different meanings of the responsibility over the period of living with dementia among individuals and its dynamic change within a specific social and cultural context.

4.3.1 Superordinate theme 1: Negotiating the roles

The superordinate theme captures when participants are talking about responsibility which reflects the changes in the participants’ life through the participants’ descriptions of what life was like in the past and what their lives are like now. All of the participants believe that living with dementia or taking up a caring responsibility with people with dementia has changed their ‘normal’ life. In the narratives gathered from participants, the meaning of living with dementia and caring for those with dementia was explored. Experiences of stress, impact on family relations and how this has changed participants’ lives and shaped the meaning of responsibility were themes emerging.

![Diagram](image)

**Figure 2 Superordinate theme 1: Negotiating the roles**

This main theme includes four subordinate themes (see the figure 2): It is my responsibility; my role and responsibility has been changed; I cannot cope and I have
no plan for the future. ‘It is my responsibility’ describes the reasons for the participants making caring decisions and their perceptions of caring responsibility. ‘My role and responsibility have been changed’ describes the experiences of loss, which is related to losing identity, losing/changing roles, sense of self, and how these factors have affected the meaning of responsibility for the participants. ‘I cannot cope’ is related to the difficulties that participants face in managing daily activities and its impact on them. This includes the reduced social activities and social connections, the changed relationship with family members, friends and others, and the affected body. ‘I have no plan for the future’ expresses the participants’ loss of hope for the future and their future perspectives, which is associated with the lack of support from health professionals, politicians and the society.

4.3.1.1 It is my responsibility

Having been influenced heavily by Confucianism, Chinese people hold a strong sense of family responsibility. In the study, all of the participants have the awareness that looking after their loved one is their responsibility. However, because of the cultural value and the law enforcement, as well as many other social factors, looking after parents has become a compulsory mission and personal burden, rather than a personal decision in the contemporary China. The sense and the meaning related to responsibility has been expressed differently from family caregivers. Here, I have not analysed the precise detail of responsibility. Rather, the aim is to capture the perceptions and feelings by letting the participants tell the stories and the meaning of responsibility from their experiences. The following extracts of family caregivers explain the different meanings of family responsibility.

With Yan, looking after her mother is an obligation and repayment. She says:

‘…My mum has had a hard life since she was married to my dad. She looked after the whole family and worked hard, like an ox. That is also the reason she got ill at this age, therefore as a daughter I need to take my responsibility and look after her. I don’t want my mother to have a bad quality of care, I want her to have a good life.’ [FC13, Yan, line116].

For Yan, feeling as being indebted to her mother’s past life created a sense of responsibility for her mother. While she agrees that as a child she has a responsibility to look after her mother, a strong feeling of repayment also appears. As well as being aware that looking after parents is children’s responsibility, a perception of being
forced or obligated also appears with the participants. For example, in regarding children’s responsibility, similar ideas were expressed by Xue and Shou:

‘…It is my responsibility to look after my parent… after all, he is my father, whatever difficulties I have…I must look after him.’ [FC3, Xue. Line 67].

‘What is my thought? I have no opinion, she is my mother, what else can I do?’ [FC10, Shou, line 96].

In these two extracts, either Xue or Shou were used compulsive words such as ‘must’ ‘have to’ to present the situation of no alternative option for taking their caring role. It clearly reflects the meaning of looking after their parents has become a compulsive duty for them. In the meantime, the sense of not being willingness to take caring responsibility is also presented in their narratives. Yu also holds an idea of children’s responsibility when talking about whether to send his mother to a care home.

‘I never think about it (sending mother to care home), she is my mother, it is not reasonable to let a care home take the caring responsibility, is it?’ [FC9, Yu, line116].

The above extracts point out that looking after parents is children’s responsibility. It is necessary and compulsory. This enforced responsibility has enhanced and encouraged the participants to take on a caring role and looking after the person with dementia at home rather than sending them to a care home. However, despite the participants agreeing that taking care of parents are children’s responsibility, a feeling of being forced was expressed from most of the participants. This feeling may increase with the law regulation and the traditional culture. This enforced responsibility has been viewed as a compulsory mission and personal burden by them, rather than a personal choice. The sense of being forced may likely become a negative factor in creating a harmonious and caring relationship and might affect the quality of care.

Talking about why he decided to look after his wife by himself, Huai holds a different view of responsibility.

‘I have no choice, what I care about is the marital relation, this is the reason, I (feel that) I have more responsibility to look after her. My son works all day at the field and my daughters go to work. They cannot look after her, who could look after her except me?’ [FC8, Huai, line33].

A strong sense of marital responsibility appears in Huai’s description. This sense of responsibility has not been bounded by the traditional culture of filial piety and policies,
but it is a man’s responsibility as a husband. Three out of four participants in the study, who look after their spouse point to marital responsibility and clarify their caring responsibility as a wife or husband. In the extract, the participant seems to experience a forceful and helpless feeling which is caused by the unavailability of children. Most of the participants agree that the responsibility of looking after a person with dementia should be shared among all of the family members. This idea may be related to traditional family care provision and the sense of family responsibility in Chinese traditional culture of co-residence.

‘Three of us (sisters) take turns to look after our mother… each person takes care of her for 48 hours and then it’s the next person’s turn.’ [FC6, Mei, line 51].

It appears that sharing the caring responsibility with her siblings is better for Mei. It gives her a break and creates a feeling of being supported. Similarly, Ling expresses a comparable view about job sharing:

‘My younger sister and I all help with the daily activities. She is mainly responsible for washing the dirty clothes while I take care of our father’s personal hygiene and do most of the cooking. This is not difficult for us.’ [FC5 Ling, line106].

It is clear sharing the care responsibility is a burden release for Ling. He is coping well with his caring role which under family support. However, the statements from some participants about the impact on their relationship of sharing responsibility with other family members have revealed a meaning of tension among family members.

‘…if my sisters and brother don’t look after our mother well, I cannot say anything to them, but I do know if they didn’t provide good care for our mother. I know it from whether the potty is clean, whether mum’s clothes have been changed…’ [FC11, Xu, line97].

This extract reveals a tense relationship between the siblings due to the shared responsibility. It seems that a communication problem has appeared among them regarding the allocation of daily tasks. A feeling of unfair expression in the words can be caught. However, in the above two extracts sharing the caring tasks reduced the participant’s workload and makes the job easier for them. This supportive care model likely gives the participant breaks and a sense of being supported, but the relationship between the main care provider and the supporters needs to be carefully handled.

Children have a responsibility to look after their frail older parents; it is required by the law as well as being a part of traditional Chinese culture. Influenced by this, the
participants with dementia in this study claimed that children have a responsibility to take care of their frail older parents to a certain degree. Reflecting this, one participant with dementia said:

‘What are we relying on for the living cost? We have a small piece of land. I …have a son and daughter. They would buy the materials that we need for life. We have no need for physical care at the moment, and anyway, we don’t need high quality things for living because we are older.’ [PWD10, Shao, line36-38].

From Shao’s perspective, children are responsible for taking care of their frail old parents if necessary. This can be providing essential living items or providing physical care. Along with children’s responsibility to look after their parents, the idea of parents not putting a heavy caring load on their children is also reflected in Shao’s statement. Sticking with his opinion, participant Chuan says:

‘I have one son…he would buy stuff for me if I needed it…I don’t need good quality stuff, I am not doing any jobs, I don’t need go to work.’ [PWD5, Chuan, line65].

In the above two extracts, the reciprocal relationship between a son and his father in terms of caring for one another, reflects the functioning of the traditional Chinese family support network. We can also see from the interviews, that providing the basic living cost for older parents symbolises a fundamental form of support that should be provided by children.

Consistent with family caregivers, most participants with dementia also agree that the caring responsibility should be shared among the family members. Such as:

‘My daughters, my daughter-in-law and my son all help me, whoever is needed…I need assistance to walk. My son, my daughter-in-law, and most of my daughter-in-law look after me. After the food is ready, they assist me to walk to the table, I can eat by myself.’ [PWD7, Yin, line 29].

This extract reveals a sense of supporting and sharing within the family that lie in everyday life activities. Helping each other is a common view for a Chinese family. Whoever is in the family has the responsibility to help each other which builds a stronger family connection and easier life for Yin. Ye presents a similar sense. When talking about family support, she says:

‘They all help me, my daughter helps me to wash clothes once she is here and my son helps with cooking.’ [PWD6, Ye, line70].
From these two extracts, we can clearly see that children’s sharing of the caring responsibility has significant meaning to people with dementia. It is not only about sharing daily tasks, but also having a feeling of being supportive, respectful and connected to the family.

Most participants with dementia are also still keeping their parental responsibility or they are eager to take some family responsibilities. This is reflected in their conversations concerning their children and in their sense of not being a burden for their family. Following the conversation with Ye, not going to the kitchen does not only mean she lost a role and her autonomy in the family, it also reflects a ‘failed’ responsibility for her. She says:

‘It is a pain, I cannot do stuff, I’m heartbroken, before my daughter died, she asks me to cook dumplings for her… I cannot cook, I didn’t cook for her, then she dies of hunger.’ [PWD10, Ye, line 54-56].

The feeling of guilt and an unfulfilled responsibility for her family reflects in Ye's description. She feels that she is responsible for her daughter's death because she didn’t cook for her and the meaning of ‘can’t cook’ seems to represent a ‘failed family responsibility’ for her. Ye was looking after her ill daughter. She blames herself for her daughter’s death and tears rolled down her face when she recalled it, but she did not want to stop the conversation although I offered her the opportunity to have a break. I think that this may be the first time she has talked about her feelings regarding her daughter’s death. Ye is also isolated by people around her, or it seems that they do not treat her as a complete, whole person. The following is an extract of my field note during the time I stayed with Ye, which can evident it.

During my several visits to the hospital, almost every time, I saw Ye stumble along the corridor by herself, she always keeps silent and keeps her head down while she walks, her eyes seem only to focus on the floor. People hardly notice her as they pass by her. I also saw her twice on the hospital bed with her whole body curved like a hedgehog. Nobody talks to her, including the staff, she hardly has any visitors as well, I have seen her son once when I was sitting with her. Her son only stays about 10 minutes and the conversation between them was very simple and was only limited to whether Ye has had her lunch and whether she needed anything, then the conversation ended and the son was gone [Field note, 04.10.2015].

During the interview, I was surprised by Ye’s active engagement with me, compared to how I had observed people around her in the hospital. They acted towards her as if she is a “thoughtless” and “speechless” person. Her son treated her as a stranger.
and was unwilling to say anything. His visiting appears only to fulfil a children’s responsibility. The scenario shows that people with dementia need to have a voice and a chance to speak out their feelings. This could be a way to help people with dementia adapt to their ‘altered’ life, to build new relationships with them and to enhance the quality of life for them.

In Chinese traditional culture, older people are more experienced and wiser, they are often a respected and responsible member of the whole family. Despite the changing opinion of the younger generation, the older generation still maintain this idea to a certain extent. In the study, eight out of ten participants with dementia have shown their parental responsibilities in different ways: reflecting concern with their children’s safety, worrying about financial problems with children or trying to reduce the burdens of children. Zong is an 87 years old man who is looked after by a personal carer that he employed. Even though he is not taken care of by his children, Zong still believes that he has responsibility to watch over his son’s life even though his son is now himself a grandfather. He says:

‘I have no financial problem because I have a large pension. I cannot use all of my money, except to pay the person who looks after me, I left some money for my son, for him to spend on his family since he has a low salary.’ [PWD9, Zong, line 71-73].

For Zongmei, directly giving money to his son means that he is carrying on taking his parental responsibility.

The sense of other types of responsibility were getting weak among the participants with dementia. The term ‘I am too old to do anything or expect something’ is a common issue among most of the participants. The idea of being too old to take responsibility is common among older Chinese people. This may reflect the old Chinese words ‘anxiangtianming’, meaning older people should not worry about anything and accept whatever the life has brought for them. One extract particularly echoes this idea:

‘The older people shouldn’t take more responsibility, not work with many tasks. I haven't done many things in the recent year except a little job on the land.’ [PWD10, Shao, line42].

4.3.1.2 My role and responsibility has been changed within the family

A traditional Chinese family relationship is all about being together and interdependent. This creates a strong sense of Chinese family responsibility. For instance, grandparents help to look after grandchildren as the adult children go for
work, and in return, the adult children would look after their old parents when they need to. Because of dementia, a person may be perceived to change from being independent to dependent. The situation would change the sense of responsibility and relationships between people with dementia, people who look after them and other family members/friends. In the study, changing a sense of responsibility is closely linked to the ability of being dependent, a topic that was associated with the dynamic change of social relationships and losing roles in family and community. For Jing, being told he has dementia was a very significant event in his life. He says:

‘There is nothing important, I have food to eat and bed to sleep in, this is enough for me. I don’t care about anything, I don’t need to worry about anything, and I don’t think about anything.’ [PWD3, Jing, line 57].

After being diagnosed with dementia, Jing appears to be fed up with life and does not care about anybody or anything. The feeling of ‘my life is finishing’ reflects the sense of responsibility for self and others has gone or at least weakened. Liang has a similar comment, he says:

‘… I don’t need to worry about anyone once I have food to eat because I have no family.’ [PWD4, Liang, line 76].

The sense of personal responsibility and responsibility for others both seems to be lost in the above two extracts. And also in the case with Liang, the losing sense of responsibility connects to the conception of family. Having been diagnosed with dementia seems like the end of the world for the participant. This feeling may be the initial reaction of many patients with critical diseases; it might not only apply to people with dementia.

Losing responsibility is also associated with a loss of self-value or self-identity. Terms like ‘useless’ and ‘burden’ have been used by many participants in this study. A description that is similar to most participants comes from Jing.

‘…I have become a useless person. Do you think I have any use? I cannot contribute to the country and have become a useless person. Like now, I can walk but if it becomes worse, I cannot go outside, just waiting for death. (I am) a useless person.’ [PWD3, Jing, line 165].

‘A useless person’, ‘I have no plan’, ‘I just wait for death’. These phrases reflect that a meaningful life is being valuable, useful, and responsible. A useless person can be interpreted from both perspectives of not taking responsibility for others which is reflected in the phrase "cannot contribute" and being unable to take responsibility for himself which lies in ‘cannot go outside’, being physically incapable of looking after
himself. In this extract, being useless makes life meaningless for Jing and may also reflect a sense of fear of not being able to contribute in the future.

The sense of being betrayed or discarded appears in the interviews. One of the specific statements from Wen describes his feelings about losing value within the family, and how this has changed the relationships with family members and his role within the family. He says:

‘I only think now, I feel betrayed. Everything was ok when my health was in good condition, now I can’t do anything, I’ve been moved here and there…nobody cares. I had a good job in the past…nobody cares about me ‘. [PWD1, Wen, line166-170].

Wen had a high position and high paid job before he retired, he thought that he has greatly contributed to the household income in the past and it is the time for the family to repay the caring responsibility to him. The responsibility of taking care the whole family, which was held by him, should be switched to the family to looking after him, as he is not well. However, even though he still receives a big amount of pension each month, the fact that he has dementia makes him feel like his position within the family has been changed. This change makes a person with dementia feel as if he/she has lost their unique role within the family. For Wen this leads to a sense of being betrayed by both his family and his life as he thinks that he should be treated better.

Lapse in responsibility also reflects on losing basic life skills in daily life. For instance, a person with dementia, can forget to turn off the water tap or gas, the result of memory loss may lead to a family member taking the responsibility of the job, this reaction may let people with dementia feel that they’re losing their role and responsibility within the family. The following extract shows one of most common responses from participants that have been affected by memory loss:

‘I forget to turn off the gas oven, turn off the water tap, especially on particular days. I don’t know what happened and I am afraid. My husband said it would be very dangerous if there was an explosion. What can I do? …my children tell me not to go into the kitchen.’ [PWD 6. Ye, Line33-36].

Ye is a retired cleaner. After she left her job, her main responsibility was doing household chores—such as cooking for the whole family. Cooking for her family was also a joy for her. The result of memory loss when she started to forget to turn off the oven was a big concern and a threat to her role in the family. Ye’s cooking responsibility was eventually moved to other family members because of her
dementia. Here, responsibility loss within the family is reflected by her family banning her from going to the kitchen. This loss of responsibility seems to bring the feeling of panic, stress and discard for Ye.

For Jing, his money has been controlled by his daughter-in-law because he got dementia not only the matter of who would control the money in the family, but more important is this has changed the meaning of life for him and changed the hierarchical family relationships.

'I got ill and my son got ill, my daughter-in-law has my credit card and controlled my money since I am not well… I don’t want to ask for the money from her and despite knowing that she would give money to me if I asked for it… It’s different if I ask money from her. Domestic shame should not be made public, let’s talk about something else.' [PWD3, Jing, line 146].

Chinese traditional culture places the older person in a ‘higher position’ within a family. Therefore, parents are more likely to have the responsibility of controlling financial expenses and guide how things are run in the household. The responsibility of controlling his own money, which Jing used to do himself has now been passed to his daughter-in-law. It reflects the meanings of losing financial independence and losing the autonomy of decision-making in his family. As the participant’s responsibility and role has been taken away, it has also changed his hierarchical position within the family. The change can also be understood as ‘domestic shame’ according to Jing that brings a shameful and disrespected feeling for the participant.

For the participants who are family caregivers, taking caring responsibility has had a significant impact on their life as well. The most frequent issue that was highlighted by them was the reversal of responsibility. The following extracts are evidence of this change.

‘Of course, there would be differences, at least my health wouldn’t be like this. If he was in good health, I would not need to worry about him and of course if I would not need to look after him, then I could arrange my life better. I also have no need for worrying about him lying in bed alone when I go out for work. Moreover, I don’t need to worry about my son when I go outside, he would help to look after him. For children, the best thing is that their parents are in good health. If the parents are in good health, the children are happy, sometimes…they can help to look after grandchildren, and this also makes them happy.’ [FC2, Xue, line161].
In the above extract, Xue has talked about the physical, emotional and financial impacts on her due to looking after her father. However, the topic that she talks most about is the role reversal within the family. In her past life, her father had the role of looking after the whole family, including the next generation. She was the one who had been looked after, but now their roles had been entirely reversed whereby she is now caring for her father. This change has brought negativity into her life and has left huge pressure for her. The reversal of responsibility causes physical ill-health, inability to go to work and mental stress for Xue, a concern expressed by a majority of participants in the study.

Some participants of the family caregivers who have talked about role reversal think that they need to treat people with dementia like a child. One of the participants says:

‘... I need to get up several times a night. She never goes back to bed by herself unless I get up and tell her to go back to bed. I need to gently talk to her and say “Mum, you need go to bed because it’s too early to get up; you need stay in bed until morning”. I need to sing to her: “Sleep mum, sleep mum” and treat her like a child.’ [FC13, Yan, line62].

In the extract above, the role reversal reflects Yan’s action on taking her mother back to bed. She has to treat her mother as if she is her child in order to maintain her mother’s well-being. She needs to tuck her mother in bed and sing lullabies like her mother used to do for her. It is clear that Yan’s actions to her mother seems to make her feel more responsible and aware of her position. During the interview, Yan appears a bit embarrassed to talking about this, although she was smiling throughout the interview. I could sense her feeling that losing her position as a child is not an easy thing to take. This kind of role reversal was also presented in other participants’ descriptions. Such as, Mei says:

‘I persuade her (to eat), like I persuade a child...’ [FC6, Mei, line186].

For Huai, taking care of his wife has put him in a situation of financial crisis and financial dependency on his children.

‘If she hadn’t gotten ill. I could have planted flowers to sell, then life would be better. I have to stay at home to look after her now and I cannot do anything. Everybody cultivates flowers in our neighbourhood, they get money from selling flowers...’ [FC8, Huai, line42].

In Huai’s description, caring responsibility does not only mean the daily caring duties need to be done, but is also about the financial stress caused by not earning money. When earning to meet the living cost for the family collides with the caring
responsibility for his wife, the participant feels that caring for his wife has made him lose the chance to earn money and leads to him being in a worse situation than his neighbours. This creates a feeling that his caring role is a forced duty.

Juggling a number of roles has also appeared in several other participant’s interviews, especially those who have children and/or grandchildren who need to be looked after.

‘...I do not stay the whole day with her (mother)...after I prepared lunch for them, I go home to cook for the children and my husband, if my husband gets time he sends our grandson to school, then I would have a little bit of time to have a rest. Then after the break, I will go to my parent’s house again...’ [FC1, Guang, line196].

Guang points out that one of the difficulties she faces as she looks after her mother is switching between caring for her mother, caring for her own family and caring for her grandchildren, these responsibilities seem to make things more of a burden for her. Luckily for Guang, her siblings share the caring responsibility of looking after their mother and therefore she has managed to balance these responsibilities.

Ling has stopped working, as he is taking care of his father full time. Because of this, he has lost the balance of caring for his father and financial responsibility for his own family. This has led him to feel guilty. A conflicted relationship between his responsibility to look after his father and his parental responsibility seems to have appeared during our conversation.

‘For me, being filial or not depends on one’s economic situation...however, as a man (husband and father), I feel guilty because I did not take my responsibility for my family as I look after my father full time. However, he is my parent, I need to look after him.’ [FC5, Ling, line124].

In the quotation above, losing the balance between different family responsibilities and the sense of being ‘forced’ to take care of older parents results in feeling guilty about balancing responsibility and confusion in the meaning of being filial can be seen. For Ling, he chose physically looks after his father rather than to earn a living income, this cause him financially depends to his parent. The dilemma of being filial or being financially responsible for the whole family lead him to inquire about the concept of being filial. This kind of perception can be seen with many participants in the study.

4.3.1.3 I cannot cope

This subordinate theme mainly explains the experiences of stress which arise as taking caring responsibility for family caregivers and living with dementia, and the
difficulties that the participants recount in coping with daily activities. The experiences of stress which are caused by taking the care responsibility can lie in everyday life activities, such as assisting with toileting, washing and feeding or handling a fall. In all of these reasons, managing behavioural problems is one of the most challenges and a common reason of causing stress for family caregivers. One of the participants describes the stress which was caused because of her mother’s changing behaviour and well-being.

‘My sisters, my brother and my sister-in-law all tell me to keep calm when my mum is in a bad mood, but sometimes I just cannot control myself. Sometimes I get angry when she behaves badly. She does things such as: weeing or pooping wherever she goes, and after that she treads on it, then walks around everywhere. I get really cross with that…’ [FC13, Yan, line 81].

This extract reflects a sense of stress which is caused by managing their mother’s ‘bad’ behaviour. Even though Yan is aware of her mother’s problems, she says ‘I get really cross with that…’, which indicates her feelings of frustration when scenarios described above take place. It also reflects a feeling of being out of control in her caring role. After she talked about this, Yan laughed, I think that the laugh was sarcastic and shows her helplessness of her situation.

In contrast to Yan, Wan looks after her husband, who has Alzheimer’s disease and has lost the ability to walk. As a caregiver, she is old and she physically cannot bear the working load. However, she had to take her husband in by herself as their children are unavailable and care homes would not accept her husband. She thinks that the most challenging thing is coping with daily activities. She says:

‘…He cannot get up by himself. If he needs to go to the toilet, I need to put a belt around his waist and pull him hard to get him up, then use a pot to catch the urine…I have become old now, I am going to be 80 this year, I cannot look after him anymore, it is too hard for me. I want to send him to a care home; however, they do not accept a person with a condition like him.’ [FC7, Wan, line 34].

In this extract, Wan has described how she assists her husband with using the toilet, this discloses the conflicted term of incapacity of doing daily tasks between taking the care role. It has also pointed out that long-term care services are unavailable for people with dementia who lose the ability to be independent. In China, it is very common that long-term care institutions refuse the admission of people with dementia which is more likely related with the care home’s capacity because of the lack of facilities or professional staff in these care institutions (Wu et al, 2011, Wong et al.,
Consequently, the situation ‘I cannot do it but had to do it’ makes Wan feels helpless and powerless as she cannot control her life.

In the study, 13 out of 14 family caregivers believe that taking a care role has certain negative impacts on their health with only one participant who has said that looking after her mother had brought positive impacts to her health. Like most participants, Liu believes that the busy schedule creates stress which has damaged her health, she says:

‘... I rush to go shopping, rush for everything, this causes stress. I feel very tired since he (her husband) got ill, my health is going down because of this. Such as, when he got dizzy, I needed to send him to hospital and after coming home, he can sleep for a while, but I cannot. I still have jobs to do. I never get to have a rest. This has (resulted in a) deterioration in my health’ [FC4, Liu, line73].

The extract from Liu illustrates how a caring role can have a negative impact on personal health. A common example of escorting a patient to the hospital gives powerful evidence of how the caring role affects the participant’s health and emotional reaction. The perceived experience of tiredness can feel from this hospitalization case.

For Xue, taking care her father not only affects her health and the capacity of taking a caring responsibility, but also the stress is caused by dealing with specific events which are accounted for in the caring duties.

‘...sometimes when I really need help, there is nobody there. Such as: when he falls down on the floor fully, it is very difficult to get him up from the floor by myself. It is easy to get him up if he falls down partially, he just needs a little bit of support from me, but when he falls down (on the floor), it is very difficult (to get him up), and it feels like he pulls in the opposite direction. Let me tell you, what I have to do... I first pull him to a low chair, then pull him to a high chair, and then use all of my strength to hold him up. I have gotten ill last year... I know that the reason of my illness is because of taking care of him.’ [FC2, Xue, line48].

The description from Xue has shown how difficult it is to handle her father’s falls and how it is connected to her health. As a result, the poor health condition has left her in a vulnerable situation in coping with the caring responsibility. The participant blames the caring role, claiming it has let her down. Because of this, she also perceives the feelings of isolation, stress and being unsupported. Hiding behind the story, other meanings related with healthcare service have also appeared: lack of equipment to handle a fall and lack of social and health professional’s support. It is clear that Xue can manage the basic daily activities of the caring role, but struggles when an incident
arises. If there were social support or appropriate equipment available for her, the difficulty and stress might be reduced for her. As a result, it would be an improvement for both her and her father’s life.

The issue of ‘cannot see my friends’ is important for Ying. It is not just related to moving around, also to social activities, social connections and social relationships. Many participants have talked about it.

‘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…’ [FC3, Ying, line 31].

The extract indicates how the caring role has heavily affected her normal life by disrupting her social connections with her peers. The repeated sentence, ‘I cannot play with others’ emphasises the negative effect for her, the sense of isolation and stress can be strongly identified in the context. The sentences ‘I like to go…’and ‘I cannot go…’ reflects the feeling that the participant was stifled by the caring responsibility. This experience leads to feelings of loss of connection with others as well as loss of self-attribute for the participant.

I cannot cope is also discussed by the participants with dementia. When talking about the feeling of immobility, Wen says:

‘Pessimistic, it’s not a meaningful way to live, it’s not a meaningful way to live. I need help from others all of the time. I can only stay on the bed because I cannot walk. I’m never getting well.’ [PWD1, Wen, line 88].

The extract reveals that the participant has lost the ability to move around, being dependent on others and in a bad health condition. Because of the loss of these things, he appears to be losing hope for life and his ability to cope with the ‘alter’ life. The sense of being fed up, feelings of helplessness and despair appear in this extract.

Lack of emotional support can be constructed by the reality and the characteristic of cultural value. The sense of eagerness for emotional care from the family is interpreted by all of the participants of people with dementia. One common description was showed in the below extract from Yi:

‘I hope my family can often visit me. I don’t like them coming and going so soon, or just come to give me something and then go. I am alone
and I feel lonely. I like them to stay a little bit longer and chat with me…they have nothing to say to me.’ [PWD2, Yi, line 54].

Yi expresses his dissatisfaction with his children by complaining that they don’t chat with him. The word ‘lonely’ also expresses isolation and lack of emotional care from his family. With a low rate of public awareness, lacking the knowledge of dementia or people’s negative attitude of dementia, family members or friends often hold the opinion of ‘it is not useful to talk to people with dementia’ or ‘they cannot understand what I say’. For example, one of the participants who are family caregiver says ‘…I thought that people with dementia never did anything except sit, they would never talk; they wouldn’t eat until you feed them, so they only sit all the time, it was my opinion of dementia.’ (FC13, Yan). Another participant also talked about his sisters’ reactions to their mother; he says ‘…my sisters said that it is not useful to visit our mother because she never talks to us when we visit…’ (FC11, Xu). The statement from these two family caregivers may reflect a general misconception in the lay population that ‘no conversation is needed with people with dementia’. Unfortunately, this incorrect conception of dementia may instead enhance feelings of loneliness in people with the condition, whilst also reducing the responsibility of emotional care for them.

Overall, the above extracts from people with dementia and family caregivers suggest that lacking emotional support is more likely happening when there is a lack of understanding about dementia; improving public awareness may change person’s conception of dementia and increases social support to this group population. Furthermore, providing emotional support to people with dementia may help to build a harmonious relationship between people with dementia and family members, and make life easy for both of them to adapt to the changed life.

In addition, difficulty coping with the alternative life can be associated with learning new knowledge or using new technology. For example, the extract below is from one participant with dementia.

‘… For the mobile phone…My daughter has bought a simple phone (designed for older people in China) for me and taught me many times how to use it, but I still don’t know how to use it. I forget how to use it after she teaches me. It has a big effect on me if I want to contact somebody as I am unable to use the phone…’ [PWD3, Jing, line50].

The extract draws our attention to the relationship between using a new technology and social connection. For Jing, inability to use a phone blocks him in building a social network, and that creates a feeling of loneliness and incapacity to receive new
knowledge. Jing went on to explain how memory loss leads to a cycle of learning and forgetting for him and then impacts his life. Inability to use a phone has also become a signifier of not coping with the changed life.

4.3.1.4 I have no plans for the future

The subordinate theme of ‘I have no plans for the future’ reflects the decline in responsibility which is related to no future care plan and life arrangement for people with dementia, and no future perspectives for family caregivers. These phenomena are associated with lack of health professionals support, lack of knowledge of dementia and the despairing living situation for the participants. In the study, over half of the participants of family caregivers have no plan for themselves and the person they are cared for. The following statements from participants are family caregivers which were associated with lacking health professionals’ support or lacking knowledge of dementia, lack of responsibility for themselves or the person they cared for. Some extracts have provided the evidence.

‘Any plan? No, what is the plan for? I am just making do with what I have. I leave my personal things for later. I have to look after her (mother) unless she dies. There is no end if she is still here…’ [FC9, Yu, line127].

In the extract, a future plan seems to be an illusionary thing for Yu as he had to look after his mother. In this sense, his caring responsibilities limit Yu in his ability to plan for the future. The sense of unwillingness, hopelessness and being obliged clearly appeared from the tone and the words which he used in talking about the issue. Then the attitude of irresponsibility can be discovered from the sentence ‘what is the plan for’. Thirdly, a link of no future plan with losing responsibility can be seen from the conversation.

Since Liu is illiterate and has no knowledge about dementia, enabling physical care is the best thing that she can do for her husband. Making a care plan for people with dementia is an impossible and unimaginable thing for her. First, when talking about whether the participant should have some training related to dementia care, she responded with this:

‘I don’t know about dementia. I take care of my husband, not somebody else, why do I need to take any training courses for doing this. No need for any training, I can look after him…’ [FC3, Liu, line74].

Then with her answer about future plans, she says:
‘I have no care plan for him, I will look after him until he is dead. There doesn’t need to be any plan. If one day I am not able to look after him, we will wait until that day.’ [FC3, Liu, line100].

From Liu’s point of view, she sees the post-diagnosis care plan as the detailed care schedule in everyday activities. For her, the caring responsibility is only limited on providing physical care. She feels that taking care of a family member does not need professional knowledge or other relevant services, and that this knowledge would only be necessary if the person who she is looking after is a stranger. If she had the physical ability to look after her husband, the ‘altered’ life seems manageable for her. The feeling of not being bothered too much and the continuing of life can be found in the extract. In China, people with dementia are less likely to get follow up health support from a health professional. Therefore, once people with dementia have been diagnosed, their future life is just waiting for death. Having no future care plan sounds reasonable and is fairly normal for most family caregivers in China.

The following very different view of a future perspective from Gui is related to a hopeless situation of financial burden which lead to a miserable future perspective for her.

‘I haven’t got any plan for the future. I have no money, if the local government doesn’t provide any support for me, I will get some poison to kill all of us, anyways, I cannot live for too long at this age. I am applying for the minimal social security allowance for them, I am waiting for the answer…’ [FC12, Gui, line198].

Gui’s thoughts about suicide and her eagerness for help reflect the deficit of the social security system and social support. A conflicted relationship between the protection of children and remaining caring responsibility, which were associated with financial distress, can be identified in Gui’s talk - continuing to live in the changed life and being dependent on the government’s financial help. The sense of ending parental responsibility because of low expectations of receiving help and the despair of their situation shows in the extracts. For example, the feelings of despair and hopeless experiences are expressed by Gui above.

Contrasting with family caregivers, most participants with dementia had no future plans. This can be associated with losing hope and having low expectations of life due to the illness itself, as expressed by Wen:

‘There is no plan for the future, I feel pessimistic and don’t want to take any treatment. I’ve had enough.’ [PWD1, Wen, line153].
In losing confidence with his treatment, Wen also loses hope for his life. The same expression about future life is a perspective from Shen, below, but he describes in a different way having no future plan by claiming his wish of death. In the extract, death seems to be his only future plan. The sense of losing hope for life appears here.

‘I have no plan; the only plan is how to die soon. I want to die, however, I haven't got something to kill myself, medicine or rope. I only thinking about this, how to die soon…’ [PWD8, Shen, line136].

For Jing, being a useless person and losing ambition to fight with the changed life has lead Jing to wish to escape from life. Continually talking about his future plan, Jing says:

‘I have no plan. I have to live until I stop breathing… I just wait for death day by day. It is not the same from when I was young, I aimed to achieve. I have no plan now, I am not scared of dying and I really hope one day I don’t wake up.’ [PWD3, Jin, line171].

It appears that the participant has lost orientation of his life and is waiting for ‘fate’ to make a decision. In contrast to the above extracts, one participant with dementia says:

‘I have no plan, I hope the state can provide some help, but it is impossible. We haven't got any plan; it will be good if the state can make a plan to help a person like me. Anyway, if the government cannot do it, I don't care…’ [PWD10, Shao, line161].

It is interesting that the participant’s future plan links to government’s support. A dilemma of the governmental support appears in Shao’s talking, on the one hand, his hopes to get help from the state but on the other hand he doesn’t believe it would happen. The word ‘impossible’ connotates the participant’s low expectations of social support.

To conclude, this first theme reveals the meaning of responsibility in association with the changed life. A range of feelings associated with responsibility are expressed about the changes which include: helpless, frustration, being forced, reluctant, sadness and personal effort. It is identified through the lens of altered self, roles, capacity, relationships, financial situation, body condition and futures. I have used the theme ‘negotiating with the roles’ because it accurately reflected the conflicted relationship between taking responsibility and the heavy caring workload for the participants in the specific Chinese context.
4.3.2 Superordinate theme 2: The meaning of life in the social context

The living world is the social environment that the participants live in, and it is closely linked with their quality of life and quality of care. When a person has been diagnosed with dementia, the effect of the social environment appears to be more important for them. Especially for people who are living in rural areas, because the public services and the health services in the real world of rural areas are likely to be less developed than in the urban areas. This theme discloses the participants' real living environment, how the public services and health services are conducted where they live and how the changed community environment has influenced their lived experiences; how these social factors affect their life and are meaningful to them.

There are many descriptions from the participants that express the meaning of family responsibility which is associated with who should take the responsibility, how they take the responsibility and how this works for them. It also captures how responsibility relates to the social constraints of social support, public services, healthcare access, long-term care services and social stigma. It highlights how the participants' perspectives of the lived experiences have been affected by these social factors and social transitions. This superordinate theme includes five subordinate themes (see figure 3). ‘My life beyond the social environment’ discloses the changed community environment where the participants live and how it influences the participants’ perspectives of their lived experiences. ‘I need your support’ is associated with the reality of lack of health professionals and community and state support which causes distrust and dissatisfaction in the relationship. ‘The dilemma of long-term care services’ shows the participants’ perspectives of the long-term care institutions, their view of sending parents to a care homes and the challenges that they experienced as the formal long-term care services were unavailable to them. ‘They don’t believe me’ reflects the social attitude toward people with dementia and family caregivers and how it effects their lives. ‘I need more money’ describes the conflicted relationship of family financial responsibility and burden which reflects on the reality of financial scarcity and the sense of unavailable resources; money is also a foundational resource for keeping the caring responsibility and maintaining a good quality life.
4.3.2.1 My life beyond the social environment

The changing environment of neighbourhoods means people are getting to know each other less and less, and the sense of supporting others has become weaker and weaker. For example, one participant says:

‘...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. If the community centre can organize something that will make people get together, then people would get to know each other...then people might help each other in some cases...’ [FC1, Guang, line 333].

In this extract, the participant describes the changing customs leading people to becoming more private and having less connections with other people than they used to do in the past. This trend seems to have become a barrier to creating a friendly community and getting support for people with dementia and family caregivers. It also reflects the lack of connection and support at the community level. Jing also expresses a similar opinion regarding the community support. He says:

‘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. If the older people can meet and chat regularly, we would feel like we have been cared for by the society. Like now, everybody only cares about himself.’ [PWD3, Jing, line91].
In the above extract, a feeling of isolation, being lost or discarded reflects the lack of local community support services. Alternatively, community support seems very important for Jing as it brings him a feeling of belonging and being supported. Apart from the changing custom, the scarcity of community-level support may be due to social transition of migration and accessible job movement. This has also happened more severely in rural areas as most of the young people and adult move to the cities for studying and working.

In addition, a social change of migration and shrinking family size is occurring in China. Many adults now move away from their older parents or, which makes the possibility of providing physical care more and more unavailable for adult children. These have significant impacts on older care services, especially for people with dementia. Several participants who are family caregivers mention this.

‘Normally, it is only me who looks after my father, I have one brother who lives in Shanghai, sometimes he will visit, and then he can give a little bit help, however, it is only occasionally...’ [FC2, Xue, line 173].

This example clearly shows the phenomena of migration and the effect for Xue. This is a common trend of the contemporary China and the result of social development, this cannot be reversed or stopped, and the only way is to improve the current older care services. The same issue was also found in the participants with dementia due to the smaller family size. Such as, Yi who has one son who is unavailable to look after his mother even though he has not moved away from her.

‘I have only one son, [he] is filial to me, and he would buy whatever I needed. I have no daughter...I want stay at home with him, [however] he is not available to look after me so that I had to stay in hospital.’ [PWD5, Yi, line 63].

Yi would like to stay at home for the rest of her life, however she cannot stay at home because of the reality of her health condition, and her son is not available to look after her. It shows that the traditional Chinese family care has been eroded because of the reduced family size.

For some participants, the traditional meaning of family as ‘being together’ has been changed as their children have moved far away.

‘Family, family (with a sad tone), I don’t care. I...my wife passed away many years ago. I have a daughter who lives with me. My son and son-in-law live in Shanghai. Only one daughter stays with me.’ [PWD1, Wen, line 97].
Family became a difficult word for Wen in the above excerpt. This can be seen from him repeating the words ‘family’ with a sad tone. In Chinese traditional culture, the son is the inheritor of the kinship for a family. With his wife passed away and his son having moved away from him, the family seems to become a source of pain and sorrow for him, rather than the traditional meanings of unit, close and together for him. The married daughter seems to be excluded in the word of family by Wen even though she lives with him. For Wen’s son, moving away into a big city may be an opportunity, to bring fortune, but instead it has had a negative effect on Wen. Another participant, Zong points out a similar issue.

‘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.’ [PWD9, Zong, line 98].

Zong’s situation is the same as many other families in contemporary China. As the concept of ‘family’ has changed its traditional value of ‘being together’ and ‘unity’. The home seems to have lost its value of living in, Zong sounds as if he prefers to stay in a care institution.

Apart from feelings of isolation and stress which is created from ‘I cannot go anywhere’, Yu has interpreted the meaning of ‘cannot go anywhere’ differently. The following quote reveals what the meaning of a caring role for him is.

‘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], she needs help with the toilet…I cannot go anywhere. Somebody invited me to go together with him for a job two days ago, I said that I cannot go. I cannot go anywhere; I can only stay at home.’ [FC9, Yu, line165].

As many rural workers move to cities for jobs, Yu had to stay at home looking after his mother, For Yu, ‘I cannot go anywhere’ means losing the opportunity to earn a life fortune for himself and for the whole family. Taking on a caring responsibility not only means being trapped at home, but also the perception of self-sacrifice. Yu also has a dependent daughter that he needs to bring up, he says:

‘There is nobody who can help me. Everyone is busy with their life. The thing (look after mother) is relying on me, I have one daughter who goes to school, there are three in the family. I need look after both of them, I cannot go out for a job. Because of stuff like this, how can I go out for a job, I cannot do anything.’ [FC9, Yu, line51].
Losing the chance to move to the city for a job, the three people can only rely on the income from their land to cover their living costs. This means that the quality of life has gone down as they have less money to spend. Yu is not only struggling between taking a caring responsibility and earning a living, he is also juggling several other roles: caring for his mother and daughter, earning the living costs for the whole family. This multiple responsibility has left Yu with not many options in life, which makes him feel powerless and stressed. In this complex situation, participants feel that have no choice and are frustrated.

For Huai and his wife, they depend entirely on their children’s support and the little amount of senior allowance from the local authority for their living costs. This is a very common thing among older people without a pension and with the loss of the physical ability to work on their land in the rural areas. Talking about the hardship he goes through whilst looking after his wife, he says:

‘There are many difficulties, it is hard to say what it is. For food, my daughter sometimes buys some. (My wife) was stayed in hospital for 7, 8 days (recently), I spent all of my savings, I can only rely on my children. I have no pension, we two…the government gives 200-300 yuan (£22-33) each month for us. We mainly rely on this for food.’ [FC6, Huai, line28].

This extract reflects a life of hardship with people who have lost the ability to earn and also need to take care of a person with dementia in some rural areas in China. The financial pressure has clearly left the participants in a dependent and vulnerable situation. If the basic living materials cannot be guaranteed, it becomes difficult to ensure the quality of a person’s life and the quality of care services.

4.3.2.2 I need your support

Providing a good life and a good quality care for people with dementia is not only up to the individual nor is it a single responsibility, it is a task for the whole. If there is not a friendly, harmonious, fair and supportive society, a quality of life cannot be

\[5\] In this case, the land of the whole village has been expropriated by the local government for the expansion of the city and roads. Therefore, the villages have this amount of money every month for compensation as they lost their land. However, this amount of money is not enough for the living cost, the villagers had to have other ways to earn money. Other villagers in other villages haven’t got this amount of money.
guaranteed for people with dementia and family caregivers. However, social support for people with dementia and family caregivers is very limited in most regions in China, except in a few big developed cities. There is not only a lack of formal support from the health professionals, such as post diagnosis support; there is also a lack of informal support from the governmental sector and voluntary organisations. This issue will be addressed further in the discussion chapter. The following acknowledgements from the participants who are family caregivers have evidenced this.

‘I hope there some staff who can do home visits. They could give some support if some problems appear. You see, most of the children are away from home, only old people are left at home alone. If anything happens, there is no one who can help, it would be better if we have this support. However, there are no such services that exist at the moment. I hope that we will have some social support in the future. Anyway, this would be a social tendency as there are more and more ageing population.’ [FC 1, Guang, line283].

This extract reflects that there are unavailable supporting services from both health professionals and social services through the participant’s description. The participant has recognized that ageing is becoming a social problem and talks about the lack of social support in this field of older care services and expecting this kind of support in the future. The feeling of concern with the current situation and worrying about future is presented.

Even though the participants express a need for help, they hold very low expectations for access to social support. This may be related to the government’s inactions of taking the responsibility of looking after the old population and the traditional belief that looking after older people is the duty of the individual families.

‘What community will help? There are staff who (social worker) work for the government, I have never heard of them helping with these kinds of things. The health service in the community occasionally rings me to ask about my father’s condition, but they never visit us.’ [FC2, Xue, line178].

This extract reflects the lack of social and professional support at the community level. The sentence of ‘I have never heard them help…’ expresses that the participants have a perception of getting little help when it comes to social support. It highlights how people with dementia have been neglected from the social services, and the rhetorical question reveals the participant’s negative view of social support.
Most of the participants think that the state should somehow take care of people with dementia or at least provide some support to the family caregivers or people with dementia, and not only rely on individuals and families. Descriptions from the participants about the government’s responsibility are mostly associated with policy making on health support, social support and financial support. The following are two extracts from Mei that show the defect of the long-term care services in China and the feeling of dissatisfaction of the health professionals’ responsibility on old care services.

‘...people who do this (care job) mostly come from the bottom class, life forces them do it. They haven’t received proper training and they are less likely to be educated…’ [FC6, Mei, line270].

The extract reflects the deficit of long-term care institutions - lack of qualified care staff. The sense of disappointment also appears in the excerpt. Responding to this problem, Mei says:

‘This is the current situation of older care. I hope that the government can pay attention and do something about it in the future. I hope that our children won’t have the burden that we have now, and I hope that we can be looked after well when we get older.’ [FC6, Mei, line271].

Mei holds the same view as Ling: the government should take the caring responsibility for the older population. She also states the same concern about future care problems for herself and for the next generation, this also due to the reason of most of the family caregivers themselves are getting older and they are starting to worry about their care arrangement in light of the current situation of older care services.

For Wen, social support seems a contrived thing in his life and he also doesn’t trust this type of service if there are some. This reciprocal view has been widely spread in the Chinese social relationships followed by the rapid social and economic development, which may also penetrate family relationships. Evidence of this idea was seen in the interviews with a few participants. The extract reflects that there is no social support and that the participant’s low expectations of this kind of support. The sense of isolation, distrust and power inequality can also be found in Wen’s description. Support from health professionals for people with dementia are also very limited according to Wen. For example:

‘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.’ [PWD1, Wen, line72].
A sense of dissatisfaction and being unsupported by health professionals appears in the complaint.

In the study, the only available support that can be confirmed for the participants is the little amount of money that the government gives (80 yuan per month) for older people who are over 65 years old without pensions. Participants therefore have a low expectation of support from the local authority. Below, one of the participants expresses his wish for available support from the government when he talks about the situation of older care in his village.

‘If the government can arrange healthcare for older people 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?’ [PWD3, Jing, line2].

In this extract, Jing talks about his wish, for the older people who live in the rural areas to be able to get the state’s support with healthcare; this reflects the unavailability of a social support system for people with dementia and the limitations of older care services in rural areas. However, despite people needing help for their care, in reality, Jing used the phrase ‘cannot imagine it’ to reveal people’s low expectation for getting help. The sense of not being able to get help and his concern for others appear in the conversation. This may be because of the tradition that family has to take responsibility for older individuals rather than the state.

Issues associated with social support, quality of life and quality of care are different depending on urban and rural areas. For participants from urban areas, the problem raised is more likely related to the issue of social connection and disability access. One participant who is family caregiver says:

‘I have many times pushed my father (in a wheelchair) to see the doctor. In the old buildings, 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. If they can visit a patient at home, it would be better.’ [FC2, Xue, line189].

Going down the stairs and transportation to hospital are difficult things for Xue. This may become a factor that stops family caregivers from going outside, getting help from health professionals and creating a sense of isolation. This similar issue has been discussed by Mei.

‘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. 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. 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.’ [FC6, Mei, line238].

In the extract, several issues were raised that were associated with disability access, living environment and older care costs and burdens. It reflects a conflicted relationship between people with dementia’s interest of staying at home and the difficulties which are faced by families in their real life. These factors are a signifier of lack of public services, dissatisfaction with older care services and the incapacity of family care. Some factors may have related to political or legal issues. Consistent with Xue, one participant with dementia also says:

‘I would like to go outside, however, the wheelchair cannot go down and up the stairs because there is no lift.’ [PWD1, Wen, line131].

The extract reveals that a lack of the appropriate facilities for disabled people with dementia is a main barrier to facilitate outdoor activities. This may also be a barrier for receiving other types of services. Therefore, real world materials and social service are linked to the quality of dementia care. From the above three participants who live in the city centre, it shows that the barriers of mobility access and community support are common issues among the participants who live in urban areas.

Issues arising of social environment from the participants who live in rural areas are more related to the bad living condition, low quality of healthcare and financial burden. Regarding the house heating issues, the living environment has been described by some participants:

‘It is freezing, we lit a coal stove. Yep, it is freezing, but it is not only for one family, all of the families are the same. Nobody will feel warm, everybody is in the same situation. You’re cold, I’m cold and everyone is cold.’ [PWD10, Shao, line 114].

The participant uses the parallel sentences ‘…cold...cold’, to emphasise the bad living condition for people who live in the rural areas. This living condition especially effects people with dementia’s life. For instance, during my fieldwork one potential participant with dementia passed away during the cold weather, just before the interview. Even though this might not have been the only cause of his/her death, it illustrates the potential dangers of the low living standards for vulnerable older adults. One family caregiver has complained that the cold weather made him unable to get his mother up from the bed, he says:
‘…Now that the weather has become cold, I cannot get her up.’ [FC10, Shou, line 76].

In the study, for all of the participants who live in the rural areas, the only available heat in the winter is available by burning coal. The cold living condition stops people with dementia from getting up from bed and go outside. ‘I cannot get her up’ reveals the real living environment for people with dementia and the family caregivers, this has to a certain extent affected their quality of life. Even though the living conditions and the quality of life in rural areas has improved remarkably in these past two decades in China, the situation of dementia care in the rural areas has not changed much as dementia care is not covered by the health care insurance system in China.

Shao has also talked about the muddy road beside his house, and this muddy road issue may reflect the inadequate public services or transportation problems. Again, this could be a barrier for people with dementia to going outside. Then he complains about his chicken that have been stolen, these things seemed to annoy him very much as these issues directly affects his quality of life. He says:

‘…I didn’t go anywhere. I cannot see a long distance. I am at home also because I need to keep an eye on the house. I have raised some chickens, sometimes they have been stolen. There is always somebody around to steal it …it is the reason that I cannot go anywhere…’ [PWD10, Shao, line96].

Shao described an unfriendly and unsafe neighbourhood where he is living. The chicken being stolen not only means a loss of resources for him, but also gives him a feeling of living in an unfriendly environment for people with dementia.

For Xu, the quality of healthcare services in the village has annoyed him very much, this creates a mistrustful relationship with local health services and has stopped him from seeking medical help in the village clinic for his mother whom he cares for.

‘…these things cannot be discussed. The quality of health services in rural areas (village clinic) is very bad. I haven’t been there for more than one year, sometimes they sell some fake medicine. My father died there by a medical accident…’ [FC11, Xu, line177].

In China, social support like peer support groups and day respite centres are hardly available. In the study, the issue of social support has been raised by most of the participants who have dementia as well. Participants used ‘I can’t believe’, ‘I cannot image’ or ‘I never think about it’ to point out there have no such service available and
their disbelief about getting support. Wen’s description below clearly expresses his opinion of social support services.

‘It is difficult to say, why would people help me? They cannot get anything from me, I never think about it. I have no social relationship left, no connections (with others). I cannot do anything in returning. Why do they care about me?’ [PWD1, Wen, line136-140].

4.3.2.3 The dilemma of long-term care services

This subordinate theme indicates the failed responsibility of older care services through stories told by the participants. It reflects the lack of long-term care services in China. One of the views of family caregivers has been pointed out by Yu:

‘…care homes wouldn’t accept her. 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. There are three residents in our village that stay in care homes, they have no children…’ [FC9, Yu, line110].

The idea that family members are better care providers than long-term care servers is also reflected in most participants’ narratives. The idea of not sending an older parent to a care home is most likely associated with the low quality of long-term care services and stereotypical views of sending older parents to a care home which is that people who are childless stay in care homes. In this extract, the traditional social attitude stops Yu from sending his mother to a care home, even if he is struggling with the caring burden, he has to look after his mother at home. A social constraint plays a very important role in stopping people from going to care homes as it is frowned upon in Chinese society. Apart from the participant’s traditional opinion that children should look after their parents, he has also mentioned the fact of the unavailability of long-term care institutions.

Participants who have dementia have raised an issue with care homes as being a place where people with no children to look after them go. This is because of Chinese tradition and culture.

‘… I have son and daughter. I have no need to go to a care home, do I?’ [PWD10, Shao, line184].

For Yan, the quality of care is not secured in long-term care institutions. When talking about sending her mother to a care home, she says:

‘No, a care home is worse… if we send her there, she would be dead soon. In care homes, there is nobody to look after her. 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. We have consulted the psychiatry hospital, for my mum’s behaviour, they would give her tranquilizer medicine and restrain her on the bed. Therefore, I don’t want to send her to a care home or psychiatry hospital…” [FC13, Yan, line 171].

In the extract, a strong feeling of distrust, insecurity and the disapproval of long-term care institutions discloses how people with dementia have been viewed and treated by long-term care services. Xue describes a similar scene in care homes.

‘…I have been looking 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, I don’t want to send my father there. I want my father to have a good quality of life.’ [FC2, Xue, line116].

The participant uses the words of ‘bad odour’, ‘no facilities’ and ‘other problems’ to reflect the bad conditions of a long-term care services. This scare people away from the idea of staying in a care home. Xu also has the same opinion of the care homes.

‘…my sister-in-law said that if there is no way, we need to send our mother to a care home. I am against it so I ask her which care home we should send our mother to? And which one is good for our mother? A news program reported that there was fire in a care home and most of the older people were dead there, what is the reason for the fire? Is it the irresponsibility of the care home or is it arson? If we, as the children cannot look after parents well, how can the care home look after them well? Anyway, all of the care homes are not up to standard.’ [FC11, Xu, line118].

Xu expresses a disapproving opinion towards the older care services in the extract. The media reports seem to have put a heavy influence on his personal view. On the other hand, the traditional cultural value of filial piety may act as an important factor against sending the mother to a care home. In China, many long-term care institutions are only available to provide physical care for old people, but have no capacity to manage the cognitive problems of people with dementia. This could be due to a lack of qualified care staff, equipment and proper regulation. Thus, the care home’s services are less likely to meet the needs of people with dementia if family cannot look after the person with dementia. In these two extracts, quality is a big concern where the sense of distrust with care homes’ services emerges in these statements.

Apart from the above issue, the descriptions below which are from people with dementia also raise some very different views of whether staying at home or a long-term care institution is better. This opinion may be related to the current social
transition of family structure, migration and the older care system. For example, Shen does not care much about where he stays for his later life as long as his needs can be meet.

‘... it is alright for me once I have a place to live and food to eat. I cannot see anybody in the house as I stay at home, at least I could see people in the hospital. Nobody can help me if anything happens. It is not possible to stay at home alone’. [PWD8, Shen, line180].

Living alone and apart from his children, Shen sounds like he is expecting to be sent to a care home. He is only concerned about the needs for a basic life. The statement reveals unavailable family care and unmet care requirements at home under the current model of family structure. Therefore, a long-term care institution may be a better option for him.

Jing has compared the different living experiences between the life at home and the life at the health care setting. He raises his concern about the quality of life in the hospital.

‘There are big changes. I used to go to the local market by bike, and I could buy any food that I would like to eat. Life was much better. The hospital’s catering is bad even though I pay 300 yuan (£34) for meals. The meals are often without meat, and only Mantou (A round steamed bread). It is worse than when I used to cook my own meals. It is also lonely, there is nothing you can do here. The only thing is to chat with one of my roommates. Sometimes somebody asks me to play Poker together, however, I forgot how to play it.’ [PWD3, Jing, line 69].

In this extract, we get a clear view of what life looks like in a hospital setting from a patient’s point of view. The low quality of life and the sense of loneliness reflects in everyday life which is described by Jing. Food, amusements, social activities and social connection are linked to the question: what responsibility does the health care system have and what should health professionals do to help people with dementia? Overall, under the current situation of social transition that has distorted the traditional family care model; a new provision of older care should be considered, along with the need for improving the current healthcare services, especially in the older care section. The current long-term care services have brought pressure and inconvenience for people with dementia and family caregivers.

Several participants who were family caregivers also expressed their concern of supporting/older care services for themselves when they are older. The following is one typical description from Ling.
'For example, if one day when I am old, I get the same problem as my dad. I only have more than one-thousand-yuan income (monthly) now, how can I afford a personal carer? 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? From the view point of a country, it is a social problem, it is the result of ageing. (But) from the individual’s point, we are now having 4 adults or 6 adults look after one child, but in the future, how many older people that one child needs to look after for? This is a problem that need to be sorted by country…' [FC5, Ling, line74].

Lin is not only concerned about his future care arrangement, he is also concerned about his son’s. It seems that his concern has moved from a personal query about what or how he will be cared for in the future to social problems about who would take the caring responsibility for older people, especially people with dementia. His statement also reveals the current unique family structure (4-2-1 family structure) in China. When an individual is unable to take the care responsibility and if there is no available social support, who would look after our seniors? From the above extracts, the sense of the government should take healthcare responsibility for the older population can be identified.

Another family caregiver, Xu is not only raising the issue about older care services, his conversation also reflects the current problem of the social security system and the reasons for the impractical and unavailable older care services.

‘I am retired with pension. If somebody without income, they had to go out looking for job, they cannot look after their parent even though they want to. Such as my young brother, he came home twice in order to look after our mother, then he got fired. My young sister is taking care of her grandson in Tianjing, so what she can only do is phone our mother…’ [FC11, Xu, line 199].

The above excerpts also reveal a product of the social revolution and the situation of older care services in China. As the result of the unavailable family care, people with dementia and family caregivers need some help from the society or the government. A good social support network may help this group of people to cope with family-based care.

Regarding the above issue, one family caregiver says:

‘I think that the government advocates ‘old people should be looked after; old people should have a meaningful life’. How you can support yourself and make yourself enjoy life without money? If your basic living cost cannot be secured, how you can keep a good health? Dementia care is difficult in rural areas.’ [FC13, Yan, line 267].
4.3.2.4 They don’t believe me

This subordinate theme illustrates the attitudes of the lay population, healthcare professionals and family members toward people with dementia and family caregivers, and how this stereotypical view has created a sense of social stigma. In China, the rate of dementia awareness is lower compared to western countries. Most participants in this study have shown a lack of knowledge of dementia. Misconceptions of dementia not only create an incorrect attitude towards people with dementia and family caregivers, but also cause frustration and bad family and social relationships. For instance, one participant says:

‘I told my family that the reason I forget something is because I am ill…they didn’t believe it, they said that I just tricked them…this makes me really cross’ (voice raising) [FC7, Yin, line55].

In this extract, the word ‘trick’ which has been used by the participant has disclosed the lack of understanding with dementia among family members. This has caused the participant’s feeling of frustration, it also can be seen by the participant suddenly raised his voice and burst out with anger whilst he is telling me about this. Family members show poor communication skills when communicating with people with dementia due to a lack of knowledge of dementia.

When Ye talks about the neighbour’s attitude toward her, she says:

‘They all said that I am demented, what can I do? The neighbours all go for outside exercise, they go out for exercise every day, it is necessary to do physical exercise.’ [PWD6, Ye, line163].

Then she kept on saying:

‘Neighbours, the neighbours said it was good to do things together [with Ye]. But now all of things gone as she is demented. She could do everything before, but now she cannot do anything, it is ending’. [PWD6, Ye, line166].

These two extracts disclose a negative attitude toward dementia in the neighbourhood which reflects on the neighbours’ response to the participant by saying that she is ‘demented’; fear to play with her reflects on the action of taking physical exercises together with her in the past, but not since she has been diagnosed with dementia. Ye seems sad and stressed by this situation. Her response of "what can I do" shows her vulnerability to becoming isolated, being stigmatised and being labelled. For Yan, taking her mother to a public place is an embarrassing thing. Responding to questions about social support services, she says:
‘No, I don’t know. There is no support of this kind. Even if there were, I wouldn’t take her there because she would shout or speak nonsense. Before I often took her out, but now she always wants to go to the toilet, so we hardly go anywhere. I only take her to go outside the house for some sun shine…’ [FC13, Yan, line195].

The extract describes a lack of social support and negative attitude towards taking part in social services. ‘I wouldn’t take her…’ reflects a shameful feeling of looking after people with dementia and the negative attitude of the lay population. From the above three extracts, the sense of social stigma which is associated with a lack of understanding of dementia in the lay population is clearly illustrated. This negative attitude would affect a person with dementia and family caregivers regarding their personal responsibility or caring responsibility to a certain extent.

Gui tells me that having family members with dementia make her feels hopeless in life and shameful in the neighbourhood.

‘…Who can I rely on? I cannot rely on anybody. I was wishing they (two sons) would grow up when they were little, but now, I not only need to go through the hardship, but also I lose face…’ [FC 12, Gui, line190].

Looking after her two early on-set dementia sons. Gui is not only to bear with the hardship of the caring duties and the burden of caring cost, but also is losing hope for the future life, and has the shameful feeling of having a family with dementia as well as the shameful feeling of taking care of people with dementia. Apart from feeling negative, the social environment seems to have more influence on stigma of dementia.

The following is from Gui about an event where one of her sons was beaten and gives evidence of this stigma.

‘Last time he had been missing, and walked to a house with a dog in. (the owner has suspected him as a thief and sent him to the police station). You look at his arm that has been beaten by police offices…he went to repair his phone, but lost the way home, and then he went into that house. Their dog was lost the day before, so that they think he stole the dog…’ [FC12, Gui, line18].

In China, lack of awareness of dementia is not only limited to a particular individual, but is wide spread over the whole society. This misunderstanding enhances the social stigma toward people with dementia. In the above extract, the owner of the house and the police offices do not realise Gui’s son has dementia until they contacted the village clinic. On the other hand, it also reflects a lack of community support and network in the area. In addition, the support toward people with dementia or family caregivers
can hardly be operated within a society of people who hold a stereotyped view with dementia.

Some conversations that take place between the caregivers in this study and health professionals reveal that social stigma also appears in the healthcare field. For instance, one typical statement says:

‘…the doctors don’t tell me anything. They just discharged him from the hospital. They said that it is better to bring him home. There is no point in spending 200 or 300 hundred yuan (£22 to £35) per day in the hospital…’ [FC14, Jin, line 30].

The extract reflects health professionals’ attitude towards people with dementia and how it is seen as a terminal illness. This has strengthened social stigma around dementia. The sentence ‘it is better to bring him home’ also shows the irresponsibility and unsupportive attitude of the current health care system towards people with dementia and family caregivers. The negative attitude from the health professionals is also reflected in the participants with dementia’s description.

‘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.’ [PWD8, Shen, line 38].

These two extracts disclosed the health professionals’ attitude towards people with dementia and family caregivers which have highlighted a stereotypical view of dementia disease and a society that stigmatises this group of people.

4.3.2.5 I need more money

I used ‘I need more money’ as the subordinate theme here because it either links directly to financial problems that the participants face due to looking after their family members or indirectly relates to the lack of resources because of financial problems. In the study, money is described as the main source for maintaining the quality of care and a foundation for remaining the responsibility. Lack of money create the feeling of powerlessness, stress, guilt and hope which have been discussed by many participants. The main issues of money with people with dementia is the fact that they have no income or pension or that their family is controlling their money which makes them feel powerless as if they lose autonomy. With family caregivers, the issue of money is more likely related to the health care cost and family responsibility which causes stressful experiences.
When people with dementia talk about their financial situation in the family, they interpret the meaning of money to them as the signifier for the quality of life or care, a factor of stress or a root of guilt for them. Talking about the difficulties that the participants encounter, Ye says:

‘Currently, we have little money, I have no pension, no income, (the government) gives me 85 yuan (£10) each month, what can this amount of money be spent on? It is not enough for spending on medicine.’ [PWD6, Ye, line 123].

Again, responding on how to deal with this situation, she says:

‘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.’ [PWD6, Ye, Line 139].

The above extract indicates that the participant is not only worried with financial issues related to the stress, but that unavailable health service and health care services are also a great concern for her. She repeated ‘the medications are too expensive’ to highlight the meaning that money has for her in terms of accessing health services. This has directly affected the quality of care and life for her. Lack of money makes Ye experience feelings of worry as well as financial dependence and insecurity, especially with healthcare services. Similar expressions can be seen from Wen:

‘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, now, I have a carer (private) who helps me.’ [PWD1, Wen, line141].

Most people with dementia in China cannot afford a private carer. The person with dementia might only have three meals provided if their children are not available to look after them. For many people who live in the rural areas, especially the older people without a pension are not as lucky as Wen in terms of the availability of care services and the quality of their life. Wen has a good pension that has allowed him to employ a private carer, however, he still complains of the financial pressure because of the high cost of employing a private carer and also the high hospital cost. This may disclose the importance of the infrastructure of the healthcare service for the older population.

The extract from Jing’s description reflects the meaning of money as the foundation for the quality of care in rural areas.
For people who live in rural areas, they cannot afford to stay in hospital. For most of the older people (in the rural areas) who (people are dependent on someone) have been looked after by their children in turn, give them some food to eat, then leave them alone as the children have to work on the land. If some jobs take time, the older person might not have something to drink for a long time; if the older person sits outside, there might be rain.’ [PWD3, Jing, line225-23].

In China, because of the financially unstable healthcare system and cultural values, people who have dementia rely mainly on their family to put bread on the table. If the person with dementia financially depends on their family whilst their family lives in poverty, the quality of care would not be secured. From Jing’s description of his neighbourhood, the quality of care would be close to starvation.

Financial burden of the health care cost is one of the major barriers for quality of care in China. Most of the participants have shown their satisfaction with the in-hospital cost which is supported by the reimbursement from the resident healthcare insurances. However, long-term healthcare is not included in this healthcare insurance system, it is paid by individuals, and therefore this cost is a big burden for most participants. In China, pensions are only available for people who have worked in a governmental sector, industrial sector or in organizations. In my interview, 4 out of 10 people with dementia had no pension and 10 out of 14 family caregivers had no pension or job, it means they are financially dependent on the family or the person they look after. This situation has left people with dementia and family caregivers in a vulnerable financial situation. Such situations may leave participant in a somewhat conflicting relationship with people with dementia or other family members. Statements from the participants are evidence of this.

‘…Another is the financial issue, my father didn’t need to see the doctor before, and his pension was passable for the three of us. Now he often visits the doctor or stays at the hospital, the money is not enough for us. Of course, without enough money I need to find a job. It also has a bad influence on a child as I am a parent out of a job, and going out for job also lifts up the personal spirit…’ [FC2, Xue, line 82].

In the extract, Xue describes some conflict between finding a job and looking after her father, a negative parental model and future perspective which are caused by the financial strain. Lack of money has left a shameful, stressful feeling for Xue, and also creates a tension in the relationship between her responsibility for the children and the responsibility for her parent.
Gui lives in a remote village with her two sons, who are 43 and 48 years old, and both with familial early onset dementia. Gui hasn’t got a pension and her two sons have lost the ability to work on the land to earn the living costs, therefore their life is in poverty. In her statement, the financial burden has left Gui in a desperate situation.

‘I don’t need to buy vegetables because I have planted some; I just occasionally bought a little bit meat for them (her two sons) to eat. The neighbour has given us a fish yesterday. What can I do? I have no solution. Every day I spend 7 or 8 yuan on bread…I cannot let them be starving once I am here. It is their fate if one day I am to die. I must feed them once I am alive. 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, helplessness and cannot do anything about it…’ [FC12, Gui, line110].

In the extract, the experience of financial stress is described by the participant through everyday living costs. Money issues have left them with a poor quality of life and a hopeless future. A sense of despair and helplessness can be identified in her crying about life and worrying about her son’s future. Money shortage leaves Gui’s parental responsibility in a vulnerable situation and an insecure care service for her sons. This also reflects the phenomena of limited social support, the drawbacks of the current health system and social security system. With social and personal pressures, Gui lost her confidence with the continuity for the ‘altered’ life. This is embodied in her wish that she was going to die with her family all together. On the one hand this reflects the participant’s feelings of despair, and on the other hand reflects her parental responsibility to stop her children from getting into a worse situation and suffering.

For Huai, lack of money is directly linked to the quality of life and quality of care. When talking about the difficulty which he encounters at the moment, Huai says:

‘I haven’t got enough basic life materials, I lack money, I feel sad…it is hard without money, money would make things better. I could make her life better as I can buy some high-quality food for her to eat and give her more nutrition. I would buy some ribs and cook some soups for her. It would not be possible without money. (Sigh)...the life becomes hard for people getting older, it is a truth, it is hard for me…’ [FC8, Huai, line149].

This extract creates a sad emotion through the conversation. As a husband, Huai feels that he has the responsibility to provide a good life for his wife, but his wife’s situation stops him earning money. Lacking money leaves him incapable of providing
a high-quality care for his wife. The description reflects his frustrating feeling of helpless and stress for the situation and unfulfilled responsibility for his wife.

Overall, this superordinate theme indicates how responsibility has been distributed among individuals, health care services and the society and how social factors influence the sense of responsibility. Following social transition, the individual still keeps the sense of caring responsibility for older family members. However, many factors distort the concept of responsibility. The role of the health care system and older care services need to be reconsidered.

4.3.3 Superordinate theme 3: The meaning of responsibility in the cultural context

This superordinate theme illustrates the meaning of being filial from the Chinese traditional view by explaining the cultural concept of being filial, the ways of being filial and the changing value of filial piety by contrasting the meaning between filial piety and responsibility. Participants viewed filial piety from two angles: filial piety is something that is very important in their daily life and filial piety is a principle or standard. It includes three subordinate themes (see figure 4): ‘Being filial is a cultural continuity’ which relates to traditional cultural value, customs and Confucius’ philosophy; ‘Different ways of Being filial’ explains being filial can be presented in different ways; ‘The changing perception and norms of filial piety’ reflects how social transitions affect the cultural value by clarifying the difference between filial responsibility and obligation. This is associated with attitude, meaning and the concept of filial piety.
4.3.3.1 Being filial is a cultural continuity.

Being filial is embedded in traditional Chinese culture. Filial piety is one of the dominating concepts of Confucian philosophy; the value of filial responsibility regulates the roles and relationships between children and parents. Holding on to this belief, the topic of ‘filial piety’ was mentioned by all of the participants in the study. This subordinate theme interprets the meaning of filial in the traditional view of some participants.

‘...I will get older later, looking after my mum is not only my responsibility, but I am also a role model for my son. If I am not filial to my mum, my son might not be filial to me, this may happen like I say it might, but anyway, I think people must take their responsibility of looking after their parent....’ [FC5, Ling, line 111].

For Ling, looking after his mother is not only a task and an obligation, it is also a responsibility for him to carry on the cultural continuity for the next generation and a potential investment for his future. Caregiving responsibility has been interpreted as a cultural heritage and traditional value in this context. A similar sense is also created from Xue’s description. She says:

‘Do I gain anything? ...It is my responsibility to look after my parent.... After all, he is my father, whatever difficulties I have...I must look after him. The most important thing for me is the fact that I have played as a
role model for my son, he will carry the culture of filial piety as he watches me do it. Err… this is the biggest gain.’ [FC2, Xue, line68].

With health issues herself, Xue had to send her father to a hospital to give herself a break. Despite going through a hard time due to looking after her father, she still thinks that looking after her father is something very important in her life. Whatever difficulties she will face, being filial to her parent is also to showcase to her son, to continue the traditional value to the next generation. Caring responsibility for Xue represents cultural continuity.

When talking about whether there are effects on the family relationships as Yan takes care her mother, she responds:

‘No, filial piety is the most important. Looking after parents is a priority for me, my child is also filial to his grandmother and he is a good kid. Parents are first, I’d rather sacrifice my job and my little family to look after her.’ [FC13, Yan, line 111].

In Yan’s opinion, being filial is not only a virtue, but is an indicator to judge a person’s character as she says, ‘he is a good kid’. From talking about herself to her son, the belief in filial has been treated as culture heritage in the whole family. Yan’s role of looking after her mother translates to the role as a carrier of the traditional culture value. For Yan, whatever is needed in order to complete this responsibility is worth doing. A strong feeling of willingness and pride that is related with the culture value can be identified here. Similar to Yan, Guang says the same thing:

‘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…’ [FC1, Guang, line230].

In this extract, Guang has raised a stronger feeling of willingness. The meaning of filial is not only a culture belief and an important thing in her life, but it is an inspiration and spiritual healing for her. For Mei, being filial is more like being a self-comfort. She says:

‘It doesn’t affect my family relationship, because being filial is a priority in Chinese traditional culture, all of the family members do their best to help each other in order to do it. The only thing is that I had to sacrifice many social activities and things which I am enjoying. I think that my life shouldn’t be like this. However, on the other hand, being filial is a self-comfort for me as I am fulfilling my caring responsibility’ [FC 6, Mei, line117].
Several meanings appear in the extract. First, it is a clear indicator of a sense of a culture of continuity of filial piety by talking about the actions of the whole family. In addition, the participant’s self-sacrifice has emphasized the critical responsibility of taking care of her parents as a child. Third, Mei refers to taking the caring responsibly as a ‘self-comfort’. She acknowledges that being filial is a spiritual placebo for her and yet also a responsibility that cannot be avoided in the Chinese culture. Therefore, the caring responsibility has been interpreted as an action of being filial in the above participants.

The views about filial piety from participants with dementia were mostly focused on the details describing how their children were being filial to them. This will be discussed more in the following sections.

**4.3.3.2 Different ways of being filial**

All participants in the study believe that being filial to parents is the children’s responsibility; however, each participant interprets the meaning of ‘filial piety’ differently. In Chinese traditional culture, being filial includes several components (It has been discussed in the literature review chapter). During the interviews, more than half of the participants with dementia hold their views of being filial as to whether the children/ family provide finance for them, especially with the participants who live in rural areas. For example,

’It is filial if they can provide the basic living material. Being filial can be in different ways. For me, they (his children) are filial as they provide food and drink to me. It is not filial if somebody wouldn’t provide the basic living material for their parents.’ [PWD7, Yin, line65].

Even though Yin claims there are many ways of being filial, his experience of filial piety lies in what he needs for the basic living materials. Chuan has said similar things:

’I have one son, he is filial. He would send food and other stuff, whatever I need. I have no daughter, he buys clothes for me whenever he sees others wearing things that might suit me…’ [PWD5, Chuan, line 63].

In the above two extracts, the foundational meaning of being filial is where one can provide basic essentials for their parents. This may be associated with the current social security system, older people who don’t have a pension so they are financially dependent on their children. Children can provide the physical materials that are critical for life. This is especially important for the participants who have no income or pension.
For Yin, the meaning ‘be filial’ can be interpreted with ‘food’.

‘The meaning of ‘be filial’ includes too many aspects. For me, being filial is providing food for me...children have their jobs to do, so I only can stay at the hospital’ [PWD7, Yin, line65].

It reflects that filial piety has not been conducted in the traditional way from Yin’s description.

For Shao, being filial does not just mean providing things for their parents, it is more important to have concern and respect towards their parents. This may be because Shao and his wife are still able to work on the land and get income from it. Shao says:

‘What is filial piety? The first and most important thing is to listen to your parents and do whatever they say. They provide the materials that they need. Children must care about their parents and talk to them’ (grin). [PWD10, Shao, line71].

Consistent with Confucius’s concept of filial piety, the sense of listening and obeying can be seen clearly in the above extract. Therefore, the meaning of filial piety for Shao is to provide emotional support.

For Ye, the way of being filial is presented in everyday life activities. Such as, doing house chores with children.

‘Children are good to me. I have five children. They often help me with cooking, they like to listen to me’. [PWD6, Ye, Line 38].

I think that cooking together doesn’t mean just helping with a chore for Ye. The process of sharing the task with children is more important. For Ye, being filial is reflected in the actions between parents and children. Liang expresses the same perspective as Ye.

‘...coming and visiting me, helping me to do some stuff. I don’t want them to spend money on me, just come and help with washing and tidying.’ [PWD4, Liang, line59].

Liang does not want to ‘waste’ any money for his family, but he is eager to spend time with family by doing some domestic duties together. The meaning of being filial links to the family connection and being together that lies in daily life activities.

Xue says that being filial can be in many ways, but for her, it is physically looking after her father that is ‘paying’ filial piety. She says:
‘I think if someone can (physically) look after their parents it would be ‘Xiao’. We can’t value ‘Xiao’ by money, it isn’t ‘Xiao’ if one only gives lots of money to parents, and we do need to consider the person’s income. It is better to look after parents (physically), take care of them in daily life. Err… we must consider the situation of everybody. For my situation, I can look after my father which is ‘Xiao’.’ [FC, Xue, line 143].

In the above extract, Xue interprets the concept of filial piety in two different ways: a spiritual way and a realistic way. ‘We can’t value ‘Xiao’ by money’ reflects the spiritual world of being filial which is something (cultural value/ belief) very important in life. Providing physical care is reflected in daily life which links to physical materials and daily tasks. Lastly, she mentions her personal situation which suggests that the meaning of the concept of ‘Xiao’ should be interpreted in the personal situation.

However, Shen has a different view of filial piety, he says:

‘I cannot say that whether my children are being filial to me currently…but remember this, if parents are wealthy and useful, children would be filial; otherwise, if parents lose the ability to be useful, the children would not be filial to the parents.’ [PWD8, Shen, line106].

In the case with Shen, he lives in a rural area and his family has a big debt. He seems afraid to be discarded by his children. This situation might lead him to have different experiences with filial piety. He has judged filial piety by the value of the parents to their children. Shen’s perception of filial piety may be related to the current family care model which requires too much emotional and financial burden on an individual. Once this burden exceeds their ability to cope with it, being filial may not happen within the family.

In the following section, this subordinate theme shows a different view from the participants that are family caregivers which are associated with losing job opportunities, lacking social activities, time occupation and no freedom because they are taking the caring role. Most participants agree that being filial is the children’s responsibility and a priority of the Chinese traditional culture, this has been discussed throughout the whole chapter. However, the participants still raised the issue about how they have to sacrifice something to take care of another person. For example,

‘In fact, I have given up a lot… I gave up marriage and gave up my job as well. I had a job in a bank, I only worked for a few days but then my mum had a fall at home so I stopped to look after her full time.’ [FC13, Yan, line190].
In the extract, the participant says, ‘give up’ three times, this emphasises the strong feeling of the cost of taking care of her mother and the sense of self-sacrifice. For Yan, being filial is not only a thing needed to fulfil her responsibility, but to be filial she had to give something up. Under such situations, being filial can be difficult.

Again, Mei agrees that she has a responsibility for her mother, but the price is that she had to sacrifice her social activities and free time. The sense of having no alternative but to take care of her mother appears.

‘…because being filial is a priority in Chinese traditional culture, all of the family members should do their best to do it. The only thing is that I had to sacrifice many social activities and things which I am enjoying. I think that my life shouldn’t be like this…’ [FC6, Mei, line117].

A query of the relationship between filial and responsibility seems to appear from Mei’s description. It reflects a doubting attitude on the traditional family care model and may suggest that an appropriate approach to strengthen family responsibility or an alternative care model in China to ‘fit’ with the changing cultural norms should be introduced. In China, following the rapid social change and economic development, many adults cannot, at least physical look after their older parents because they have to invest their time in a fiercely competitive society to earn a living. Therefore, social transition has left the traditional culture of filial piety in a predicament. In the study, being filial has been interpreted by the participants in different ways, the meaning of filial piety seems to become more realistic and material rather than the cultural symbol of Chinese society.

4.3.3.3 The changing perception and norms of filial piety

Despite the fact that filial piety is an important cultural expectation and social goal in Chinese society. However, following the change of social conditions, as well as the regulation of supporting parents being required by Chinese law, caring responsibility as part of the belief of filial piety has been interpreted by some participants as an obligation rather than a cultural and moral belief. For instance,

‘erm, this won’t take many years, 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.’ [FC9, Yu, line 85].

In this extract, the meaning of looking after his mother isn't based on the traditional value of filial piety. It is a task which Yu 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. It may be one of the components of filial piety, but cannot be treated the same as filial piety. Shou also raises the similar sense of being filial. He says:

‘What my thoughts are on being filial? I have no choice (looking after his mother), it just happened (his mother has Alzheimer’s). I have no way (not looking after his mother). Sometimes I get agitated, because of the situation, I cannot do anything, so how can I not get agitated?’ [FC10, Shou, line 114].

For Shou, the surface view of taking care of his mother is being filial to his mother, however, the deep meaning of being filial did not reach the standard of the traditional value of filial piety. It has been distorted by a confusion of the concept. In the extract, the meaning of taking a caring responsibility for parents reflects the sense of unwillingness and stress which is associated with no freedom and heavy duty of daily activities.

Mei has combined the above two participants’ views, and developed her unique opinion of who should take caring responsibility. She says:

‘…we grew up in this era and we should adapt ourselves into it. Each era has its duty, in this era, the government focuses on developing the economy, therefore leaving the responsibility of education, medical, housing and older care for individuals and family. Thus, the generation of 50s, 60s and 70s have to sacrifice their personal interests to cooperate with the state on construction. There is no other way; this is the task of an era.’ [FC6, Mei, line 231].

In this extract, it is clearly shown that looking after older parents is a task for the individual. The sense of caring responsibility has been interpreted as an obligation for an individual rather than a cultural belief. Mei also indicates that the responsibility of taking care of older people can be transferred from one to another. As caring responsibility wasn’t cultural belief, she thinks that the government should to take responsibility of older people with dementia. When talking about the meaning of filial piety, Mei says:

‘…the children should be filial to their parents since their parents are still healthy, and the children should to try their best to be filial, to give their parents what they can give and let their parent enjoy life. This is being filial. If they wait until their parents get frail and ill, then you start worry about them, it is not meaningful.’ [FC6, Mei, line121].
In the above extracts, it is clear that Mei has separated the concepts of being filial and taking a caring responsibility. She interprets being filial as a cultural value that crosses the life course. This kind of filial piety is not only limited to physical level, but more about spiritual level. A caring responsibility is only about a task to take care when parents get old, which can be done by anyone. Ling manifests a same sense of who should take the caring responsibility for older people.

‘...I hope the state can give some support to people with dementia and family caregivers. For children… although children have responsibility to look after their parents, but I think that the state should give children some compensation for doing it …’ [FC5, Ling, Line52].

In the extract, caring responsibility has been taken out from the component of filial piety. Taking care of parents becomes a job that needs to be paid for, to a certain extent. If we take this idea in account, the value of filial piety will go down. Although filial piety has been advocated again by the current authority in China, the stories from some participants have still evidenced the trend of the cultural value going down. Here are some extracts from participants that illustrate this:

‘I don’t know what is filial piety, how do you be filial? I think that most people are being filial to their parent, so I do same as what they are doing for their parents. My oldest nephew lives in Gansu (a very long distance from where the participant lives). He doesn’t visit even when he passes by. I don’t need him to spend money on me, I only want him to come and see me and chat with me, but he doesn’t come.’ [PWD4, Liang, line 110].

Liang brought up his nephews after his brother died, so his nephews are as same his own children. The nephew didn’t visit during his stay in the hospital, and this made him question the meaning of filial piety. However, the extract also reflects that the traditional value is declining. Another participant directly expresses his view of filial piety, he says:

‘Nowadays, not many children are listening to their parents. It would be filial if children can often visit their parents, and sometimes buy stuff for their parents. Someone who is not filial to their parents when their parents are still alive, but after they die, they offer a big funeral. I don’t approve of it…’ [FC10, Shou, line206].

Shou illustrates that the value of filial piety has collapsed through talking about children’s actions to their parents. The episodes of visiting parents, buying presents and holding a funeral reflects the way in which being filial has changed from the traditional ways. Filial piety has been presented in the form of providing physical
resources but less presented in a way of love and caring. For children, taking a care responsibility to look after their parents is becoming an obligation which is bound by family responsibility and even law or custom.

‘Currently, being filial has been advocated by the government as a mainstream culture. However, less people can be filial like in the past. There are not many people doing it, being filial has become a formalism. There are less and less people sacrificing themselves to do it.’ [FC6. Mei, line 140].

With the social conditions changing, the way of being filial and the view of filial piety have also changed. Even though the current Chinese authority try to promote the culture of filial piety in order to enhance the children’s responsibility to their older parents, value of being filial is still declines in the younger generation. People have become more and more focused on personal rights and identity as Mei said there are less and less children that are willing to sacrifice their time to being filial to their parents. They may be willing to provide physical resources to their older patents, but paying less care and love to them.

When talking about filial piety, Jing reveals an experience about older care in his village. He says:

‘…I remember that there was an older lady in our village, who has incontinence, she often wet herself, her son and daughter wouldn’t change and wash her, but they feel shameful when she went out with wet clothes on, so they locked her inside of the house. In winter, she froze and died in the house. Err, the older people were very poor (in the rural area). Compared to them, I am living in heaven…’ [PWD3, Jing, line 216].

Jing discloses a detrimental care services for older people where he lives, however, this may be a particular case and cannot be presented as common. However, it reveals the dearth of older care services in rural areas, or at least a shameful situation that is evident in some rural areas. It is from another angle revealed as: the collapse of the traditional family care model.

In conclusion, this superordinate theme reflects the changing value of filial piety and the changing sense of caring responsibility through analysis of the participant’s stories. Comparing the norms of filial piety with family responsibility, it manifests how the changing society’s condition has changed the meaning of filial piety and caring responsibility toward older parents in China.
4.3.4 Superordinate theme 4: Coping with the ‘altered’ life

In order to take control over their own lives, this last theme illustrates that the influence of the cultural value of taking a caring responsibility and how the participants maintain their responsibility by using different coping strategies. It also specifically explicated death as one of the coping strategies by revealing the relationship between death and responsibility. This superordinate theme includes three subordinate themes (see figure 5): Being filial is a coping strategy and other ways of coping, death is a way to reduce burden and the settled life.

![Diagram showing the relationship between the settled life, coping with the ‘altered’ life, being filial, and death.](image)

Figure 5 Superordinate theme 4: Coping with the ‘altered’ life

4.3.4.1 Being filial is a coping strategy and other ways of coping

This subordinate theme reflects the ‘coping’ experience which links to how participants use different strategies to cope in different situations. The coping strategies are mainly presented in two ways: a problem focused strategy or an emotion focused strategy. Across these coping strategies, cultural beliefs appeared to have a larger role than problem-solving strategies, where filial piety was described by most of the participants.

Despite the value of filial piety is declined in the contemporary China, eight out of 14 participants who are family caregivers hold filial piety as the main spiritual impetus for taking their caring responsibility and coping with their new roles. Some of the
participants take it as a moral judgement while others view it as a stimulator or comforter. For instance, for participant Xue, being filial to her parents is the most important thing because she thinks filial piety is a cultural value that must be passed down from generation to generation as she said: ‘...I have played as a role model for my son, he will carry the culture of filial piety as he watches me do it. Err... this is the biggest gain.’ (FC2, Xue). It also indicates that this cultural belief is a powerful spiritual force that makes her take the caring responsibility and is spiritual support to adapt to her new role. Another participant who looks after her mother views being filial to her as making herself feel at peace and conscience-proof. For the participants with dementia, filial piety seems to be a safety net and a backup resource which brings the sense of security for them. For instance:

‘I am not afraid of the financial problem. I don’t need to worry about the difficulties, it is not my problem to borrow money, is it? I have children, the children will shoulder it up...’ [PWD7, Yin, line 97].

The extract reflects a safe feeling being perceived by the participant as he knows he would get support from his children if anything happened. This feeling of support made him adapt to his new life quick and easy. Half of the participants with dementia use their belief of filial piety as their coping strategy.

In order to adapt into their new roles, a few participants who are family caregivers have changed their life style of personality. For example, one of the participants who is a family caregiver, coping with the ‘new’ life is to change herself.

‘I told myself that she cannot change herself, let me change myself (helpless laugh). Then slowly I adapted myself to the life. I am here now, trying to get into her world and to adapt to her.’ [FC13, Yan, line96].

This extract reveals that the participant’s coping strategy with her caring role is to change herself. In Yan’s experience, dementia has changed her mother’s personality, and this change cannot be reversed. The method of adapting to the new life and building a new relationship between her mother and herself is only achieved by changing herself. This strategy may be associated with changing the past skills, changing the environment around her or changing her personal identity and attitude. ‘I am here now’ obviously refers to the continuity in her present ‘coping’. Indeed, this changing herself strategy has helped her to settle in to the changed life, the following description from her has further evidenced it.
For participant Guang, being filial is a coping strategy and stress reliever while she is looking for her mother.

’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…’ [FC1, Guang, line230].

For Shao, family support is the force of life continuity and the emotional coping strategy for him. He says:

’Life is alright for me, I can look after myself, I live with my wife. We have one son who lives on another side, 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. The government also looks after older people. So, life is alright for us…’ [PWD10, Shao, line 29].

As well as the belief that filial piety is a coping strategy that Liu also believes that Buddhism is another strategy. For, Liu, the belief of Buddhism is an emotional strategy to cope with this ‘different’ life. She says:

’Now I try my best to adapt to the life. I have no other option. I try to comfort myself through the belief of Buddhism and believe that I owe him to do it in my life of the last generation. I comfort myself in this way. Otherwise what can I do?’ [FC4, Liu, line79].

Belief is a spiritual support and a source for Liu to carry on with the current life. The caring responsibility is something that has already been arranged and a fate for her, so in this case, Liu can only accept the caring responsibility. Coping with the changed life seems to create a complex relationship of ‘responsibility’, ‘belief’ and ‘coping’ in this extract.

For Shao, having the ability to manage the daily activities seems like a success for him. Then with the social support either from the family or the state becomes a positive factor to strengthen this ability. The phrase ‘life is alright for me’ indicates that he copes well with the ‘new’ life. Raising chickens and ducks reflects the meaning of his life continuity and his positive life attitude. Moreover, for Shao, knowing he would get support from his son is another backup resource for him, his personal responsibility seems remaining well with these strategies.

One wife who looks after her husband thinks that leisure activities can help her to relieve stress which is caused by her husband’s health condition. She says:
'I will go outside to have a walk if I get free time, playing poker with others, to release stress. I like playing poker and cards since long ago.' [FC3, Ying, line97].

It is clear that continuing with the normal life is a strategy for Ying to cope with the stress experienced from looking after her husband and a strategy to continue her future life.

For Mei, keeping a 'good' life for herself is a foundation to provide good quality care for her mother. She says:

‘… I enrolled in several training courses, such as dancing course, fitness course and music course, I will go there if I have free time, if I do not have time, I will stay at home and look after my mother. I do this because I do not want to drop out of society. I try to make my life better… I am more than 60 years old, I want to keep living a joyful life while I look after my mother…’ [FC6, Mei, line168].

For Mei, keeping an enjoyable life is key to keeping the balance between the old life and the new life. She seems to try hard to work out a useful way to do it. The sense of striving herself can be identified in the phrase ‘I try to make…’ The sense of taking personal responsibility for herself can also be found in the extract, such as the participant taking fitness-training courses to maintain her physical health. Furthermore, when talking about how to manage her mother’s swallowing problem she says:

‘I try to persuade her to eat more by using the same method to feed a toddler. Sometimes I use a tissue to cover her mouth and make a joke ‘swallow it, don’t let the food out’. I use many ways to persuade her…’ [FC6, Mei, line186].

The sense of endeavour is reflected in the description that Mei gives when she tried several methods to persuade her mother to take more food. This also reveals that Mei takes her caring responsibility seriously as well. There is a sense of endeavour in Mei’s depiction of the several methods she is using to encourage her mother to eat more. This also reflects the responsibility she feels when caring for her mother.

In contrast to Liu, the coping strategy is more related with the family financial situation for Xu.

‘I have no difficulty, we have money, my children are working, I have a pension as well. It is not so difficult for most of families, the income from the land and plus the financial support from the government, my mother has 3000-yuan (£336) income each year, it is enough for her basic living cost. The payment for children to look after her is free, anyway older people don’t need to eat the expensive food…’ [FC11, Xu, line216].
This extract communicates continuity in Xu’s life as he has sufficient monetary resources. Even though, Xu has no financial issues whilst looking after his mother, his description points out that the financial condition of the family reflects the main problem of the current family care services and the relationship of caring responsibility and care burden. Moreover, ‘older people don’t need to eat expensive food’ also reflects the financial restriction and the quality of care in the rural areas.

For the participants with dementia, trying their best to maintain personal responsibility has also appeared in several participants’ narratives. Some of the participants focus on individual strategies, and some may need extra support from others. For instance, one participant says:

‘After getting up, I will put the key on my neck, then I wouldn’t forget it if I go outside, or I tie it to the shopping basket, then I will bring the shopping basket to go shopping, things like this, so I wouldn’t forget it. Otherwise I will forget it.’ [PWD5, Chuan, line54].

This problem-focused strategy is reflected in Chuan’s everyday life, where she describes her strategy of dealing with the memory loss by giving an example of how she keeps her key. Her method of how to adjust to change and finding a way through difficulties, reflects the sense of taking personal reasonability and her exertion on the life continuity. This also shows her capability with adapting to the changed life. Another family caregiver participant says:

‘To be honest, everything was difficult for me in the beginning. But gradually, I got used to it and I feel that I have adapted to it…’ [FC13, Yan, line54].

Here, ‘I have adapted it’ reflects the meaning of coping with the ‘new’ life and remaining with the caring responsibility. In addition, ‘getting used’ is also a strategy for Yan to cope with her new role and the ‘altered’ life.

Some participants with dementia talked about their hopes for the future, this hope is either related to taking personal responsibility for life continuity or wishing to be able to take family responsibility for others. Keeping hope is a coping strategy for some participants. For example, the following two descriptions from Liang indicates that recovering from the illness is not only taking personal responsibility for himself to be healthy, it is also the foundation for him to keep his parental responsibly.

‘After I get better, after my legs recover, I will go home to help my nephew on the land, to do something on the land.’ [PWD4, Liang, line126].
‘I have no thoughts. I only want to get my bank card (controlled by his nephew’s wife) back. I want to save money to buy a house, I have worked for 66 years, I haven’t saved anything for myself (all spent on his nephews) …’ [PWD4, Liang, line63].

These two extracts reflect the sense of responsibility that is embedded in the context of being healthy and doing something for children. While the phrase ‘to help my nephew’ reveals the remaining parental responsibility for his nephew, Liang’s wish to buy a house reflects the personal responsibility for himself and the growing sense of life continuity for the changed life. Parental responsibility also is a stimulus for him to fight the illness. The perception of personal and parental responsibility can also be found in Ye’s description.

‘I wish my condition (forgetting) will get better, so I could cook for my family…’ [PWD6, Ye, line187].

Yi explains that his wish is to keep physical health. He says:

‘I think about how to do exercise and to keep healthy. I wish I didn’t need a wheelchair in the future and (I wish) to live longer. I think about the things which happened in the past, I didn’t take my filial responsibility for my parents when I was younger. Now, I cannot do anything about it.’ [PWD2, Yi, line 95].

In this extract, a strong sense of taking personal responsibility is felt in participants through maintaining physical health. For Yi, planning to do physical exercise is both a perspective for the future life and a strategy for coping with the ‘altered’ life. In addition, a guilty feeling of not being responsible to his parents in the past can also be identified in the description.

Another participant with dementia, Chuan has expressed that a settled life means to be around with family and friends.

‘…I am very good in here (hospital), the relatives and friends often come to see me. They buy food I like and which I can eat, I have high blood sugar. They all treat me very well. I have food to eat and a house to live in. I don’t need any extra help.’ [PWD5, Chuan, line102].

The extract indicates that ‘coping’ can be strengthened by other people or things, such as emotional support from family and friends, living materials and many other things.

All of the above extracts likely reflect coping associated with struggling or content which link to the aspects of problem solving or emotional strategy. But with Yin,
stopping to fight with the situation or accepting it as 'normal' is another way of coping. He says:

‘There is no effect. My children will bring food to me if it is the time for food. Then I will eat it, what the effect? They would look at the time, if it is the meal time.’ [PWD7, Yin, line 76].

For Yin, just accepting what life offered to him is his strategy of coping, where the sense of personal responsibility seems lost to him. His desire of life is only limited to survival. Another participant has also expressed the meaning of accepting.

‘I don’t need any help, if you are talking about financial support, I never think about it. The government could give it to somebody in need. I am alright, I can cope.’ [PWD10, Shao, line187].

Accepting is a way of coping and its implications can be further found in Zong’s description.

‘The life…The life is OK. There is one person (carer) who looks after me in the daily life. She will cook for me, so I have three meals on time. Sometimes we buy breakfast, but we always have home cooked food for lunch. My health is relatively OK. So, I am alright.’ [PWD9, Zong, line5].

In the description, Zong seems settled and satisfied with a life that relies on the basic life materials—including food, health and personal support. The sense of acceptance that was expressed in these two extracts may seem to contrast with the perceptions ‘tianming’ which has been expressed by Jing in the theme, ‘death as a way out’ (see next section). For example, the phrase ‘I just wait for death day by day …I have no plan now...’ (PWD3, Jing). However, both these extracts also reflect the participants have given up their personal responsibility which lie on their expressions of accepting. However, accepting seems to be a false appearance of coping.

4.3.4.2 Death is a way to reduce burden

This subordinate theme reflects how psychological and social factors, such as stress, social support, healthcare cost, caring burden and medical practice has influenced the participants’ view of responsibility and the reason of why they believe death is a way to reduce burden. In the narratives of participants’ lived experiences, death appears as an alternative coping option with the ‘altered’ life, especially with people with dementia.
Half of the participants with dementia discussed the topic of death. This is more likely linked to the care burden which they brought to their family or others. One of the participants says:

‘…I will be dead one day; I don’t want to bring pressure to my children. It is a relief for them if I can die soon…’ [PWD9, Yi, Line 158].

Yi indicates that death would be a relief for his children, which shows that he treats death as a way to reduce his children’s burden at this stage. For Yi, dying earlier is better because living longer would be more of a burden to his children. In this extract, it seems death is a relief for both people with dementia and family. Accepting death as the next step makes it easier for the participant to cope with the ‘altered’ life. This idea might be a consequence of the current health care system in China where the cost of the care services needs to be paid by the family. Again, Xin presents similar response.

‘I hope I can die soon. Dying soon, death is an ending and with everything will be gone. It would be better (for me) to die now. As the saying goes, ‘better to die, not to live’ if the situation is like this. 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…’ [PWD7, Yin, line 78].

This extract illustrates two layers of experience; one is the psychological influence that reflects the feeling of depression and despair. Another is associated with the social factor of financial problems. Taking care of Yin has caused the family financial burden and has limited his children to go out for a job, therefore, Yin appears to think that the idea of death is a way to reduce family financial and caring burden. Death maybe also a way to reduce his emotional burden as he has dementia.

Another participant presented a view of not being scared of death, but not wanting to suffer, the idea has been presented in Jing’s interviews.

‘…When the time arrives, death will come. The problem is that I cannot die conveniently and the way I want. If somebody could not walk or eat they would be suffering (what he thinks would happen to himself in the future). (In this situation) It is better to die than to live. It is also a relief for the family and a relief for the individual. It is not meaningful to live like this.’ [PWD3, Jing, line 183-188].

This extract reflects three aspects of experience with death. First, Jing shows certain similar opinions with others of death, but he also mentions issues with death and his fearlessness. Then, the sense of being a burden appears in the word ‘relief’. Thus,
the meaning of death is a solution that can be identified. Apart from these ideas, his description of this extract also reflects end of life care, personal centred care and professional support that have not been available to people with dementia in China. Unlike the western health sector, the health services of post-diagnosis care and advance planning have not been widely applied to people with dementia in China.

With some of the participants who were family caregivers, the issue of death is relatively less discussed. This may be because the topic of ‘death’ is too sensitive. Only a few participants have expressed their views on death. The following extracts explains the meaning of death for Huai.

‘I have no thought (about taking care of my wife). My son hasn’t got money, if she dies, we will just bury her…’ [FC8, Huai, line 91].

Huai and his wife financially depend on their children. As his son has a low income, the care burden becomes a huge pressure for him. The statements of his son having no money and that he has not thoughts with his role of taking care of his wife reflects that he is in a dependent situation and does not have a lot of power on making decisions to change the situation. His wife’s death is the only way for the family to reduce the life burden. In contrast to Huai, the view of death from Gui is related to the social factors of the social support and security system.

‘…they have said that they would give them (her two sons) the social minimal allowance since last year, however, they haven’t done this…if the application fails, I have no other way, my plan is that we will all die in the house (by killing herself and her sons) …’ [FC12, Gui, line207].

The extract manifests a predicament between life and death for Gui. The sense of sorrow, helplessness and powerlessness have been emphasised in the situation. The narrative reflects the quality of life for the participants and how it is dependent on the financial support from the government. However, the request for financial support not being met reveals the defects of the social security system in China and the reality of the lack of social support which caused the participant to lose hope for the future. In conclusion, death may be a way to relieve the burden for Gui. This also reflects the struggle of how she copes with a changed life and the helplessness of the situation for her and her sons.

One wife who looks after her husband has said that she is too old to look after him and that the only way out may be death, she says:
‘...I have no solution. I sometimes cry during the night because of the stress, sometimes I wish he could die soon. I cannot afford to get a personal carer. My two sons are both in debt; I cannot get money from them. We are relying on my husband’s pension, which is what we rely on. I want to...’ [FC7, Wang, line 50].

This extract reveals the reality of Wang’s physically inability to look after her husband as she is old and frail, and also that her children cannot provide financial support. In this case, death has been discussed as a solution for her. The perceived experiences of stress, helplessness and lack of support from family appear in the extract. On the other hand, the extract also reflects how social factors heavily influence the quality of a family caregiver’s life as well as people with dementia, such as the defective social security system, the unavailable long-term care services and the financial insufficiency.

The idea of ‘death as a way out’ has complicated associations with taking responsibility and paying responsibility. Many of the participants with dementia claim that pursuing death is a kind of responsibility which avoids bringing burden to the family. This idea has been reflected on Shen’s views of being valuable to others and not being a burden to others.

‘...I think that I am getting older and older day by day, it is better to die soon. It only stresses other people, if later I am bed-ridden and with incontinence, life would become meaningless. I am not afraid of death, if I die without suffering than I would rather die soon.' [PWD8, Shen, line63].

In this extract, first, we can see, because of the awareness with the progress of his illness, the desire of death is expressed by Shen. Then, a sense of responsibility of not disturbing others/not troubling others can be identified. His fear of suffering may be contributed by the lack of support from health professionals. And this may point out a question about what the health professional’s role is in dealing with the end of life for people with dementia. In addition, being useless to others for Shen means that his life is meaningless.

‘...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.' [PWD8, Shen, line 144].

This extract reflects the sense of responsibility beyond the meaning of being useful to others. For Shen, losing the ability to be useful and not contributing leads to thoughts
of death. Therefore, death can be interpreted as a responsibility to avoid being useless.

Regarding the issue of the value of life, another participant with family caregiver says:

‘…there are complex feelings about taking care of my mother. Because she is my mother and because of the close relationship with her, I hope that she can get better and she can live for longer. But on the other hand, I think, I think that it is not meaningful to live like this. How to say it… It is not meaningful for her to live in such a situation, it is not meaningful for her to live as she doesn’t understand anything, it is only because we want to do that (keep her mother alive) …’ [FC6, Mei, line101].

In the extract, the word ‘death’ isn’t mentioned by Mei, but we can see that the sense of death appears in her view about whether her mother should live as her condition is deteriorating. The metaphor ‘life is too short’ signals her view that her mother should not live anymore and death may be the solution for ending a meaningless life. This ambivalence reflects the negative attitude towards people with dementia and the ethical issue of whether people with dementia who lose their ability to understand the world should be alive.

Responding to this same topic, another participant with dementia says:

‘… My situation (financial) is better, I have a big pension and a personal carer who looks after me. But in the long-run, I feel sorry as I spent a huge amount of money from the government. What is the meaning for me to live like this (not doing anything) day by day? Sometimes I just think that there is no meaning to live.’ [PWD9, Zong, line57].

For Zong, receiving but not giving creates the feeling of guilt. This leads him to question the meaning of his life. In his opinion, it is meaningless if a person cannot be useful or cannot take any responsibility. This also brings a sense of guilt for being a burden and a feeling of being useless.

In contrast to other participants’ view, Wen’s view of death relates to being unable to walk and being dependent on others. He says:

‘Pessimistic, it’s not meaningful to live, there is no meaning to life. I need help from others all of the time. I can only stay on the bed because I cannot walk. I’m never getting well.’ [PWD 1, Wen, line88].

In the extract, the participant perceives the feeling of sadness and despairing which is reflected in the words of ‘pessimistic’, ‘meaningful’ and ‘never’. For Wen, his life has lost meaning because of the physical inability. ‘No meaningful to live’ links to losing
health and losing future perspective. The following two extracts from Wen further emphasises the link of death, health and future perspectives and explained the meaning of ‘death as a way out’.

‘I have been unwell for a long time, I don’t want to take any further treatment and I don’t want to stay at hospital. I want go back home.’ [PWD 1, Wen, line 159].

‘Wait for death. That is all. My daughter can look after me at home. I cannot do anything, even get a drink’. [PWD1, Wen, line 163]

A feeling of despair as a result of the ‘altered’ life appears in Wen’s descriptions. Death is viewed as a way for escape from the situation of dependent.

For participants of family caregivers, Gui manifests that death is a way to give up fighting.

‘…what can I do? I cannot leave them (her two sons) to starve, it cannot be avoided if one day I am to die, but I need to feed them once I am alive. I already said that if the life cannot be carrying on for me, I will drink bleach with them together (suicide) …’ [FC12, Gui, line113].

In the extract, Gui mentions two methods of death: death by nature and death by suicide. Firstly, the sense of parental responsibility is present when she talks about the future death of herself. Second, the sense of parental responsibility is present in her talking about bringing her sons together with her if life cannot go on. For Gui, death is a kind of responsibility rather than escape. It is a protector to her children and an alternative way to fight against the bad life situation.

A few of the participants expressed their future perspective as dying and accepting that death is a natural process of life, which they can only accept, and not to fight.

‘I have no plan. I have to live until I stop breathing. It means my life has still not come to an end yet. I just wait for death day by day …I have no plan now. I am not scared of dying and I really hope one day I don’t wake up.’ [PWD3, Jing, line171].

For Jing, accepting death is an alternative way to coping with the ‘altered’ life. In the above extract, death also reflects the natural process of life and the ending of everything. In Chinese traditional culture, one’s destiny has already been decided by heaven, it is called ‘tianming’/fate, and how a person shall die has also been decided by ‘tianming’. Once a person has been diagnosed with an incurable disease, they would have accepted it as their ‘tianming’. On the other hand, the issue of death has revealed a serious problem with dementia care services, in which social environment,
healthcare support and financial security don’t support people with dementia and their families.

4.3.4.3 The settled life

This subordinate theme reflects the personal responsibility remaining or recovering from the changed life, it is associated with personal effort/arrangement to make things easy or the participants’ hope for the future. For family caregivers, the issue of settling into the ‘new’ life is more likely linked to the strategies they are going to use for adapting or continuity. For Yan, keeping her caring responsibility is to continue looking after her mother.

‘I try my best to do it. I told my sisters and sister-in-law, I would bring my mum with me if I marry somebody (laughs). It has been a long period of time since I started looking after my mum, I cannot leave her behind. I worry about her all the time when I go to the shops or whatever.’ [FC13, Yan, line282].

From Yan’s description, the sense of responsibility and willingness for her mother can be clearly seen from the phrase ‘I try my best…’ and it spreads through the extract. ‘I will bring her with me…’ not only reflects a caring responsibility for her mother, it also may reflect the value of traditional family culture – children should be filial to their parents, whatever the situations they are in. It also reveals a close relationship between herself, her mother and her siblings.

Furthermore, there are factors that can strengthen the responsibility according to Yan. She says:

‘Once we lose her, I will feel like I’ve lost the supporting pillar of the family, she is the core of the big family. 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. Once she is gone, the connection would slowly reduce, then the chance for us to be together will become less and less.’ [FC13, Yan, line129].

In this extract, we can see that Yan is eager to have a close relationship with family and this has strengthened her sense of having a caring responsibility. Furthermore, as her mother is a spiritual pillar of the family, the caring responsibility has upgraded to a spiritual level. It is consistent with other participants, such as Xu said ‘…a family with older parents is a happy family…’ (FC11, Xu, line152). These enhancers have strengthened Yan’s personal responsibility, caring responsibility and family responsibility. From these two descriptions of Yan, we can see the links of the sense
of responsibility, willingness and the future arrangement. For Ying, the sense of responsibility is simply to continue to look after her husband.

‘I have no future plan; I will look after him until I cannot do it.’ [FC3, Ying, line100].

In this extract, not much talking or feeling has been described from Ying, but the sense of caring can be seen from the phrase ‘I will…’

‘The settled life’ has further explained by Jing, He says:

‘I have food to eat, I don’t need her (daughter) to buy anything for me. I cannot eat lots of food even if she buys food for me, my digestion is unwell. She just needs to come and see me, I feel happy. Otherwise I would feel lonely.’ [PWD3, Jing, line 136].

In the extract, a settled life also links with basic living materials being met. However, this settlement may need to be further enhanced by emotional support from the family.

Taking control of their own life reflects how the participants themselves strive in order to cope with the changed life. The subordinate theme ‘I try my best’ may best represent the meaning of their endeavours.

For Xu, trying his best is also present in his daily activities, such as taking a shower, changing clothes or cleaning the bed for his mother.

‘…at least I will change clothes and make her take a shower for her every 5 days, and wash her feet every night. In summer, I wash her every day. I always keep her bed tidy and clean. I take her out for sunshine every day. I try my best to look after her.’ [FC11, Xu, line100].

The sense of having a caring responsibility and doing his best appears in Xu’s description. From Xu’s point of view, a mother is also the symbol of happiness and emotional bond for the family, just like he says ‘…a family with older parents is a happy family. The feeling would be different if there were no older parents.’ (FC11, Xu, line152). This reciprocal relationship strengthens his responsibility of taking care of his mother.

Yan’s effort on taking her caring responsibility has also been reflected in everyday life. She says:

‘A day… to provide three meals, take medicine, and then take her go out for a walk. Playing music for her if she wants to sing. My dad has left a radio player, it has old songs and operas recorded. Sometimes I
chat with her. She cannot communicate well, I just talk to her.’ [FC34, Yan, line34].

In the extract, the sense of responsibility and support appears in the everyday activities. A good quality of care can be seen from the detailed description of the physical duties and the emotional support which is provided by Yan.

In order to look after her husband better, Liu uses the media to learn more about how to take care of somebody. She says:

‘I haven’t taken any training courses before. But I was a teacher. I often watch the healthcare programme on the television so that I know how to look after him. Some useful knowledge, I write down while I am watching. I know lots of knowledge about healthcare, I use it in daily life.’ [FC4, Liu, line104].

All of the above extracts reflect how the participant has striven to adapt to the changed life. Either by completing physical care or providing emotional support, whatever they have done, the sense of trying their best can be found in these extracts.

Yin settled into the ‘altered’ life and this is reflected in his cooperation with his family and doctors.

‘…at home, I listen to my children, I will eat when the time comes for meal and I will take a rest if the time for a break. At hospital, I will listen to the doctor’s suggestions and do what they ask me to do. That is all, nothing else needed to talk about.’ [PWD7, Yin, line134].

For Yin, receiving other’s help or advice is a method to cope with his life and has helped him to settle down with his new life. The description about how he cooperates with others reflects the sense of wanting to get better, taking personal responsibility and continuing with the changed life.

To summarize, whilst the first theme discussed the distortion of the responsibility and disconnection of the changed life, this last theme has been more focused on coping with the ‘new life’, finding the right strategies to deal with difficulties and maintaining responsibility. This superordinate theme illustrates the different strategies developed by the participants in order to cope with their new roles and maintain continuity, and the relationship between death and responsibility. It highlights how responsibility has been maintained and strengthened in a specific sociocultural context. Whatever the coping strategies are individually, and whilst some may need further support from others, it strengthens the capacity to adapt to the ‘new’ life and the new degree of
responsibility. Among them, social and cultural factors play a critical role in enhancing or weakening of people’s responsibility.

4.4 Summary

In this study, the participants with dementia were able to share their experience, specifically of family responsibility; their perceptions of Chinese traditional cultural belief of filial piety; what challenges and problems they face; what helps and what doesn't in coping with their 'altered' life, and some of the coping strategies they have developed. It illustrated many aspects of people with dementia and their family caregivers’ life and relationships in a specific Chinese cultural and social context. The analysis of this study data, first and foremost, evidences that people with dementia in this study can share their feelings and thoughts and give reflective and analytical consideration of their experiences, which points to the ability of people with dementia to share the insight into their needs and experiences (Wilkinson 2002, Clare 2003, Clare 2004, O’Connor et al., 2007).

Four themes have been identified in this study. These themes have been discussed in relation to family responsibilities and wider social relationships, which have reflected the challenges and dilemmas that the participants faced when caring for or living with dementia under the influences of social and cultural transitions. The theme ‘negotiating the roles’ has reflected a dynamic process of people with dementia and their family caregivers negotiating their roles and relationships. It is significant for understanding the meaning and the conception of caring responsibility and caring relationships in a specific social and cultural context. The themes ‘the meaning of life in the social context’ and ‘the meaning of responsibility in the cultural context’ have displayed how the physical and social environment, the changed family structure, social attitude and filial piety have shaped the meaning of family responsibilities and relationships; influenced the traditional concept of filial piety and consequently affected the participants’ quality of life. ‘Coping with the altered life’ shows how the participants have adapted to their ‘new life’ through developing different coping strategies and how they have reconstructed their ‘altered’ life to make it meaningful to themselves and in which the cultural value of filial piety has played the most important and significant role in keeping family responsibility in place and life continuity for them.
Family caregivers in the study recognise that they have responsibility to look after their family member with dementia. However, because of the changing family structure and demography of sociocultural transitions, the practice of family-based care has become challenging for them. Their choices with regard to caring roles has become very limited. Along with the insufficient social support, they experience great burden and stress in practicing everyday activities, the financial cost of dementia care, and discrimination. The family caregiver's burden of care is very significant. Spouse, children or other family members all carry the burden of care, though different in degree or other ways. For people with dementia, changed family roles, relationships and community environment, make them feel like a useless person and a burden for family and society because they have lost their role as a contributor. The most informal support was from family members and very limited formal support was available to them. The absence of formal and informal support services has made both people with dementia and family caregivers at risk of social isolation and significant neglect.

The findings highlight the influence that cultural, social and physical environment has played and their critical role in shaping the lived experiences and the quality of life through discussion about the meaning of a caring role; the changed norms of cultural and social contexts; the challenges and stresses which the participants faced during care giving; and the coping strategies developed for life continuity. These findings are significant in presenting a specific sociocultural context and how this context has created the cultural differences of people with dementia and family caregivers' lived experience from other ethnicity groups.
5. Chapter Five: Discussion and conclusion

5.1 Introduction

In the findings section, I did not connect the themes to the existing literature, although my analysis of what participants said was influenced by my earlier literature review. In this chapter, I will make connections between my findings and the existing literature, indicating differences and similarities. I will also situate the research findings in their wider context. According to Smith (2009), in an IPA study, themes need to be supported with reference to contexts beyond previous studies. Therefore, in this section, I will introduce some new literature to embed the findings in the wider contexts in which they are situated.

In this study, participants with dementia and family caregivers shared their experiences of living with dementia and caring for people with dementia. Specifically, on the topic of roles and responsibilities, participants described their perceptions of responsibility; their understanding of responsibilities between individuals, families and society; and factors affecting their ability to maintain their responsibilities. It is evident that both people with dementia and family caregivers face great pressure in coping with the ‘altered’ life of living with dementia at a time when the traditional family support care system is also changing. Some pressures are clearly related to cultural factors, while others are a direct response to social and spatial resources, and political issues, such as changed neighbourhood environments, unavailable healthcare support services or poor quality of the long-term care facilities. The findings show that participants’ expectations of social support, the cultural role of filial piety, and the capacities of individuals to recover their sense of self and to continue to find meaning in life, all shaped the meaning of responsibility for people with dementia and family caregivers. Although the challenges of coping with the ‘altered’ life are considerable, the situation could be improved with the support from the world participants live in, especially through the provision social services and social support. The significance of the findings is that social, cultural and economic factors have heavily influenced the meaning of responsibility and lived experiences in participants’ lives. In this section, I will discuss several key points taken from two areas (social and cultural influences): neighbourhood change and ageing in place; the physical and social environment; interdependent family relationships; social exclusion and inclusion; filial piety as...
obligation or affection; reciprocal filial piety versus authoritarian filial piety; and filial piety as a coping strategy.

5.2 Social space for people with dementia and their family caregivers in China

The findings of the current study indicate that social space has a significant influence on the quality of life, the meaning of living with dementia and the conception of filial piety for people with dementia and family caregivers in China. To discuss what social space means for participants and how social space affects their life and their lived experiences, I will use four elements: (1) the meaning of ‘home’ and ‘ageing in place’; (2) physical and social environment; (3) social inclusion and exclusion; (4) interdependent family relationships.

5.2.1 Perceptions of ‘home’ and ‘ageing in place’

Participants made specific references to how community and environment change has influenced the meaning of their lived experiences with dementia, and I will now give it some focused attention. In the study, some participants discussed how migration and their changing neighbourhood, and living spaces influenced caring responsibility and the meaning of living with dementia. Modernization seems to negatively affect participant’s lives because it has eroded the traditional family care network by increasing family mobility and disrupting the co-residing lifestyle. This has resulted in fewer and fewer adult children living together with frail parents and even if they live together with their parents, they still have no time to spend with their parents. This changing demographic and lifestyle means that there are fewer family carers around to provide help and support (Zhang et al., 2012a). The findings also show that the meanings of ‘home’ and ‘family care’ have been changed due to changes in family life style and sense of community network. The meaning and practice of filial piety is also changing in terms of demographic change, migration and modernization.

In the study, both participants with dementia and family caregivers encountered great difficulties with regard to their caring responsibility because of limited capacity or availability in the practice of everyday activities. As a result of increased social mobility, more and more adult children migrate to bigger cities seeking job opportunities, which has left older parents at home (Shang and 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 current study, some
participants thought they were better off in a care institution than staying at home alone, reflecting 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). In the subtheme ‘my life beyond the social environment’, participants described their loneliness and said that they did not want their children to visit them only for practical reasons such as food and clothes, but to come to chat with them, and keep them company. This means that even though older people remain in their own homes and communities, their feelings of connection to home and community is getting weaker. It also means that parent-child relationships centre on caring responsibilities based on legal or familial obligations rather than caring and passion. Without their children and neighbours around due to migration and movement, some participants with dementia now felt that home was ‘not my home’, that community was ‘not my community’. Participant Zong said: ‘why should I live in this house, when there is nobody at home…’ Another participant complained about the decline of old community-based activities as old neighbours and friends had moved elsewhere, reducing his social ties and sense of connection to his community. This phenomenon challenges us to understand very dynamic changes to individuals’ sense of connection and disconnection in the changing Chinese sociocultural context.

Furthermore, Burns (2011) indicates that, for older people, not being able to attend outdoor activities with their peers is an aspect of the isolation and exclusion caused by migration, demolition or resettlement, which changes a community’s physical and social environments, making older residents feel like ‘strangers’. In line with Burns’ argument, participants in the current study described the phenomenon of old neighbours moving out and new neighbours moving in as a result of urban reconstruction, renewal and resettlement. In some areas, intensive commercial flats have replaced older residential areas, diminishing the former community environment. With this change, participants experienced feelings of isolation and disconnection. For instance, one participant said ‘…nowadays, the neighbours have no contact, unless we have lived together for a long period of time. New neighbours do not even know each other’s name’. This description expresses the participant’s feeling of disconnection or detachment. In this context, these changing neighbourhoods have resulted in fewer connections and less support for residents. This echoes key findings from Burns’ (2011) research on physical and social environment changes that made older residents experience feelings of strangeness and insecurity even though they
remained in the same place. Burns also indicated that inequality of social space in the community for older people would lead to social disconnection and invisibility in terms of political influence. In this study, the specific characteristic of social and economic development generated different findings from other research about the importance of connections to home (Wiles, 2011, Cutchin, 2005, Sixsmith et al., 2014, Van Dijk et al., 2015).

In the current study, the narrative experiences of participants reflected the idea that “home” means not only a familiar physical place, but is more about connections with people. The sense of familiarity with the community has gone as social relationships with others have changed. The findings are in agreement with Wiles et al (2011) and Van Dijk et al (2015) who found that ‘ageing in place’ is a broad concept, with meaning beyond more functional issues for people with dementia, and who showed how ‘changing’ neighbourhood creates disconnections in a changing sociocultural context. 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 between maintaining a person as an insider and connecting a person to the outside. This may mean that when thinking about ‘home’, we need to consider the relationship between home and neighbourhood or community’ environment in a cultural context (Cagney and Cornwell, 2010). If this connection has been broken, we need to reconsider the meaning of ‘home’ and the function of ‘ageing in place’.

The current study offers some specific information about the impacts of a changing social and cultural environment on the lived experiences of people with dementia and family caregivers within a community, and their understanding of social and physical spaces. The altered social environment in the community has alienated its residents, and reduced connections and support among its residents. For example, some participants said that one of the problems caused by changes in the community is that neighbours are getting in contact less even though they live in the same community because of the faster pace of work and lifestyles. Participants felt that people did not care as much about others around them due to fierce social competition for their attention. A few studies exploring ‘ageing in place’ (Gilliard et al., 2005, Wiles, 2011, Wu et al., 2005, Vreugdenhil, 2014, Soilemezi et al., 2017, Herron and Rosenberg, 2017, Van Dijk et al., 2015, Sixsmith and Sixsmith, 2008), argue that the social model of disability should be extended to those with cognitive impairments, and that the interpersonal environment plays a significant role in shaping lived experience. This
accords with Kitwood’s (1997, p.67) concept of personhood for people with dementia which is maintained by ‘living in the context of relationship’, with person-centred care being based on a person’s feeling of attachment. Kitwood’s concept of personhood may not fit in exactly with Chinese culture and society because family is more of a priority than the individual in China, but the concept can help us to understand the negative effects of physical and social environments on individuals’ lived experiences, especially for those with cognitive problems who feel excluded.

In research on the meaning of ‘ageing in place’, Wiles et al (2011) indicated that older people who remain at home were more likely to experience feelings of attachment, security and familiarity. For example, ‘being greeted by known people’ or ‘knowing local shops or cafés’ were evidence of belonging and security within the community for older residents. This is not only about familiarity with place, but also the sense of knowing people, and involvement in the community. Therefore, an ‘ageing in place’ policy may not be sufficient in supporting people with dementia if they lose their sense of connection with their home or community. 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, regarded as especially important in Western cultures. However, the authors also investigated the challenges and barriers to ‘ageing at place’, and argued 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. Their research provides support to the findings of my study where the community environment seems to become negative for participants because of undergoing socioeconomic and demographic change in China. Participants did not perceive attachment or connection while they still lived at home. This means that “ageing in place” could lead to a sense of disconnection and exclusion or even threat for older residents with dementia in some rapidly developing and changing areas in China. If older residents with dementia become more invisible in their communities they could lose their political voice in neighbourhood planning.

Despite previous studies about ‘ageing in place’ that offer us a better understanding of the benefits, challenges and barriers for older people who stay in the same place, there has been very limited investigation of the effects of social and cultural change in communities. Previous studies have instead focused on the effects of remaining in place for the general older population, and not specifically looked at the meanings of
underlying sociocultural change for people with dementia. In most of these studies, the home environment and neighbourhood are seen as an advantage in terms of a sense of attachment, social connection, security, familiarity, and practical benefits, and as being related to people’s sense of identity through independence and autonomy. Divergent findings on ‘ageing in place’ may prompt further research.

In the current study, despite most participants with dementia holding the view that family care was better than institutional care, they also viewed home as a place of disconnection and loneliness. Home was not a word that had connotations of ‘caring’ or ‘security’ for them in view of community environment change, which weakened children’s capacity or availability to physically look after or visit their parents often. This finding was also evidenced in research into ‘ageing in place’ which has been studied by a number of researchers (Burns et al., 2011, Davis, 2004, Brittain et al., 2010). Many researchers indicate that studying family relationships can help uncover interaction between people with dementia and family caregivers. Even though community environment and dementia care research has gained greater attention since the 90s, most of these studies are limited to exploring the benefits of maintaining a familiar physical environment for the older population. In the current study, I explored what a changing neighbourhood meant to people with dementia and family caregivers in relation to continuities, identifying participants’ feelings of disconnection and loneliness, and the many weaknesses of social and physical environments. Participants claimed that the changing environment in their community increased the distance of social activities they wished to attend, and contributed to a sense of loss of social space for them. Although many positive factors associated with home are important to people with dementia, the current research offers a specific meaning about ‘home’ for people with dementia and family caregivers. With reduced social network security, little public understanding, and no appropriate community level support, home has gradually become a place of isolation, detachment and stigmatization for people with dementia as well as their family caregivers in the changing social-cultural context in this study.

5.2.2 Physical and social environment.

Being able to get out and about does not only refer to safe physical environments for people with dementia (Davis et al., 2009). As important is 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’ or ‘without governors’ appeared in participants’ descriptions as they spoke about: ‘who cares about me?’ or ‘why do they care about me?’ 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 uselessness to others and society. The findings also show that both the quality and quantity of family-based care services in China are not currently able to meet the needs of older people. It is possible that lack of appropriate community level support is related to some of the participants’ negative feelings about ‘home’.

In the study, some of participants with dementia who lived in their own home, indicated that lack of understanding from family and friends had left them feeling isolated, lonely and helpless. In contrast, those who received support from family felt settled and secure. Therefore, a harmonious, supportive community environment is more important than just a familiar physical environment. The findings also show that the community environment has a significant influence on care quality. For instance, some family caregiver participants refused to take the person they looked after outside either because they feared ‘losing face’ or because of the barriers in the physical environment; and some participants with dementia found it hard to attend social activities due to rejection by their peers. For example, Ye talked about her neighbours making her feel unwelcome at local morning exercises which made her feel isolated. Negative attitude towards those with dementia within a community or neighbourhood environment may restrict the building of formal and informal support networks.

The findings show that social support experienced by the participants of this study, either from the local community or at national level, are very limited. Indeed, in China, only large developed cities have dementia or family support groups, as described in the introduction chapter. Participants used the phrases ‘I can’t believe’, ‘I cannot imagine’ or ‘I never think about it’ to express their low expectations for this kind of social support. For example, the participant, Xue said: ‘What community will help? There are staff (social workers) who work for the government, I have never heard them helping with these kinds of things.’ The above factors represent huge challenges to the traditional family base care and these are challenges which the informal care model cannot deal with. Among the challenges, the main drivers are the cost and the quality of health care service problems, where limited resources are not able to meet
the demands of people with dementia, and there is scarce support for family caregivers as well.

One interesting point is the concern that participants have for not only their own future but for the future of the next generation and their country. For example, one participant said, ‘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? This is a problem that needs to be sorted out by the country…’ (FC, Ling). The participant is not only concerned about his future care arrangements; his concern has moved from a personal query about how he and his son will be cared for in the future to the wider social problem of who will take the caring responsibility for older people. When an individual or family is unable to take care of their family member, with the added unavailability of social support, who will look after our seniors? However, despite the question of who should take responsibility for older people’s care having been posed by many families, caregivers and politicians, the answer is still unclear. In the study, the capacity and the availability of long-term services has been questioned by many participants, which may be associated with the traditional negative view of long-term care services and the high cost of long-term healthcare services in China.

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. They 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). Therefore, a suitable living environment is a place where people with dementia can be outside but not be an ‘outsider’. While a supportive physical environment helps people with dementia to be outside in practical, convenient ways, a supportive social environment should focus on helping individuals feel they are ‘insiders’. The current findings show that social and physical space plays a significant role in shaping the lived experience of both people with dementia and family caregivers. In the subtheme ‘they don’t believe me’, participant Yin expressed anger and frustration when his family didn’t take his words seriously, e.g. ‘they didn’t believe it, they said that I just tricked them…this makes me really cross’ (PWD, Yin). The conflict between Yin and his family might have been caused by his family members’ lack of awareness or information about dementia symptoms. Another family caregiver discussed her feeling of being looked down on by the community which has
led her to stop being connected with social events. World Alzheimer Report has the experience of stigma for people with dementia in the four key domains: stigma from workplace; stigma related to family and friends; personal concealment; and anticipated stigmatization and emotional reactions to stigmatization (ADI, 2012b). In the current study, both participants of people with dementia and family caregivers perceived stigmatization from family, community and health professionals.

A distinct finding in relation to the social experience of stigma in the current study is stigmatization from the healthcare professionals. Several participants with dementia described being told that there was no need to get further treatment from the health professionals after they had been diagnosed, and said that they were unable to obtain information or support from health professionals. Participants experienced fear and despair about their future because their doctors refused to provide them with any medical services on the basis that dementia is not curable at this time. Participant Yi said, ‘the doctors told me to go home and said that it is not useful to take any treatments as this cannot be cured.’ Some family caregivers also experienced stigmatization from healthcare professionals. Previous literature has also studied stigma associated with health professionals or services, but these studies emphasized diagnosis labelling and discrimination (Gove et al., 2016, Cahill et al., 2008, Moore and Cahill, 2013). The current study is more focused on the widespread perception that the disease is untreatable (Renshaw et al., 2001, Liu and Woo, 2013, Lee et al., 2016, Wu et al., 2016, Seo et al., 2015). To the extent that patients, their families, and the general public incorrectly believe that treatment is not useful, this notion has brought helplessness, fear and hopelessness for the person with dementia and their family, and may access to resources and opportunities for treatment and related social services. This highlights the fact that health professionals who work in dementia care should require specialist skills based on an accurate conception and understanding of dementia.

In addition, lack of awareness and understanding of dementia among individuals with dementia, family members and the general population can be seen in participants’ narratives. Some family caregiver participants showed a low level of awareness of dementia, reflected in statements such as ‘the life of a person with dementia is sitting still’ or ‘no communication is needed for people with dementia.’ Many of the participants with dementia experienced loneliness and frustration as they felt misunderstood by their family members and friends. In consequence, this
misunderstanding would have significant impacts on people with dementia as well as themselves. In a systematic review, Chan and her colleagues estimated the burden of dementia in China, concluding that the burden of dementia has been underestimated in previous studies (Chan et al, 2013). This suggests that low dementia awareness has important implications for people seeking medical help and for the provision of training for the recognition and management of dementia in the healthcare services. As family and relatives are an important support network in China, public awareness campaigns needed to challenge misconceptions about dementia.

5.2.3 Interdependent family relationships

In Chinese society, the ‘web of interdependence’ within a family is a critical element of the continuity of filial piety (Zhang et al., 2014b). Interdependence in family relationships is a key feature in supporting activities of daily life, which has been passed down across generations. In Confucian philosophy, this kind of relationship is reciprocal: parents treat their children with kindness and care; in return, children serve their parents with filial piety and obedience. Reciprocal or interdependent parent-child relationships exist across generations. For instance, grandparents help to look after grandchildren when their adult children go to work, while adult children will provide economic support and care for their parents when their parent gets old. This interdependent and reciprocal relationship breaks down if the older parents lose the capacity to be a contributor within the family. As a result of dementia, family relationships change from interdependent to dependent, which affects all family members. The current study highlights dynamic changes within interdependent family relationship under the influence of factors in a specific social context. Due to changes in interdependent family relationships, some participants with dementia, described being excluded or controlled by their family. Under the theme ‘my role and responsibility has been changed’, participants experienced the feeling of ‘being a useless person’ as their ‘higher position’ within the family was changed when they became dependent. Furthermore, some participants also expressed their feelings of loss at no longer being able to perform life skills. For instance, in losing the ability to cook, Ye experiences stress and guilt as her parental responsibility has been lost, making her feel like an ‘outsider’ within her family. Maintaining family responsibility remains very important: even though a person has dementia, this person still views his/her responsibility to other family members as more important than caring about him/herself. This concurs with the Chinese cultural value of family harmony being
higher than individualism. This is similar to Chu and Yu's study, in which the authors discussed the issue of reciprocal relationships between adult children and their parents. They indicated that adult children are more willing to give their filial piety duty to their parents in return for their parent's earlier contributions to them or their children (Chu and Yu, 2010).

Reciprocity in parent–child relations is a main principle in explaining the reason why adult children support their old parents in Western studies (Bowlby et al., 2010, Silverstein and Giarrusso, 2010, Silverstein et al., 2002). This reciprocal relationship which involves monitoring, caring and supporting in everyday activities, is based on the parent's earlier emotional time, and finance investment for their children (Silverstein et al., 2010). The authors have investigated the reasons why adult children provide support to their parents by using an exchange model. They found that children's repayments to parents are based on their parent's earlier transfers to the children. This reciprocity theory concurs with the theory of care decision-making of some participants in the current study who viewed their caring relationships as a repayment. Bowlby et al (2010) have also argued that the reciprocal relationships between family members is central to building and maintaining an interdependent household network, and that conflict in the household usually leads to the breakdown of the webs of interdependence and reciprocity. This is consistent with Zhang et al's study (2014b), which have shown that perceptions of lack of parental support among the younger generation tends to lead to cases of old people being neglected in later life. It is clear that this type of reciprocity model, which is based on exchange theory, has built a bonding responsibility between parents and children, but may also have a negative impact on the quality of care given to ageing individuals. In the current study, the social and economic changes appear to have weakened the bond of this mutual relationship and made some participants perceive themselves as 'being useless' and 'being an outsider'. In contrast, several other participants believed that looking after parents is an inspiration and a spiritual healing process for them as they feel that being filial (taking caring responsibilities) to their parents is a way for them to carry a cultural continuity into the next generations. Thus, this kind of reciprocal relationship between individuals has a spiritual and moral basis. It is a unique reciprocal model, which differs from the view of the exchange model, being drawn from the value of Confucius's filial piety. This reciprocal relationship seems to have a positive impact on both the caregivers and care-receivers in the study. This means that the parent-child interdependence relationship is presented in two ways: one is an implicit moral
contract in filial piety whilst another is a process of social investment with an expectation of later repayment.

In the Chinese vision, personal ‘role’ or family relationship within the family is more important than personal ‘self’. Paradoxically, this may set ‘personhood’ in an opposite position compared with many Western studies in which family relationships are posited as a foundational resource to support ‘self’ (Kagitcibasi, 2005, Surr, 2006). Similar to many other studies, the feeling of being undervalued and losing self-identity were also discussed by most participants with dementia in the study. The issue of self-identity has been associated with losing roles and changing responsibilities in the family, which is captured in the theme, ‘my role and responsibility has been changed’. It suggests that family relationships play an important role in shaping the meaning of responsibility in the Chinese specific cultural context. In a number of studies (Zhan, 2004, Sheng and Settles, 2006) that highlight how cultural and social values can affect family interactions, the authors indicate that a consequence of social and economic development is a dramatic change in traditional family structures. Consequently, the interactions and relationships between family members have changed. Parent-child relations in China are becoming more egalitarian as members of younger generations gain access to better paying jobs and begin to adopt more Western attitudes toward children’s responsibilities (Zhang and Fuligni, 2006). In one recent ‘Ageing, migration and familial support study’, the author further found that the breakdown of interdependent family relationships was the main reason for the collapse of the family support and caring system, but he denied that migration was behind this (Liu, 2014). This complex finding is similar to some studies in Indonesia and Thailand that found, through providing financial support, the migration of children to urban areas contributed positively to the material well-being of their older parents who remained in rural areas (Kreager, 2006, Knodel and Saengtienchai, 2007). These findings may challenge us to further investigate the correlation between family relationship and economic development.

In the study, even the participants who were able to physically look after their frail parents or family members had many other responsibilities, such as jobs and children, and these increased the barriers to caring activities and limited their ability to provide help and support. This has been demonstrated in the conflicting relationship between a caring responsibility and other responsibilities, in which some participants had to take several responsibilities whilst they were caring for the person with dementia.
Along with the rapid social-economic development, family caregivers face more stresses in a competitive Chinese society. Family caregivers experience extreme stress and powerlessness because of this social and cultural convention of filial piety (Yu et al., 2016). As a result, family caregivers may hold a reluctant attitude toward their caring responsibility, which may bring negative effects into the inter-relationship between caregivers and care recipients.

In the current study, some people with dementia and family caregivers both viewed death as a solution for releasing the caring burden. Here, both the family caregivers and people with dementia have defined the caring relationship from the point of view of caring responsibility, rather than a relationship of mutuality. Some participants with dementia also believed that death was a release of suffering from dementia. These views of death are likely to be the specific product of the burden which results from the specific healthcare services system, social security network and filial obligation in China. For example, in the study, participant Gui, who looks after her two sons, has shown despair with their financial need as both of them have no pension or income. She said that: “if the application (for the minimal social allowance) fails, I have no other way, my plan is that we will all die in the house (by killing herself and her sons)” This has also specifically reflected the defects of the family care services seems ‘responsible’ but not ‘guaranteed’ as its lacks a national welfare regime support from the country; a person with dementia without an income will become totally financially dependent on their family, which may, in turn, lead to the breakdown of mutual relationships of caregiving. How to deal with this issue is beyond the purpose of this study and it is recommended that future study must pay attention to it.

For participants with dementia, interdependent family relationships have changed to dependency, which makes them feel excluded from family life. This is consistent with Gove et al’s (2016) study about General Practitioners’ (GP) perception of the stigma of dementia, in which the GPs think that loss of reciprocal relationships is one way people with dementia perceive stigma within society. This finding could apply to my study, as people with dementia lose reciprocal relationships within their family and community, eg, such as not being able to continue to look after a grandchild or losing the ability to cook for their family. These changed family relationships have left participants with dementia in a vulnerable situation within the family. Losing a role or position and not being able to contribute to others made it more likely that participants felt ‘useless’ and excluded from the family and the society. For most participants with
dementia, the meaning of ‘being useless’ does not only mean ‘self’ being dependent on others: it is also about not being able to contribute to others in the Chinese context of interdependent family relationships. As a result of changes in interdependent family relationships, some participants described the feeling of being excluded or being controlled by their family. Under the theme, ‘my role and responsibility has been changed’, one participant with dementia thinks that he is ‘being discarded’ and ‘being betrayed’ by his family which may be because his ‘high contribution’ in the family has been reduced as he becomes dependent. This highlights that retaining family responsibility is more important than keeping personal responsibility: even though a person has dementia, this person still treats his/her family responsibility as more important than him/herself. This accords with the cultural value of family harmony being higher than individual identity. As the trend of interdependence within a family seems to weaken under the social transitions and economic development in contemporary China (Liu, 2013), changing family relationships have also created a sense of being disconnected from home for people with dementia.

5.2.4 Social exclusion of dementia care and the geographic gap

There is a great gap between rich, developed regions and poor, less developed regions in terms of healthcare services and resources (see literature chapter) in China, whereby many resources are available for the urban population, but those left behind in rural areas are largely ignored (Shang and Wu, 2011, Wu et al., 2016). In my fieldwork, some participants were wealthy and lived in en-suite hospital rooms while others could hardly afford medicine or basic dementia care services such as regular check-ups. Participant narratives also showed that rural residents were more likely to be stressed by their living and care costs as they were without pensions, compared to urban residents who were more likely to draw attention to their emotional needs.

Within China, due to the disparity of health insurance and the pension system between urban and rural areas, modernization has affected the lived experiences of people with dementia and family caregivers differently. Therefore, the social environment and the physical environment seem to have different meanings for participants depending on whether they were rural or urban residents. In the study, physical resources such as access to the healthcare and public services seemed more important to rural residents; meanwhile, emotional need such as being eager for children’s company appears to be more important for urban residents. Participants
who were rural residents were more likely to fall into difficult financial situations, making them unable to afford health check-ups and treatment. Some participants made specific reference to being unable to access the healthcare services due to the high cost of health care services. In China, most rural residents are without a pension unlike most urban residents who do have a pension. As a result, financial resources are a big issue for rural residents, especially for people with dementia who have lost the ability to earn a living. Family caregivers who are rural residents face similar issues of financial and emotional stress. They may have to give up paid work to look after someone with dementia, and they often cannot afford medical services for the person. Another concern is the poor quality of healthcare in rural areas which was associated with stress, helplessness and desperation. Participants expressed worries about the quality of healthcare services they received because they lack specialised psychologists and appropriate equipment.

Wu et al (2015), in a recent study, discussed the quality of dementia care services in one township hospital\(^6\). They indicate that people with dementia often do not receive specialised services to meet their basic needs, and family caregivers are often not provided with efficient information on dementia, often due to lack of hospital resources. This was consistent with the current findings, for instance, one participant refused to use the village clinic service and the local township hospital services because of the poor quality of health services there. Participants who were urban residents, put a stronger emphasis on their relationship with others and were more eager to receive emotional care from their family. For example, some participants would rather spend time with their children than receive practical help which was different from the participants who were rural residents who were more concerned with their living costs. This finding highlighted the different subjective living experiences of people with dementia and family caregivers who live in different regions. It also reflected the drawbacks of the current healthcare and pension system in China described by Cai and Cheng thus: ‘China’s social insurance system for old people has been criticized

\(^6\) In China, hospitals are organized to a 3-tier system which according their ability to provide medical care, medical education, and conduct medical research. Based on this, township hospitals is the primary healthcare institution with less than 100 beds and providing preventive care, minimal health care and rehabilitation services. Available at [http://baike.baidu.com/view/1429004.htm?func=retitle](http://baike.baidu.com/view/1429004.htm?func=retitle) (A Hierarchical Approach to Hospital Management).
'as segmented, regionally imbalanced, fiscally inefficient and socially and economically unsustainable' (2014, p.636).

Compared to the situation in China, the ageing of the UK population is well documented, and older people with mental health problems have strategized care and support within the community, aided by action at a national level (Mental Health Foundation, 2015). The findings of my study show that people with dementia and family caregivers in China are in an unfavourable position regarding health resources and the quality and level of support. A search of the literature shows that there is no national level strategy or plan for dementia care services. Statistics on dementia from both government and non-governmental organizations in China are unclear. Even though dementia has become a global and national health priority, according to participant accounts, the availability of formal support for people with dementia and family caregivers in China is scarce. The cost of dementia care was not included in the category of healthcare cost for reimbursement in the healthcare insurance scheme (Dai et al., 2011, Chen et al., 2017). The majority of people with dementia in China, physically, emotionally and financially rely on their families, a situation which participants in my study have discussed. Most participants thought that the caring responsibility for older people, especially people with dementia, should not only be shouldered by individuals and families, rather the government should also take on responsibilities for older people’s care, or at least provide physical resources support to families, including the provision of support ranging from equal, supportive social environments to care expenditure.

In the UK, in order to reduce social exclusion among adults with mental health problems, the Mental Health and Social Exclusion Programme, developed by the Social Exclusion Unit, identified five main reasons for social exclusion in this social group. One of the key reasons is that people face barriers to engaging in community life (Office of the Deputy Prime Minister, 2004). In 2012, a national programme called ‘dementia friendly communities’ was launched to ensure that people with dementia are understood and valued within their community. The programme aims to build supportive and understanding communities through, for example, teaching bus drivers, post office staff and other public services workers with the basic knowledge and awareness of dementia (Alzheimer’s Society, 2013b).

While there are many studies about social exclusion, it is not clearly defined in dementia care. A number of studies (Keady et al., 2012, Badland et al., 2014, Wright
and Stickley, 2013, Office of the Deputy Prime Minister, 2004) on mental health and social exclusion use indicators across a number of domains or dimensions such as housing, education, income, employment, social support and neighbourhood deprivation to measure social exclusion. These studies tend to focus on social resources and public services that are shaped by political decisions. This creates a number of questions: what dimensions are relevant to people with dementia? Which, if any, have the most effect on their lives? Is investigation of these domains sufficient to understand the meaning of social exclusion for people with dementia? Without an understanding of the social, cultural, economic and political contexts of living with dementia, social exclusion measures lack precision.

The study by Morgan et al (2007, p.479) suggests that: ‘social exclusion was increasingly used to capture the consequences of material deprivation in terms of restricted opportunities to participate in wider social and cultural activities’. In China, low public awareness and negative attitudes towards dementia have increased the stigmatization and marginalization of people with dementia and family caregivers. In the current study, some people with dementia have been misunderstood and mistreated by the general public as a result of lack of awareness of common symptoms of dementia. For example, some participants often felt rejected by their neighbours and peers, and shunned at regular social events and activities, as a result of their dementia. For example, one participant with dementia, Ye, described how her friends put her down by telling her to stop attending a morning exercise group because she had dementia. Meanwhile, family caregivers are afraid to take people with dementia into public places because they think having dementia is shameful. This behaviour from neighbours and family members is a reflection of social stigma in a specific cultural context.

In the current study, not only did participants with dementia feel socially excluded, participants who were family caregivers also experienced cultural and social exclusion. A distinct form of social exclusion reflected in many participant narratives was healthcare professionals’ negative attitudes towards dementia and poor access to healthcare services. Some participants had been told by their doctors that ‘no further treatment is needed’ or ‘dementia is untreatable’. Participants experienced despair and heartbreak because of the narrow, stereotypical ways in which healthcare professionals typically view dementia. Furthermore, caregivers’ lack of understanding about dementia had implications for how they understood their own experiences of
looking after people with dementia. Some caregivers believed that there was no point in talking with a person with dementia and others thought that if a person was diagnosed with dementia they could not lead a meaningful life. One daughter raised questions about the lack of meaning in her mother's life and claimed that it was only because of her children's wishes that she was still alive. Another daughter was reluctant to visit her mother because her mother could not talk to her when she visited.

Participant perspectives of social exclusion in the current study can be instructively contrasted with Burns et al's (2011) dimensions of social exclusion and isolation for old people (see Box8):

**Box 8 Burns et al's dimensions of social exclusion and isolation**

- Symbolic exclusion (negative images, overrepresentations, and invisibility)
- Identity exclusion (multiple identities are dismissed and a person's identity is reduced to belonging to one singular group, for example, "old", "frail", "burdensome")
- Socio-political exclusion (barriers to civic/political participation)
- Institutional exclusion (reduced access to services)
- Economic exclusion (lack of financial resources)
- Exclusion of significant social ties (absence/loss of social network)
- Territorial exclusion (reduced geographic living area, unsafe neighbourhood)

(Burns et al., 2011)

Overall, in this current study, in the theme 'the meaning of responsibility in the social context', social exclusion has four main aspects: inequality in access to healthcare services; nationwide public misunderstanding of dementia; lack of formal and informal social support; loss of social network and strange neighbourhoods (see below).

**Inequality in access to healthcare services.** In China, people with dementia fall into a vulnerable situation with regard to accessing health care because dementia care costs are not covered by the healthcare insurance scheme. This makes family unwilling or unable to afford to take people with dementia to hospital. Formal training and education about dementia care are not included as part of the regular curriculum in medical school. Therefore, there is a nationwide lack of specialist training for
psychologists, mental health nurses and caregiving staff, especially in primary healthcare services in rural areas (Hsiao et al., 2016). In this study, one participant declined to use the village clinic service for his mother’s care due to the care quality issues. Together with the idea that ‘dementia cannot be treated’, unaffordable healthcare costs, lack of training, and poor service quality mean that people with dementia and family caregivers receive inadequate support from the primary health service sector. Moreover, most long-term care institutions are likely to refuse to admit people with dementia or lack the capacity to provide specialised care to people with dementia due to the lack of specialist healthcare staff or facilities. Therefore, dementia care is marginalised and stigmatized within the current healthcare system.

**Nationwide public misunderstandings of dementia.** Public awareness about dementia is low. The general population lacks a basic knowledge of dementia and mostly mistake cognitive dysfunction in dementia for the normal process of aging. A study carried out in Shanghai showed that 45% of family members and caregivers did not believe that people with dementia could benefit from medical care (Li et al., 2011). Discrimination against people with dementia is especially common in the community. For example, in the study a participant who looked after her two sons both with early onset dementia, told me her sons had been beaten and abused by members of the community and police staff due to their behavioural problems in public places. This likely reflects lack of awareness of the cognitive effects of dementia in the general population.

**Lack of formal and informal social support.** The main barriers to formal care are the unaffordable costs for individuals and insufficient health care infrastructure. These combined with the absence of policies or political decisions aimed at developing the care workforce, mean that formal dementia care services fail to meet demands. In this context, informal care provision lacks compassion and enthusiasm. As a result, except for larger developed cities, hardly any dementia support groups or voluntary originations exist in China. In addition, there is a shrinking informal care workforce due to demographic and family structure changes: ageing, migration and the 4-2-1 family structure mean that there are fewer informal carers around to provide help and support. Informal caregivers are also juggling several responsibilities which influences the quality of care they can provide. It is a common phenomenon for many people with dementia receiving informal care to be limited to only three meals daily. To ensure quality of care in this context, we not only need to consider the capacity and availability
of family carers, we also need to fully recognise the lived experience of people with dementia and the meaning of the informal caring role.

**Loss of social network and strange neighbourhoods.** Deficits in the physical environment of neighbourhoods such as there being no lift in the building or no access to disability toilets limits the ability of people with dementia to go out. Another factor, as discussed above, is change in physical and social places in communities which weaken the feeling of familiarity. In the social environment negative attitudes, stigma and discrimination restrict the participation of people with dementia and family caregivers in community activities or events. There is a lack of collaboration and cooperation from governmental policies, social support, community services, and healthcare workforce. All these factors can have an impact on the ability of people with dementia to continue to live at home and can lessen a person’s feeling of belonging in their community. Consequently, the family model of care faces many challenges in meeting the current needs for people with dementia and family caregivers in China.

Looking at the project ‘No Health without Mental Health’ (Department of Health, 2011) in the UK, the government’s central aim was to cooperate with and support local communities to ensure equality of high quality services for people with dementia. Social inclusion has been a useful policy driver to reduce inequalities and discrimination against people with dementia. In Chinese society, the conception of family is higher than personal independence and individuality. Despite a long tradition of support for ageing-in-place in China, the issues raised in this paper represent very serious challenges to providing effective help and support to frail older people at home. While the findings highlight the significance of social-cultural changes to the concept of caring responsibility, this study also reveals many other social and cultural factors which influence the lived experience of people with dementia and family caregivers. It is clear, from the data presented in the findings chapter, that from a political policy perspective, the lack of a supportive and understanding social and cultural environment for people with dementia underlies problems for family caregivers. The findings show that the value of filial piety still takes its place in family care arrangements, but the capacity and availability of the traditional family care model is undergoing great challenges due to many sociocultural influences including unstable healthcare and social security systems; very limited government organized formal support networks; limited informal social support networks; and lack of awareness
about dementia in both the lay population and healthcare services. This study also reveals contextual understandings of the meaning of filial piety and its dynamic change over time within a rapidly changing social-cultural, economic, and demographic context. The next three sections of discussion will centre on the cultural belief of filial piety and its role in taking care responsibility.

5.3 Cultural values and cultural influences

Although the practice of filial piety has evolved and been reshaped, its core principles continue to exist in people’s consciousness in Chinese culture (Qi, 2015). As Qi (2015, p.153) states, Chinese family obligation ‘is sustained by the continuing inter-generational interdependency of family members’, in which a circular type of interdependent family relationship continues from parents to adult children and conjugal family. The author agrees that even though behaviours and expectations have changed as a result of social transitions, filial piety is still the main philosophy which sustains family obligation. This is consistent with another study, which found that ‘filial piety as a virtue still lies at the heart of moral and social systems in this society where family is considered to be the key unit in human relationships’ (Park, 2015, p.283). To further illustrate, one study found that children from one-child families were more likely to presume their responsibility to look after their parent in the future than children with siblings (Gui and Koropeckyj-Cox, 2016). Therefore, it is very important to understand the dynamic change of filial piety, beyond the immediate social context, in order to grasp the current role of filial responsibility in family caregiving for people with dementia.

5.3.1 Reciprocal filial piety and authoritarian filial piety

Despite the concept of filial piety changing over time, the influence of filial piety on personality and child-parent relationships plays a critical role in Confucian countries, and has been studied by many researchers (Lew et al., 2011, Park, 2015). To discuss the meaning of filial piety in relation to caring responsibility, I draw on Yeh’s (2003a) Dual Filial Piety Model: reciprocal filial piety and authoritarian filial piety. In this dual framework, the author indicates that reciprocal filial piety is composed of two sub-factors: the rules of respecting and loving parents, and supporting and memorializing parents. In contrast, authoritarian filial piety includes oppressing children and glorifying parents. The author claims that reciprocal filial piety is based on the goodness of humanity and fulfilled through reciprocity and the nature of intimacy. In
Confucianism, reciprocity means and refers to a paying and repaying relationship between parents and children, for example, parents bring up their children with love and care and their children pay them back by supporting and respecting them when they get older (Sung, 1995). This is in line with the finding of the current study, in which some participants operated their repayment by ‘trying their best’ to provide care and support to their parents or the person they looked after. Others pointed out that their repayment to their parents is the main reason why they take care of them, which often happens in countries where the pension system does not work well. The perception of repayment draws on physical and financial aspects (Yeh, 2003). From a spiritual point of view, reciprocal filial piety was represented in the form of intimacy, where participants felt more intimate with the person they cared for; their caring responsibility was underpinned by a sense of morality, and their care decisions and tasks were based on personal emotion and spiritual action. Participants who understood their caring responsibility as reciprocal filial piety seemed to accept and be more willing to take on their caring role, and were also more likely to provide better care services. By contrast, Yeh’s model of authoritarian filial piety is ‘a strategy of social control’, constructed by social conventions such as public opinions and laws. This model of filial piety is more likely to be based on obligation and dominated by oppression of oneself and glorification of the superior (Yeh, 2003). The author also indicated that authoritarian filial piety is a negative factor which limits the development of a person’s individuality and independence. The dual filial piety model has some correlation with my present study. Therefore, I will apply this theoretical framework to my present study in order to better understand the meaning and influence of filial piety.

Yeh and Bedford (2003) discussed the beneficial and harmful effects of the dual framework of filial piety in relation to being reciprocal and being authoritarian. In the current study, some participants whose caring responsibility was based on a sense of humanity, described positive effects of their caregiving experiences. This fits with Yeh’s concept of reciprocal filial piety (Yeh, 2003). For example, some participants claimed that looking after parents was a priority in their life. They were willing to take on the caring role out of love and intimacy. Others showed that they were proud of inheriting the belief in filial piety and wished to pass it on to the next generation. This positive filial attitude inspired and enhanced participants’ responsibility, and brought satisfaction for themselves. Participants who take care of their loved ones based on reciprocal filial piety expressed willingness, pride, and caring experiences. Participants also discussed other positive experiences of caregiving such as
developing a closer family relationship, and being praised by other family members. This concurs with Yeh’s theory of reciprocal filial piety, which holds that it reinforces positive effects on the parent-child relationship. Reciprocal filial piety also leads to self-reinforcement (Yeh and Bedford, 2003) for people who take on a caring responsibility, expressed by some participants in the study in the phrase 'I try my best'. Yeh viewed authoritarian filial piety as harmful as it is based on a family structure of hierarchical authority in which children must suppress their personal needs to meet their parents’ demands (Yeh, 2003), damaging their autonomy and independence. Authoritarian filial piety was observed in the current study in participants who were more likely to feel that they had to sacrifice their own benefits, such as giving up a job, studies or social activities, and was expressed in the phrase 'I had to'.

Further studies based on this Dual Filial Piety Model reported similar findings (Wang et al., 2009, Quinn et al., 2010, Leung et al., 2010). Leung (2010) studied the correlation between children’s belief of filial piety and psychological well-being, providing further support for the theory of the Dual Filial Piety Model. However, Yeh (2003) has also noted, authoritarian filial piety is not all negative and may reduce conflict between parents and children. This supports the finding of ‘it is my responsibility’ in my current study, in which participants claimed that looking after parents was their compulsory duty. Respect for parental authority maintains filial obligations and to some extent preserves the system of family care. Conflicting and complex understandings of filial piety based on the Dual Filial Piety Model have been further studied by Yeh and Bedford (2003). The authors investigated the value of the dual model by analysing the pros and cons of reciprocal filial piety and authoritarian filial piety. Their investigation provided more support for the dual filial piety framework by identifying the differential influence of reciprocal and authoritarian filial piety on personal responsibility, attitudes and behaviour. It can be argued that, to a certain extent, an element of reciprocity is always involved in the filial piety concept as to some degree all relationships are two-way relationship. In its deepest form, filial piety goes far beyond this, with its stress on obligations. Within parent-child relationships, parents are always in a higher position and children are always taught to submit to their parents. First, children may perceive filial norms to be morally and socially acceptable; and they internalize the norms during the process of socialization or abide by them under social pressure. Second, social exchange theory explains filial duty as an act of reciprocation resulting from the fact that intergenerational relationships serve as channels for the exchanges of resources and power. The author argues for the
enhancement of reciprocal filial piety and the minimisation of authoritarian filial piety in order to support individual development. In the current study, whether with regard to reciprocal or authoritarian filial piety, the value of filial piety plays a prominent role in caring responsibilities and coping with the ‘altered’ life. The value of filial piety needs to be enhanced if traditional cultural values are to fit into modern Chinese society. Overall, as Yeh’s dual filial piety model provides a better understanding of the concept of filial piety and its values. However, both Yeh’s and Bedford’s (2003) and Leung (2010) studies were based on the views of adolescents and focused on the effects of filial piety on personality and behaviour. Few research studies include the subjective views of people with dementia and family caregivers. My current study provides further particular influences on, and meanings of filial piety for people with dementia and their family caregivers.

5.3.2 Filial piety as an obligation or affection

In a Chinese family, reciprocity is one of the important characteristics supporting filial piety in family life (Yeh, 2003, Leung, 2010). Another characteristic is hierarchy, in which family members have prescribed roles, such as older members have more authority than younger members, and parents have a higher position than their children. This hierarchy characteristic is manifested in the form of authority in which children listen to and obey their parents. Hsu argues that these main characteristics of Chinese family serve to emphasise the priority of harmony in a family by discussion of power structure, family cohesiveness, degrees of family individualization and family interaction with the outside world (Hsu, 1985). In my study, participants interpreted filial piety through two different elements: filial piety based on affection, which was culturally and spiritually inherited and was very important in their life; filial piety based on principle or obligation, which was constrained by social convention and law. This is similar to Yeh’s Dual Filial Piety Model as well as Sung’s (1995) theory of the Two Dimensions of Filial Piety. In Sung’s theory, the first dimension is behaviourally oriented filial piety which based on sacrifice, responsibility, and repayment. It is focused on compliance and fulfilling a duty, rather than satisfaction. This dimension is more likely to be reflected in children’s sense of obligation to their parents. This form of filial piety can be only measured by the degree of repayment and sacrifice that children give to their parents. The second dimension is emotionally oriented filial piety based on harmony, love, affection and respect. This form of filial piety is measured by the children’s emotional inputs. These contrasting dimensions of obligation and
affection in family relationships mean that children can be responsible for their parents without being affectionate or showing love and respect.

The value of filial obligation in the caregiving experience is controversial (Parveen et al., 2013, Revenson et al., 2016, Baldwin et al., 2017). Some studies identified that cultural obligation increases the level of care burden and depresses caregivers (Ng et al., 2016). On the contrary, others argue that caregivers with a stronger sense of filial piety were more likely to experience positive and beneficial care outcomes (Lee et al., 2017). The finding is supported by Lai’s finding (Lai, 2010) who identified as a protective factor against stress and thereby reducing caregiving burden. It concurs with my finding about the value of filial obligation. For example, in the subtheme ‘it is my responsibility’, Xue thinks that looking after her father is her responsibility. As she says: “he is my father, whatever difficulties I have…I must look after him.’ Here, filial obligation helps maintain family roles and responsibilities even though the family caregiver feels that culture expectation obliges her to care. Another new finding from my study is that filial piety obligation gives people with dementia a sense of ‘security’ because they know that their family will care for them. For instance, with regard to hospital expenditure, one participant with dementia said: ‘I don’t need to worry about debt, it is my children’s responsibility’. This suggests that filial obligation acts as a backup resource for the person with dementia. This new knowledge can be added to the existing literature on the effects of filial piety on the lived experience of people with dementia. In the light of findings on how different concepts of filial piety create different experiences of caregiving and care outcomes, we need to reconsider the concept of filial piety and its value in family-based care. Along with respect and care in informal care services, which are more likely to be a focus of Western studies, obligation in the parent-child relationship should be taken into account, and its value in practice made the subject of further research. This study has identified filial obligation as a means to ‘regulate’ the fulfilment of a child’s responsibility to his/her parents; and has also explained the role of filial obligation in the context of an unstable healthcare system and social security network.

The current study captures participants’ conflicting and complex relationships both in the early stages of care decision-making and also in advanced care services. With regard to care decisions, as a result of social and cultural requirements, some participants felt obliged to care rather than caring out of personal choice and willingness. The phrases ‘I had to’ and ‘it is my responsibility’ were often expressed
when participants recalled the reasons why they took on a caring role. In this situation, the sense of love and caring in everyday caring activities became weaker which might affect the quality of care as well as the caregiver himself (Gupta and Pillai, 2002). For some participants, the outcome of caregiving is only to complete their care duty which is an involuntary obligation. However, this filial obligation has played a role in keeping the family support care system in place. Participants who chose to provide care out of love, affection and respect, were more likely to give emotional support to their loved one willingly, more often leading to harmony and satisfaction for people with dementia as well as their family caregivers. For example, the participant Guang claimed that ‘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.’ This clearly shows that being filial is a coping strategy and stress reliever for Guang. Guang’s remarks suggest that better care is given when deciding to care is not experienced as obligation. This participant also experienced satisfaction and pride from the fulfilling care activities. This suggests that motivation to care is an important factor in the quality of informal care services. The dual role of filial piety calls for us to consider how to utilize the positive function of cultural values in the informal care workforce. Improving the quality of family caregiving might be achieved by reducing the feeling of obligation to take on care responsibilities, and increasing compassion. This also highlights the correlation between these two dimensions of filial piety.

Indeed, the study highlights the complexity of participants’ attitudes towards caring responsibility. Industrialization and urbanization are challenging the concept and value of traditional culture, and families no longer practice filial piety in the same way as they used to. Consequently, family caregivers may start to challenge the traditional view of family caregiving responsibility, and to question whether they need to put aside their own needs to meet family obligations and care for family members. The findings show that individual responses to caring responsibility are varied and complex, and that filial piety can reflect contradictions and ambivalence towards caring responsibility. Furthermore, although filial piety keeps its value and place in the family support care service, the perception of care responsibility, and whether it should be shouldered by individuals or the government, is a controversial issue in the study.

5.3.3 Filial piety as coping strategy

As filial sacrifice is an expectation in Confucianism’s filial piety, it may explain how family caregivers are willing to provide care to their parents, even if they are in an
extremely difficult situation. ‘She is my mother’ or ‘he is my father’ is the most common reason to why some family caregivers take caring responsibility. The participants clearly known that children’s responsibility is the cultural and social requirement which they must accept. As a result, accepting this filial expectation becomes a coping strategy for most family caregivers. Linking this back to Yeh’s (2003) authoritarian filial piety, the author indicates that authoritarian filial piety has enforced parent-children responsibility and secured the family care provision in specific cultural and social contexts. The coping strategy of providing care for a parent with dementia is natural in the context of maintaining family harmony and practicing filial sacrifice in Confucian countries (Lai, 2010, Sung 1995). Lai (2010) thinks ‘Filial piety may serve as a buffer that provides caregivers with the psychological strengths and endurance required to deal with the challenges and negative effects encountered during the course of caregiving’ (p.215). The implications of authoritarian filial piety also applied to participants with dementia: because ‘I have son’ or ‘I have daughter’. Participants with dementia experienced security and safety as they believed their children were a support and care resource, and they regarded this cultural value or belief as a source of ‘hope’ of the utmost importance for their coping strategy in the ‘altered’ life. In the subtheme, ‘I can cope’, some extracts from people with dementia described detailed support from their children or other family members which provided continuity and helped them to cope. The descriptions from the participants are significant in explaining the meaning of care decisions and the concept of caring responsibility from the authoritarian filial piety viewpoint.

Reciprocal filial piety, discussed in the above section, plays a major role in the emotion-focused coping strategies in the current study. Some participants think they play a part in continuing a cultural belief by being filial to their parents, while others understand filial piety as a life-cycle repayment, and believe that their children would be filial to them as they are to their parents. This cultural belief allows them to accept their caring roles more easily and to adjust themselves to the daily caring duties. In Western settings, informal care decisions are more likely to be made with reference to available resources or past relationships (Guberman et al., 1992, Becker, 2007). In these studies, the relationships between informal caregivers and care-recipients was key in decisions to take on a caring role. Caring for people with dementia can be a distressing time for caregivers who have to adjust to their caring role and new life. A close relationship is an important factor in caregiver adjustment and coping. Indeed,
this is one of the most commonly described coping strategies in early-stage Alzheimer’s disease (Clare, 2002b, Pearce et al., 2002).

In the current study, filial piety was described as a coping strategy by over half of the family caregiver participants. The finding is supported by a number of researchers (Knight and Sayegh, 2010, Aranda and Knight, 1997, Yu et al., 2016a). The sociocultural stress and coping model was first proposed by Aranda and Knight (1997). The authors suggested that the stress and burden of caregiving were related to the caregiver’s cognitive appraisals which influenced physical and emotional health outcomes. In the current study, despite participants experiencing difficulties with adjusting to their care roles, they continued to use the phrases such as ‘I try my best’, ‘filial is a priority’, ‘she is my mother’ and ‘he is my father’ to encourage themselves to cope with their new roles. For these participants, the belief in filial piety was inspiring and empowering.

In one previous study, Lai (2010, p.200) noted ‘filial piety as a protective function to reduce the negative effects of stressors and to enhance the positive effect of appraisal factors on caregiving burden’. Consistent with Lai’s finding, filial piety acts as an emotional-focused strategy for the majority of the family caregiver participants in the current study. One particular participant comment on being filial reflected another function of filial piety. The participant felt that being filial to her mother was a self-comforter. For most participants with dementia, filial piety was the main coping resource, in the form of material support or emotional support from their family. It is clear from accounts of both participants with dementia and their family carers that filial piety plays a significant role in coping with the ‘altered’ life. Some of them view it as authoritarian whereas others drew more on reciprocal aspects. The current study shows that filial piety has much more merit in the family care model of care, and supports people who live with and care for people with dementia. Filial piety is still in place, but many factors influence its functions, and it seems to have been negatively affected by the ongoing social, economic and cultural change in China. This highlights the need for social and political action.

5.4 Contribution to knowledge

There are some contributions from this thesis. Firstly, one of the most important contributions in this study is adding an understanding of the meaning of family responsibility for people with dementia and family caregivers under the contemporary
social and cultural transitions in China. It is significant in presenting a specific sociocultural context and how this context has created the cultural differences of personal experience from other ethnic groups. Secondly, another contribution to knowledge is to provide insight into the role that the traditional belief of filial piety plays in family-based dementia care, and how it has been utilised by the participants in maintaining their family responsibility. This particular understanding about Confucian’s philosophy of filial piety as a coping strategy may have implications in some countries where Confucianism has been culturally and socially valued, such as Singapore, Malaysia, Korea and Japan. Thirdly, the findings show that the social and cultural environment plays an important role in shaping family responsibility in family-based care in China. The study illuminates the significance of social and cultural contexts in the lives of people with dementia and family caregivers, and indicates how these new insights into the experience of Chinese people with dementia and family caregivers’ can inform the current knowledge base.

These contributions to knowledge have emerged from investigating the perspectives and accounts of participants’ stories on the specific topic of responsibility and related issues. The study shows that social space, social relationships and cultural value make important contributions to shaping the meaning of family responsibility, and influence the quality of life for people with dementia and family caregivers in China. For example, the participants made specific references to how their community environment influenced the meaning of their lived experiences and changed the traditional concept of home as a place of ‘being together’ and ‘unity’, which created a sense of isolation and disconnection for them. This social and cultural awareness of the lived experience is consistent with many qualitative studies (Cagney and Cornwell., 2010, Wiles, 2011, Cutchin, 2005, Sixsmith et al., 2014, Van Dijk et al., 2015, Soilemezi et al., 2017, Herron and Rosenberg, 2017). As dementia care is more likely provided by family members, understanding social and cultural impact on people with dementia and family caregivers’ lived experiences, are important areas for researchers.

This study addresses this gap by demonstrating the dual roles (its negative function and positive function) of filial piety in the family care practice. This is very important in helping to understand the dynamic change of the role of filial piety beyond the social context, which can be translate into improving family care and to practically lay the filial responsibility in it. The findings of the dual role of filial piety has implications for
health professionals in supporting and developing coping strategies with people with dementia and family caregivers in practice. This study adds knowledge of dual roles in filial piety to the functions of cultural value in the findings of Hsu and Tseng’s utilizations of Chinese family system and its relationships in the mental health services (Hsu, 1985), Sung’s two dimensions of filial piety and Yeh’s dual filial piety model (Yeh, 2003, Sung, 1995).

There is also a lot of evidence from the participants’ narratives in this thesis about establishing an equal and acceptable health care service and a wide coverage social safe network, which may be helpful for enhancing the family dementia care services in China. For example, regarding the burden of dementia care for the family, in the sub-theme ‘I need your support’, some participants drew the government’s attention to the situation faced by families with the burden of older care, and to their wish for a good health and social support system in the future for them and subsequent generations. It is hoped that the participants’ feelings, ideas and thoughts will help healthcare staff and possibly politicians to understand the difficulties and challenges that people with dementia and family caregivers have experienced in living, or caring for people with dementia.

5.5 Recommendations for future research

5.5.1 Studying the cultural perspective

The finding of the dual role of filial piety has facilitated a deep understanding of how this traditional cultural value has influenced family responsibility in caring for a person with dementia and living with dementia, and how both family caregivers and care-receivers take this into account to fit in with the contemporary health care for older people in China. This highlights the importance for future research of exploring the development of culturally appropriate dementia care services. Given the current conflicting evidence, in answering calls for the role of filial piety in family care services, it would be beneficial for researchers to test the role of filial piety as a positive factor in coping with the ‘altered’ life in both people with dementia and family caregivers. Future research might be able to explore the development of coping strategies for the family caregivers who chose to provide family care. More in-depth studies on how positive and negative attitudes of caring responsibility can be created by cultural beliefs may be needed. In addition, the correlation between caring responsibility and filial piety should be investigated further in order to design a culturally appropriate
family care service. Future studies also need to investigate how changes in interdependent family relationships have affected the lived experiences of people with dementia in China. For example, for participant Ye, losing her role of cooking for her family has changed her family relationship from interdependence to dependent which made her perceive the feeling of being a useless person at home. Further studies also need to investigate the causality of whether cultural transformations affect the concept of caring responsibility. Furthermore, attention needs to be paid to the correlation between dementia attitudes and caring responsibility as some participants admitted that looking after a person with dementia is a ‘losing face’ (shameful) thing. This may affect willingness to take the caring role.

As dementia care in China is predominantly provided by family members, understanding social attitudes and cultural conception of dementia among both the general public population and health professionals, as well as how it effects people with dementia and family caregivers’ lived experiences, are all important areas for research. Other studies suggest that knowledge in these areas is lacking. There is also a need to explore the relationship between the general population and health professionals’ concept of, and attitudes towards dementia. A positive cultural perception of dementia will help people with dementia and family caregivers live a more meaningful and better-quality life. Understanding the correlation between these two elements may be helpful in promoting people with dementia and family caregivers’ well-being, and contribute to shaping the perception of family based dementia care.

5.5.2 Research on social influences

In the subtheme ‘my life beyond the social environment’, regarding the changed meaning of ‘home’ and community environment in the findings, future studies about how the social environment influences a person with dementia’s sense of home and connections with their community are needed. How this change has had an impact on personal views of the traditional function of family-based care is also worth looking at. A further potential area for investigation is to explore where the best venue for dementia care is. Family caregiver participants in this study expressed a high level of emotional stress in their caring role, which had driven them to develop different management skills to cope with the ‘altered’ life. This suggests that more research in the area of developing social support services or designing evidence based psychological interventions is needed, specifically in the context of family supported caregivers. In addition, participant narratives in the current study highlight the
importance of social support services. It may be worthwhile to study the area of what aspects of these services are needed and valued most by people with dementia and their family members, and to look at what support needs to be strengthened and what will provide them with the greatest control over their own lives.

In the study, family caregiver participants included both spouse (husbands and wives) and children (sons, daughters, son-in-law and daughter-in-law), who may have qualitatively different experiences and attitudes towards their caring role. Pinquart and Sörensen identified significant differences in stress, psychological well-being and support levels for the person with dementia and between caregiving spouses, adult children, and children-in-law (Pinquart and Sörensen, 2011). Thus, it may be worthwhile to explore the impact of caring roles on spouses or children alone as it is possible that this experience has different implications for them. Similarly, females and males may have a different understanding of caregiving, and future research could explore this area further.

Overall, it is important to hear the perspectives of people with dementia and family caregivers in order to improve their quality of life and support the continuity of family care. However, searching the literature reveals that there are very small numbers of studies about the lived experiences of people with dementia and their family caregivers in China. This indicates the need to hear and understand them. For researchers, only by recognizing the interaction and dynamic relationships between care receivers and care givers, can we grasp, understand and interpret the process of their daily life, and to help them to reconstruct the changed life and made it more meaningful. Gaps in the research identified in the study, could potentially be addressed in the future research.

5.6 Critique of the Research

This study contributes to the limited knowledge on how family responsibility and the relationship between care-giving and care-receiving are experienced and understood by people with dementia and family caregivers beyond the Chinese sociocultural context. It reveals how specific social, cultural and political factors have shaped participants’ everyday lives, and highlights participants’ coping responses to their ‘altered’ life taking into account the current insufficient provision of long-term care services for older people in China. The study explored the perceptions and accounts of a specific group of people with dementia and family caregivers through semi-
structured interviewing which allowed the researcher to seek further explanation or clarify the answers by probing or prompting questions (Arksey and Knight, 1999). It brought together participants who had experiences relevant to the study, and the capacity and willingness to share their thoughts and stories. The interviews also provided opportunities for people with dementia to share their stories, to feel valued, and to make their experiences meaningful to themselves and others with similar experiences and conditions.

An interpretative phenomenological analysis (IPA) approach provides the theoretical underpinnings and guided the process of this qualitative study. As I explained in the methodology chapter, I gave a clear rationale for using semi-structured interviews as a data collection method which has the potential to access a rich, first person account of the participants’ experiences, and provides opportunities for readers to gain a deeper sight of others’ worlds (Finlay, 2009). As is the nature of an IPA study, there is no claim that the findings from this research can be generalised to other people with dementia. Rather, hearing and analysing the accounts of this specific group, and understanding how people make sense of their experience of family responsibilities and relationships, can inform policy making, practice and indicate areas for future research.

This research was carried out with a small population and in certain areas, and the findings cannot, therefore, be generalized to other regions where the economic development is different. It does, however, provide a contextualized understanding of the caring responsibility in modern China and provides a base for thinking about the value of the traditional culture of filial piety in taking on caring responsibility from a family-based care perspective. The proposed functions of filial piety have been discussed above, and show the associations between family responsibilities and sociocultural transitions, the underlying conflicts in family based care, the changing perception of traditional culture, and the potential for enhancing family based care. As I had a prior understanding of the embodied interrelationships of Chinese families, as well as preconceptions of Western independence and selfhood, I was able to notice and identify some important information that might otherwise have been missed.

With regard to the potential methodological limitations of the study, the nature of an IPA study does not support generalisation of research findings to other ethnic people with dementia but seeks to hear their experiences of a specific event and to understand the meanings of their experience of living with dementia and caring for a
person with dementia in the same setting. Furthermore, the research method heavily relies on the participants' ability to communicate and talk about their lived experiences. Thus, it would be difficult to use this approach to access people who have communication problems or who are in advanced stages of dementia.

The participants in this study were recruited from a hospital and four different clinics. They were initially recruited by health professionals, and this may have influenced the participation rate as the position of a health professional may have made it difficult for participants to refuse a doctor's request to take part in the research. This method of recruitment also necessarily excluded many people with dementia who don't use or cannot afford hospital services. It is possible that this may have skewed the findings. Therefore, the findings cannot represent the subjective experiences of the group of people who are not using hospital services due to financial issues. Indeed, the findings suggested that participants in the study who had financial issues experienced more stress than participants who had no financial issues. The experiences of people who can't afford to go to hospital, absent from this study, might be worth researching in the future. Recruiting through the health service gateway has the potential to exclude groups of people who have apparent cognitive symptoms but haven't been formally diagnosed. Using a snowballing approach or private network to recruit these 'hidden' participants could help.

A researcher in a particular position is often influenced and constrained by the politics, the culture and the customs of the place. My previous experience of working as a nurse in China and a senior carer in England made me more likely to view the study through a multicultural perspective which may overstate my understanding of the subjective experience of Chinese people with dementia. Moreover, during the interview, my previous work experiences and prior professional relationships with people with dementia in different cultural settings, may have potentially influenced participants in conversation, either by expanding or limiting the content and direction of discussions, or possibly both. For example, in Chinese culture, directly asking whether a child is being filial to her/his parent is not a polite question. Therefore, by avoiding this question, there may be missing data related to filial piety. However, this multicultural perspective helped me to view and understand things from different points of view, and was also a holistic way to avoid analysis being skewed. Due to the above factors, I have used a continuous process of reflexivity and rigorous analysis
in an attempt to produce responsible knowledge and increase the transparency of the study process.

The participants in this study were able to attend the interview with no more than a moderate level of support, which reflects their abilities at the time. It should also be said that in terms of dementia, symptoms and experiences of individuals are unique in pattern or progression. As the data comes from participants’ narratives, some detailed information may not have been recalled because the participant’s memory was not accurate or they may have had forgotten some important information. This may have influenced the findings. Finally, the study indicates that there is a difference between rural and urban areas but this was not explored in depth and further research is needed to explore this aspect. 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 people with dementia and family caregivers. Further studies on the subjective factors of the lived experience of people with dementia and family caregivers in other geographic areas across China are needed to ascertain whether their experiences differ from the experiences of people with dementia and their family caregivers in this study.

5.7 Personal Reflections of the study

In the earliest stages of planning the research, I decided to collect data from both people with dementia and family caregivers to achieve dual-dimensional views of caring responsibility in the Chinese context. I searched the literature and talked to people who worked in this area, and began to realise that the voice of people with dementia and family caregivers were largely missing from research in this part of the world, especially people with dementia. It was hard to find peer reviewed articles that involved people with dementia or family caregivers in China. Choosing methodological approaches and the rationale for using IPA for the study has lead me toward a semi-structured individual interview. To address the research question of how people with dementia and their family caregivers in China feel about the experience of living with dementia, semi-structured interviews with people with dementia and family caregivers were conducted to bring out in detail the participants’ subjective stories. The data were transcribed and analysed using the process of IPA. The process of conducting this research enriched my practical skills in carrying out
qualitative research. The transcriptions were kept in Mandarin to avoid wasting time and flawed data in the process of translations (Smith et al., 2008), but was coded in English supplemented with English summaries by the bilingual researcher. I am satisfied with all the preparatory work that ensured that all participants were informed and treated as an active ‘actor’ as much as possible during the research. Participants seemed to appreciate the opportunity to talk about their experiences and to be involved in the research. Twenty-four cases required considerable analysis time (over the three-year period of the PhD study). I will consider smaller sampling strategies when using IPA in future research which would allow for a very detailed engagement with research material. In addition, recording the interviews offered me the best opportunity to engage with the original data and to ensure a more explicit and accurate analysis.

During the interviews, some participants relied on me as a health professional who brought ‘hope’ with regard to their treatment, and some participants viewed me as a government representative who could deal with financial or policy related issues. Sadly, purely as a researcher, I was not in a position to deal with these issues. Transparency is an important element in the quality of qualitative research (Smith, 2009, Smith, 2015). The researcher’s own work and life experiences, beliefs, presumptions and personal roles and positions may have influenced the interpretation of the data and findings. For this reason, I kept a reflective diary during the process of the current PhD study. This reflective diary was used to record and explore my experiences and responses during data collection and data analysis (See the samples of research diary on appendix 8).

**5.8 Conclusion**

In this chapter, I have discussed several main issues that emerged in the findings, and how these issues have been informed and shaped by the findings. The impact of social space and cultural belief on this specific population group has been explored in relation to the findings. The need to create a dementia friendly social environment is critical to involving people with dementia and family caregivers in their society. Addressing the lack of social support and political attention is crucial to enabling the family care system to continue. The value of filial piety and its utilities is another important element in maintaining informal family care services, and also improves the quality of life for families living with dementia. The limitations of the study have also been considered, and several important points identified. I have also reflected on the
whole process of the study, from the starting point of research design, to the end of
the findings. Some examples of field notes have been added as appendices in order
to demonstrate the transparency of the study, to reveal my emotional responses
during the process of the study, and to show how I dealt with these emotional
responses. I also disclosed how my personal role, experiences and knowledge
influenced the study and my adjustments to this study.

In the study, the tensions, connections and relationships between the participants and
the wider social environment have reflected how social and cultural contexts have
influenced their life. Recognizing these influencing factors may help policy makers in
making dementia related policy. As family-based care is the dominant safe net for
older people in China, the study is about family responsibilities, caring relationships
and other social relationships which have important messages for the delivery of
dementia care in family care services. The findings have contributed knowledge to
the limited literature of people with dementia and their family caregivers’ lived
experiences and how the meaning of their lived experiences has been affected by
socioeconomic development in China. The study provides valuable information and
sheds new light on family responsibility and filial piety, which may inform practice,
policy and the planning of health and social support for this population group.

The study has explored both the perspectives of people with dementia and family
caregivers by focusing on the exploration of family responsibility and how it has been
influenced and shaped by contemporary Chinese society, where it is undergoing
dramatic changes in social norm and cultural beliefs as a result of socioeconomic
development. It provides evidence of the influences of the social and cultural context
on family responsibilities, coping strategies and quality of life. The findings also
highlighted participants’ stress and burden in carrying out family caring responsibility
or living with dementia under the current social situation. The message from the
participants’ narratives shows that the traditional value of family responsibility has
been influenced by sociocultural transitions which indirectly affect the quality and
quantity of care provided by families. Support from the central government, local
authority, the community, healthcare professionals and social workers is very limited.
This study makes an original contribution to knowledge about the subjective
experiences of people with dementia and family caregivers who are experiencing
sociocultural transitions in China. It recommends that while there may be continuing
support for reciprocal filial piety, a stronger government welfare system is needed in order to support older people and their families in contemporary Chinese society.
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Dear Xiubin,

APPLICATION FOR LEVEL 2/3 APPROVAL

PROJECT TITLE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TO EXPLORE THE LIVED EXPERIENCE OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS IN CHINA

Thank you for submitting the above research project for review by the Section of Nursing Studies Ethics Research Panel.

I can confirm that the submission has been independently reviewed and was approved on 25 June 2015.

Should there be any change to the research protocol, it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

Kath Mella
Professor of Nursing Studies
Appendix 1b Amendment Ethical Approval from The University of Edinburgh

Ref: NURS009

Xilubin Zhang
Doctoral Research in Nursing Studies
School of Health in Social Science
Medical School
Teviot Place
Edinburgh
EH9 3AG

22 October 2015

Dear Xilubin,

AMENDMENT TO APPLICATION FOR LEVEL 2/3 APPROVAL

PROJECT TITLE: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS TO EXPLORE THE LIVED EXPERIENCE OF PEOPLE WITH DEMENTIA AND THEIR FAMILY CAREGIVERS IN CHINA

Thank you for submitting the ethical approval amendment for the above research project for review by the Nursing Studies Ethics Research Panel.

I can confirm that the amendment has been independently reviewed and was approved on 22 October 2015.

Should there be any further change to the research protocol, it is important that you alert us to this as this may necessitate further review.

Yours sincerely

Susanne Kean
Lecturer, Nursing Studies
Appendix 2 Ethical Approval from Shandong Mental Health Centre

Dear University of Edinburgh:

Xibin Zhang is a PhD student at the University of Edinburgh. She has proposed a research project to investigate the lived experience of people with dementia and their family caregivers in China. I am aware that the study will take place during July 2015 to February 2016, for which she will recruiting participants from Shandong Mental Health Centre and will be conducted in Shandong Mental Health Centre. I understand that all information collected from individuals will be done with duly informed consent from the participating individuals and that individuals can refuse participation with no any negative consequences.

I support the conduct of this research in this organization.

Sincerely,

[Organization Name] Research and Education Department of Shandong Mental Health Centre

[Signature] [Signature]

[Date] 2015-9-18
Appendix 3a Participant Information Sheet (people with dementia)

Research title: An interpretative phenomenological analysis to explore the lived experience of people with dementia and their family caregivers in China

Invitation to the study

Dear Participant:

I am a PhD student in the University of Edinburgh. You are invited to participate in my project study, this study is part of my doctorate training in Nursing Studies. The study aims to develop a better understanding of the lived experience of people with dementia and their family caregivers in China. Before you decide whether to take part in the study, it is important that you understand why the research is being carried out and what this study will involve. Please take time to read the following information carefully before take a decision to take part in it or not.

What is the purpose of the study?

Currently, there are 9.19 million people with dementia in China, it represents 20% of people with dementia in the whole world. However, despite China having the biggest dementia population in the world, the development of dementia care and research are less developed than western countries. Especially the changing social-economic, demographic and cultural value in China make the capacity and availability of traditional family based care unavailable at the moment. These factors make Chinese people are more likely to face great challenges in coping with the illness and providing care-giving. Understanding the lived experiences of Chinese people with dementia and their family caregivers will help to identify what support they need. This will also allow decisions to be made regarding dementia care and policy strategy.

Why have I been invited?
I understand that you are a person have experience in memory problems or you have been diagnosed with dementia. You have a valuable view because of your experiences.

Do I have to take part?

It is your decision whether to take part in the study or not. If you wish to take part please contact me or ask another family member/friend to do so on your behalf via e-mail or telephone. If you take part the study, you are free to withdraw from the study at any time and you will not need to give a reason. And it will not affect any services that you receive.

What will happen if I take part?

You will be asked to sign a consent form if you would like to take part. You will be asked to give some basic demographic information about yourself (such as, ages, educational level…). You will then take part in an individual interview with myself unless you request a related member to accompany you. The interview will be conducted in Mandarin. The conversation will cover how you feel with the daily experiences of coping with the illness, how you think and feel the memory difficulties impact on you, what support you have received and what your expectations are from the social support. There are no right or wrong answers as the study is interested in hearing about your personal opinions of this experience. You can chose the interview date, location and time which is convenient to you. The interview will last approximately 30 minutes to one hour. A digital record will be used to record the conversation unless you wish not. Any information of you will be confidential.

What are the possible advantages of taking part?

I cannot promise the study will help you. It is an opportunity for you to talk about your experiences and your voice will be listened to. It is hoped that your perspectives can help to give a better understanding of what some people go through in coping with the illness.

What are the possible disadvantages of taking part?

It is possible that some of the experiences you share may be upsetting to talk about. If this is the case, you can take a rest during the interview or stop the interview, you
also can speak to your family members or friends. If you feel you need further support or advice you can speak to your doctor to seek advice and support.

Will my taking part in the study be kept confidential?

Your participation and personal information that you provided will be kept confidential. Your name and contact details won’t be shared with anyone outside the research team. The recording of your interview and the documentations identifying you (i.e. consent form) will be stored safely in a locked drawer. The recording will be destroyed at the end of the research. Transcripts will be destroyed after 5 years. Only I, the supervisor of the project and examiners have the right to access to the recordings and transcripts.

What if there is a problem?

If you have any questions or concerns with the study, you can contact me. You can also contact my supervisor Professor Charlotte Clarke at the School of Health in Social Science, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG, Charlotte.Clarke@ed.ac.uk, Tel: +44(0)131 651 6671. You can also contact the Chair of the Shandong Mental Health Centre, Dr Jingxuan Zhang, jingxuanzhang@126.com, Tel: 0531-86336700 or the Chair of the School Research Ethics Committee, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG, Dr Ethel Quayle, Ethel.Quayle@ed.ac.uk, Tel: +44 (0)131 650 4272. If you have concerns about Alzheimer’s disease or about any other form of dementia, Alzheimer’s Society National Dementia Helpline 0300 222 1122 can provide information, support and guidance for you. Or you can contact Chinese Committee for Alzheimer’s Disease International (ADI-China) Helpline 010-84110913.

What will happen to the results of the research study?

The findings of the study will be written up and submitted to the University of Edinburgh as part of a Doctorate training in Nursing Studies. The results may also be published in an academic paper. If in this case, you will not be identified in any report or publication.

Has the research obtained ethical approval?

The research has obtained ethical approval from both the University of Edinburgh’s Ethics Committee and the Shandong Mental Health Centre.
Contact for further information

If you would like to take part in the study or have any questions please contact me, Xiubin Zhang,

E-mail: S1366949@sms.ed.ac.uk.

Thank you for taking the time to read this information sheet.

PhD student: Xiubin Zhang

Supervisor: Professor Charlotte Clarke

The University of Edinburgh

Medical School

Teviot Place

Edinburgh EH8 9AG

Tel: 0131 650 4327
Appendix 3b Participant Information Sheet (people with dementia) (Chinese Version)

研究标题：应用解释现象学分析法去探讨老年痴呆症和他们的家庭照护者在中国的生活经验

尊敬的参与者：

我是爱丁堡大学的一名博士研究生。您将被邀请参加我的项目研究，这项研究是我的博士培训护理研究的一部分。这项研究旨在更好地了解中国老年痴呆症患者及其家庭照护者的生活经验。在您决定是否参加这项研究前，您需要了解为什么开展该项研究，以及该研究将涉及到的研究方面。请您花一些时间仔细阅读以下信息，再做出决定参加与否。

这项研究的目的是什么？

目前，中国有919万的老年痴呆症患者，它占据了全世界20%的老年痴呆人口数。然而，尽管中国拥有世界上最大数量的老年痴呆症患者，但其老年痴呆症的护理和科研发展远落后于西方国家。尤其是中国当前正面临着社会经济，人口结构和文化价值的不断变化，这些因素促使传统的家庭养老模式和其照顾者的能力不再适应当前的形势。因此，中国人正面临着一个巨大的挑战：如何应对这一疾病和提供护理照顾该群体。了解中国老年痴呆症患者和他们的家庭照顾者的生活经验，将有助于了解他们所需要的支持和帮助。这也将为制定有关老年痴呆症护理的政策法规提供参考。

为何我被邀请参与该研究？

我知道您是一名正遭受着失忆折磨的患者，或者您已经被诊断出患有老年痴呆症。

我一定要参加吗？
您有决定是否参与该研究的权力。如果您愿意参加，请通过电子邮件或电话直接与我联系或要求您的家庭成员/朋友代表您与我联系。如果您参加了这项研究，您仍可以自由地在任何时候退出该研究而不需要给与任何理由。这不会影响您接收任何医疗和护理服务的机会。

如果我参加该研究，需要做什么？

如果您愿意参加该研究，您将需要签署一份同意书。您需要提供有关自己的一些基本的个人信息（如年龄，受教育程度...）。然后，您将单独和我面对面的交流，如有必要，您也可要求家人陪同。谈话将用普通话进行。对话将涵盖您对日常生活的想法和感受，记忆困难或老年痴呆症对您的影响，以及您接受到的社会支持度和您对医疗和社会的期望。该研究只是想听取您的个人意见，没有正确或错误的回答。您可以选择方便您的面试时间和地点进行面试。面试将持续约 30 分钟至 1 小时。谈话将会被录音，但我们确保您的任何信息将被保密。

参与该研究的益处是什么？

我不能保证该研究是否会帮助到您本人。这是一次您谈谈您的个人生活经验的机会，你的声音将被倾听。我们希望您的观点可以帮助我们去更好的理解老年痴呆症患者的心声和他们如何与疾病作斗争。

参与该研究的缺点是什么？

谈话过程中的一些经验分享，可能会影响您的情绪。如果是这样的话，您可以中断谈话休息一会或停止接受面试，您也可以给您的家人或朋友通话。如果您觉得您需要进一步的支持或者建议，您可以寻求您的医生的建议和支持。

我的个人信息是否予以保密？

您所提供的个人信息将予以保密。您的姓名和联系方式不会与研究团队之外的任何人共享。你的采访记录，和任何有关材料（例如知情同意书）将被安全地保存。谈话录音将在研究结束时被销毁。谈话录音的资料将在 5 年后予以销毁。仅有发起该项调查的研究者和其导师及爱丁堡大学的主考官有权查看录音和有关材料。

如果有什么问题，我需要联系？
如果您对该研究存在任何问题或疑虑，您可以和我联系。您也可以联系我的导师 Professor Charlotte Clarke，邮箱：Charlotte.Clarke@ed.ac.uk，电话：+44（0）131 651 6671。您也可以联系山东省精神卫生中心医学伦理委员会，张敬悬主任，邮箱：jingxuanzhang@126.com，联系电话：0531-86336700 或爱丁堡大学医学院，健康和社会科学研究伦理委员会主任，Dr Ethel Quayle，邮箱：Ethel.Quayle@ed.ac.uk，电话：+44（0）131 650 4272。如果您想了解有关于阿尔茨海默氏症或其他任何形式的痴呆症，您可以拨打国际老年痴呆协会中国委员会（ADI-China）热线服务 010-84110913。或者您也可以联系英国阿尔茨海默氏症协会（Alzheimer's Society）全国老年痴呆症，帮助热线 0300 222 1122 可以给您提供信息，指导和帮助。

该研究的结果将被怎样应用？

这项研究的结果将被写入我的博士论文中，并提交给爱丁堡大学。该结果也可能发表在学术期刊上。但即使在这种情况下，您的个人信息也保证不会出现在任何报告或出版物中。

该研究是否获得伦理委员会批准？

该研究已获得爱丁堡大学和山东省精神卫生中心伦理委员会的批准。

联系以获取更多信息

如果您想获取更多信息或您想参与该项研究，请与我联系，张修斌。邮箱：S1366949@sms.ed.ac.uk。

感谢您在百忙之中阅读此资料。

博士研究生：张修斌
博士生导师：Professor Charlotte Clarke

爱丁堡大学医学院健康和社会科学学院

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Research title: An interpretative phenomenological analysis to explore the lived experience of people with dementia and their family caregivers in China

Invitation to the study

Dear Participant:

I am a PhD student in the University of Edinburgh. You are invited to participate in my project study, this study is part of my doctorate training in Nursing Studies. The study aims to develop a better understanding of the lived experience of people with dementia and their family caregivers in China. Before you decide whether to take part in the study, it is important that you understand why the research is being carried out and what this study will involve. Please take time to read the following information carefully before taking a decision to take part in it or not.

What is the purpose of the study?

Currently, there are 9.19 million people with dementia in China, it represents 20% of people with dementia in the whole world. However, despite China having the biggest dementia population in the world, the development of dementia care and research are less developed than western countries. Especially the changing social-economic, demographic and cultural value in China make the capacity and availability of traditional family based care unavailable at the moment. These factors make Chinese people are more likely to face great challenges in coping with the illness and providing care-giving. Understanding the lived experiences of Chinese people with dementia and their family caregivers will help to identify what support they need. This will also allow decisions to be made regarding dementia care and policy strategy.

Why have I been invited?
I understand that you are a person have experience in supporting/caring for a person you know with dementia for six months or over. You have a valuable view because of your experiences.

Do I have to take part?

It is your decision whether to take part in the study or not. If you wish to take part please contact me via e-mail or telephone. If you take part the study, you are free to withdraw from the study at any time and you will no need to give a reason.

What will happen if I take part?

You will be asked to sign a consent form if you would like to take part. You will be asked to give some basic demographic information about yourself (such as, ages, educational level…). You will then take part in an individual interview with myself. The interview will be conducted in Mandarin. The conversation will cover how you feel about providing care-giving for the person with dementia, how you think and feel the role impact on you, what support have you received and what are your expectations from the social support. There are no right or wrong answers as the study is interested in hearing about your personal opinions of this experience. You can choose the interview date, location and time which is convenient to you. The interview will last approximately one hour. A digital record will be used to record the conversation unless you wish not.

What are the possible advantages of taking part?

I cannot promise the study will help you. It is an opportunity for you to talk about your experiences of supporting the person you know with dementia and your voice will be listened to. It is hoped that your perspectives can help to give a better understanding of what some people go through of providing the care-giving.

What are the possible disadvantages of taking part?

It is possible that some of the experiences you share may be upsetting to talk about. If this is the case, you can take a rest during the interview or stop the interview, you also can speak to your family members or friends. If you feel you need further support or advice you can speak to your doctor to seek advices and support.

Will my taking part in the study be kept confidential?
Your participation and personal information that you provided will be kept confidential. Your name and contact details won’t be shared with anyone outside the research team. The recording of your interview and the documentations identifying you (i.e. consent form) will be stored safely in a locked drawer. The recording will be destroyed at the end of the research. Transcripts will be destroyed after 5 years. Only I, the supervisor of the project and examiners have the right to access to the recordings and transcripts.

What if there is a problem?

If you have any questions or concerns with the study, you can contact me. You can also contact my supervisor Professor Charlotte Clarke at the School of Health in Social Science, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG, Charlotte.Clarke@ed.ac.uk, Tel: +44(0)131 651 6671. You can also contact the Chair of the Shandong Mental Health Centre, Dr jingxuan Zhang, jingxuanzhang@126.com, Tel: 0531-86336700 or the Chair of the School Research Ethics Committee, University of Edinburgh, Medical School, Teviot Place, Edinburgh EH8 9AG, Dr Ethel Quayle, Ethel.Quayle@ed.ac.uk, Tel: +44 (0)131 650 4272. If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline 0300 222 1122 can provide information, support and guidance for you. Or you can contact the Chinese Committee for Alzheimer's Disease International (ADI-China) Helpline 010-84110913.

What will happen to the results of the research study?

The findings of the study will be written up and submitted to the University of Edinburgh as part of a Doctorate training in Nursing Studies. The results may also be published in an academic paper. If in this case, you will not be identified in any report or publication.

Contact for further information

If you would like to take part in the study or have any questions please contact me, Xiubin Zhang,

E-mail: S1366949@sms.ed.ac.uk.

Thank you for taking the time to read this information sheet.
PhD student: Xiubin Zhang

Supervisor: Professor Charlotte Clarke

The University of Edinburgh

Medical School

Teviot Place

Edinburgh EH8 9AG

Tel: 0131 650 4327
参与知情书（家庭照护者）

研究标题：应用解释现象学分析法去探讨老年痴呆症和他们的家庭照护者在中国的生活经验

尊敬的参与者：

我是爱丁堡大学的一名博士研究生。您被邀请参加我的项目研究，这项研究是我的博士培训护理研究的一部分。这项研究旨在更好地了解中国老年痴呆症患者及其家庭照护者的生活经验。在您决定是否参加这项研究前，您需要了解为什么开展该项研究，以及该研究将涉及到的研究方面。请您花一些时间仔细阅读以下信息，再做出决定参加与否。

这项研究的目的是什么？

目前，中国有 919 万的老年痴呆症患者，它占据了全世界 20% 老年痴呆人口数。然而，尽管中国拥有世界上最大数量的老年痴呆症患者，但其老年痴呆症的护理和科研发展远落后于西方国家。尤其是中国当前正面临着社会经济，人口结构和文化价值的不断变化，这些因素促使传统的家庭养老模式和其照顾者的能力不在适应当前的形势。因此，中国人正面临着一个巨大的挑战：如何应对这一疾病和提供护理照顾该群体。了解中国老年痴呆症患者和他们的家庭照顾者的生活经验，将有助于了解他们所需要的支持和帮助，这也将为制定有关老年痴呆症护理的政策法规提供参考。

为什么我被邀请参与该研究？

我知道您是一名正在或曾经照顾患有老年痴呆症家人的家属，并且您有六个月以上的照护经验。

我一定要参加吗？
您有决定是否参与该研究的权力。如果您愿意参加，请通过电子邮件或电话直接与我联系。如果您参加了这项研究，您仍可以自由地在任何时候退出该研究而不需要给任何理由。这不会影响您的家人接收任何医疗和护理服务的机会。

如果我参加该研究，需要做什么？

如果您愿意参加该研究，您将需要签署一份同意书。您需要提供有关自己的一些基本的个人信息（如年龄，受教育程度...）。然后，您将单独和我面对面交流。谈话将用普通话进行。对话将涵盖您对日常生活的想法和感受，照护您的家人对您个人的影响，您接受到的社会支持程度和您对医疗和社会的期望。该研究只是想听取您的个人意见，没有正确或错误的回答。您可以选择方便您的面试时间和地点进行面试。面试将持续大约1小时或以上。谈话将会被录音，但我们确保您的任何信息将被保密。

参与该研究的益处是什么？

我不能保证该研究是否会帮助到您本人。这是一次您谈谈您的个人生活经验的机会，你的声音将被倾听。我们希望您的观点可以帮助我们去更好的理解家庭照护者的心声和他们如何照护老年痴呆患者。

参与该研究的缺点是什么？

谈话过程中的一些经验分享，可能会影响您的情绪。如果是这样的话，您可以中断谈话休息一会或停止接受面试，您也可以给您的家人或朋友通话。如果您觉得您需要进一步的支持或者建议，您也可以寻求医生的建议和支持。

是否我的个人信息予以保密？

您所提供的个人信息将予以保密。您的姓名和联系方式不会与研究团队之外的任何人共享。你的采访记录，和任何有关材料（例如知情同意书）将被安全地保存。谈话录音将在研究结束时被销毁。谈话录音的资料将在5年后予以销毁。仅有发起该项调查的研究者和其导师及爱丁堡大学的主考官有权查看录音和有关材料。

如果有什么问题，我需要联系谁？

如果您有任何问题或疑虑有关该研究，您可以和我联系。您也可以联系我的导师Professor Charlotte Clarke，邮箱：Charlotte.Clarke@ed.ac.uk，电话：+44（0）131 651 6671。您同时也可以联系山东省精神卫生中心医学伦理委员会，张敬悬主任,
邮箱：jingxuanzhang@126.com，电话：0531-86336700 或爱丁堡大学医学院，健康和社会科学研究伦理委员会主任，Dr Ethel Quayle，邮箱：Ethel.Quayle@ed.ac.uk，电话：+44（0）131 650 4272。

如果您想了解有关于阿尔茨海默氏症或其他任何形式的痴呆症，您可以拨打国际老年痴呆协会中国委员会（ADI-China）热线服务 010-84110913。或者您也可以联系英国阿尔茨海默氏症协会（Alzheimer’s Society）全国老年痴呆症，帮助热线 0300 222 1122 可以给您提供信息，指导和帮助。

该研究的结果将被怎样应用？

这项研究的结果将被写入我的博士论文中，并提交给爱丁堡大学。该结果也可能发表在学术期刊上。但即使在这种情况下，您的个人信息也保证不会出现在任何报告或出版物中。

该研究是否获得伦理委员会批准？

该研究已获得爱丁堡大学和山东省精神卫生中心伦理委员会的批准。

联系以获取更多信息

如果您想获取更多信息或您想参与该项研究，请与我联系，张修斌。邮箱：S1366949@sms.ed.ac.uk，联系电话：0086-，07944167768。

感谢您在百忙之中阅读此资料。

博士研究生：张修斌

博士生导师：Professor Charlotte Clarke

爱丁堡大学医学院健康和社会科学学院
Appendix 5a Participant consent Form

Research title: An interpretative phenomenological analysis to explore the lived experience of people with dementia and their family caregivers in China

Name of Researcher: Xiubin Zhang

1. I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that I do not have to take part. It is my choice and I can change my mind at any time if I want.

3. I agree to the audio recording of the interview. I understand that recordings will be only made available to the research team.

4. I understand that any my personal information will be kept confidentially and will be used without identifying me (e.g. my name or where I work).

5. I agree to take part in this study.

Name of participant ___________ Signature ___________ Date ___________

Name of researcher ___________ Signature ___________ Date ___________

PhD student: Xiubin Zhang
Supervisor: Professor Charlotte Clarke

The University of Edinburgh

Medical School

Teviot Place

Edinburgh EH8 9AG

Mobile:

Tel: +44(0)131 651 6671

Email: s1366949@sms.ed.ac.uk
Appendix 5b Participant consent Form  (Chinese Version)

参与者同意书

科研标题：应用解释现象学分析法去探讨老年痴呆症和他们的家庭照护者在中国的生活经验

研究员姓名：张修斌

1. 我已阅读并理解上述研究资料。

2. 我明白我有决定是否参与该研究的权力。我自愿参与该研究，但我同时有权力在任何时候改变我的决定。

3. 我明白谈话内容将会被录音。但我同时明白录音资料将只提供给该研究团队。

4. 我明白我的任何个人信息将会被保密，在研究报告中使用的文字将不会透露我的个人信息（如我的名字，我工作的地方）。

5. 我同意参加这项研究。

参与者姓名 ______________  签字 ______________  日期 _____________

研究员姓名 ______________  签字 ______________  日期 _____________
博士研究生：张修斌

博士生导师：Professor Charlotte Clarke

爱丁堡大学医学院

手机：？

电话：+44（0）131 651 6671

电子邮件：s1366949@sms.ed.ac.uk
Appendix 6a Interview Schedule with People with Dementia (English Version)

Interview Schedule with People with Dementia

Prior the interview

- Review the purpose of the study: I will revise the purpose of the study before the interview day and keep in mind what information I intend to gain from the participants.

- Discuss the study and consent: I will briefly explain the study to the participants to ensure they fully understand why they came for the interviews and also gain oral consent from them before the interview. There are no right or wrong answers, they can refuse to answers any question during the interview if they don’t like to answer or they can withdraw from the interview anytime.

Interview questions

Can you tell me something about your life? What if anything has changed in recent years?

Prompts/ follow up questions: How long has been? What has been important? How do you feel?

Can you tell what the impacts in your life are since you had memory loss problems?

Prompts/ follow up questions: how do you feel about the changes? Positively or negatively

Can you tell how the relationships been affected since you had memory loss problems?

Prompts/ follow up questions: partner, family members, friends, neighbours?

How do you cope with the memory loss problems?

Prompts/ follow up questions: how you adjust yourself to the role? Can you give one example?

Can you tell me your feelings about the supporting work?
Prompts/ follow up questions: What kind of support do you get? (From family members, health professionals and social services). What support would you like the most? Does it make things better?

What are your thoughts with ‘xiao’?

Prompts/ follow up questions: How do you understanding ‘xiao’? How do you feel about your children taking care of you? What are your expectations from your children?

How do you think other people see you?

Prompts/ follow up questions: partner, family members, friends, neighbours?

Close of interview

Thank you for taking part in the interview. Is there anything else you want to add or you have not gotten a chance to talk about it yet?
Appendix 6b Interview Schedule with People with Dementia (Chinese Version)

会谈计划（老年痴呆患者）

会谈前

• 回顾谈话的目的：在面试前一天，我将回顾谈话的目的和做到心中有数，什么信息我从参与者获得。

• 讨论谈话的目的，并重申参与者的同意意向：我会再次简单介绍一下这项研究的目的，以确保参与者完全理解为什么他们参与该面谈，并重申他们的同意意向。告知他们谈话内容没有正确或错误之分，他们有权力拒绝回答不想回答的问题。

面试问题

1. 您能谈谈您的生活吗？最近几年是否有变化？
提示/跟进的问题：有多久了？有什么重要的改变？你感觉如何？

2. 您可以谈谈记忆困难或记忆力丧失对您生活的影响吗？
提示/跟进的问题：您对这一影响有什么感受？积极的或消极的？您理解忘事是怎么回事吗？

3. 您能不能描述您一天的生活？

3. 您能谈谈记忆困难或记忆力丧失对您和家人和社会的关系有怎样的影响？
提示/跟进的问题：伴侣，家人，朋友，邻居？

4. 您怎样在日常生活中克服记忆困难或记忆力丧失的问题？
提示/跟进的问题：你如何调整自己的角色？你能举个例子吗？

5. 您可以谈谈您对家人和社会支持工作的想法吗？
提示/跟进的问题：您获得过什么样的支持？（从家庭成员，保健专业人员和社会服务）。您最想得到什么样的支持？如果您得到您想要的帮助，您的生活会变好吗？

6. 您对孝顺有什么看法？
提示/跟进的问题: 您对您的家人照顾您，有什么想法？您希望您的孩子怎样对待您是？

7. 您认为别人如何看待您？

提示/跟进的问题: 合作伙伴，家人，朋友，邻居？

8. 为了更好的照护老年人群，您有一些建议吗？

9. 您对将来有什么打算吗？

面试结束

感谢您参加面试。您还有什么想要谈的吗？
Appendix 7a Interview Schedule with Family Caregivers
(English version)

Interview Schedule with Family Caregivers

Prior the interview

Review the purpose of the study: I will revise the purpose of the study before the interview day and keep in mind what information I intend to gain from the participants.

Discuss the study and consent: I will briefly explain the study to the participants to ensure they fully understand why they came for the interviews and also gain oral consent from them before the interview. There are no right or wrong answers, they can refuse to answers any question during the interview if they don’t like to answer or withdraw from the interview.

Interview questions

Can you tell me about your life with xx (people with dementia)?

Prompts/ follow up questions: How it used to be? Whether anything has changed? How do you feel?

What are the most difficult parts for you to look after xx?

Prompts/ follow up questions: what happens? How do you cope? How do you feel?

What are the most positive aspects for you to look after xx?

Prompts/ follow up questions: In which aspect? Can you describe it?

Can you explain ‘xiao’ (filial piety) to me from your experience of looking after your parents?

Prompts/ follow up questions: What made you take the decision of looking after your parents? (Legal obligation or responsibility) What other care options have been considered? How do you feel if you are not able caring for xx?

What would be different if xx did not need caring for?

Prompts/ follow up questions: What would you be? What do you think you have been influenced by? Positively or negatively?
Can you tell me what are your thoughts considering your current role?

Prompts/ follow up questions: How did you come into the role of looking after xx? How do you feel about it? What have you given up or gained from the current role? How would you describe your role in a day?

How do you cope with your current role?

Prompts/ follow up questions:

Can you tell how you adjust yourself to the role? What helps? Can you give one example?

Can you tell your thoughts to the supporting work?

Prompts/ follow up questions: What helps and does not help? What kinds of help do you like to get?

Close of interview

Thank you for taking part the interview. Is there anything else you want to add or have not gotten chance to talk about?
Appendix 7b Interview Schedule with Family Caregivers (Chinese Version)

会谈计划（家庭照护者）

会谈前

• 回顾谈话的目的：在面试前一天，我将回顾谈话的目的，并确定我将需要从参与者中获得何等信息。

• 讨论谈话的目的，并重申参与者的同意意向：我会再次简单介绍一下这项研究的目的，以确保参与者完全理解他们参与该面谈的原因，并重申他们的同意意向。告知他们谈话内容没有正确或错误之分，他们有权力拒绝回答不想回答的问题。

面试问题

1. 您能谈谈您和 **XX** （人患有痴呆症）的生活状况吗？
进一步的问题：和过去有什么不同吗？是否有任何变化？你感觉如何？

2. 对于老年痴呆症您有哪些认识和了解？
进一步的问题：您能谈谈患者的病史吗？有哪些合并症？您有没有学习过怎样照护痴呆症患者？

3. 您在照顾 **xx** 的日常生活过程中，您认为最困难的部分是什么？
提示/跟进的问题：发生什么事？你如何应对？你感觉如何？是否有其他人帮你照顾？

4. 您在照顾 **xx** 的日常生活过程中，您有哪些收获？
提示/跟进的问题：在哪些方面？你能描述一下吗？

5. 从您的个人经验中，您怎么理解“孝顺”？
提示/跟进的问题：是什么让您决定您自己照顾 **xx** ？（法律责任或自愿）您有没有考虑其他的护理选择？如果您不能亲自照顾 **XX**， 您有什么感受？

6. 如果 **XX** 并不需要照顾，您的生活将会有什么不同？
提示/跟进的问题：您现在会干什么？照顾 xx，对您有哪方面的影响？正面还是负面的？

7. 您对您目前的状况（照护者的身份）有什么感受？

提示/跟进的问题：您放弃了什么，获得了什么？您如何描述您在一天中的工作？

8. 您如何适用您当前的角色？

提示/跟进的问题：您是怎么让您自己适用了这一角色？什么方法？你能举个例子吗？

9. 您可以谈谈您对医疗和社会支持工作的想法吗？

提示/跟进的问题：您获得过什么帮助？你期望获得什么样的帮助？您知道哪些相关的卫生服务项目吗？

10. 为了更好的为居家痴呆症患者提供支持，您对社区医疗卫生和政策有哪些建议？

11. 您对将来有什么想法？
提示/跟进的问题：怎样安排 xx？您自己有什么打算？

面试结束

感谢您参加面试。您还有什么想要谈的吗？
Appendix 8a Sample of Coded Transcripts (English Version)
Appendix 8b Sample of Coded Transcripts (Chinese Version)
Appendix 9 Sample Reflection Notes

Reflections note: 19/08/2015

I conducted the first interview today with a woman who is looking after her father. I really enjoyed this experience as I feel that I have started to begin my research journey and do something that I actually want to do. During the interview, I felt a bit worried about whether I conduct a proper interview as a real researcher and worried about whether the conversation covered all of the research questions that I proposed to know. I have many thoughts during the interview, this may have influenced the conversation with my participant and may be the reason why the interview went shorter than I planned. I think I also feel humbled as the participant was so honest in telling me about her experiences. This feeling made me think about the purpose of my PhD study, where it will finish, and possibly, my duty as a researcher. These sounds a little bit silly, but it is truly my first reaction of this first interview. I must pay more attention about emotional responses in the next interview.

Reflection note: 27/08/2015

Finished transcribing the first interview today. Listening and typing, then listening and typing, over and over, I start to understand the warnings which I have received from other researchers about how hard and time consuming transcribing is.

Reflection note: 13/09/2015

I feel a bit guilty during the interview with PWD Shen with his experiences of his conversations with his doctor and how he told him that it was useless to take further treatment. The perceived feeling of hopeless and lack of support from health professionals has made him think about going to die. It made me think of my own experience of working as a healthcare staff, how did I treat people with dementia? Was I compassionating when listening to them? Was the information I gave to the patients are possibly harmful to them? Having cross cultural working experiences in both China and the UK, I also think about the different perceptions held by health professionals with dementia and how this influenced my understanding with the PWD experience? Now as a researcher, how my study can benefit him or other people in the same situation. I consider how my participants viewed my position and my role, whether this made them to willing or unwilling to talk to me. Whatever comes with this
study, I think that this research experience will make me reconsider myself and my position.

Reflection note: 04/10/2015

I used to see the PWD10 stumble along the hospital corridor like an invisible person. During the interview, she suddenly burst with tears when telling her experience of isolation and exclusion. I felt surprised, shocked and a little guilty. PWD 10 talked about how her family did not allow her to go to the kitchen and how her friends stopped her from attending the morning exercises group makes me think of my family and my parents. What should I do if this happened to me or my parents and how they would think? This also makes me think about the long-term care and social support in China, I grow concerned with how our society influenced family and social perception towards dementia. How should I treat my parents when they need my support? These emotional responses make me realise that the interviews and analysis can be affected.

Reflection note: 19/11/2015

Interview with Guirong, I am very shocked and sad. Looking after her two sons (familial early on-set dementia), the hardships, shame and financial deficit almost turned her mad, she cried a lot during the interview, this made me feel very guilty about disclosing her pain and also my position of not being able to help. Her discussion of being put down by the social support and social stigma makes me really think as a researcher and former health professional, what can my study do to benefit her and her sons? Is it a better choice for me to switch working area from practice to research? How I see her situation and to interpret her experience accurately without personal bias or social influence. Her story echoed in my ears for ages, I told to my parents, my friends and also told my oldest son about her story as I really want to know their view on this, and kind of, I want others to tell me that I am a 'purely researcher' when I doing my study, my research will benefit my participants.

Reflection note with analysis: 18/02/2016

Attending the course ‘working with self and others in qualitative research’. I was nervous about sharing my research experiences with other new researchers, but listened to what they said about their worries, uncertain feeling, joys or sadness, which made me understand that there are possibilities for a PhD student or a new researcher to account many problems during the process of fieldwork and data interpretation. In
general, anxiety throughout the whole process of my data collection and data analysis that somehow, I fear I might not find the right interpretation. However, with the time I share my experience with my friends and other new researchers, I was able to acknowledge that this is one of the aspects of qualitative research. Data analysis is a hard and long process of the PhD study. It really helps to talk to people about my experiences, my study field. It is also helpful to take some related courses, such as this course offers me a great deal support to get through the messy things and also the useful tools or techniques for doing research.

Reflection note with analysis: 08/07/2016

Coding the last interview today. I feel a little excited and anxious. How do I connect all of the cases together and how do I make sense of all of the database? Whether I capture all the important information? I also feel lost in the data and can never get things done. At this point, ambitious and puzzled, I talked with one of my friends who is also studying in the dementia field, and shared my findings with my supervisors, these helped me to get my energy back. Following the initially themes emerged, I know I have done something, and I have something to pay back to my participants.
Appendix 10 Published Journal Article

What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis

Xiubin Zhang, Charlotte L. Clarke and Sarah J. Rhynas
School of Health in Social Science, University of Edinburgh, Edinburgh, UK

Abstract
The filial piety model of family centred care has dominated Chinese society for thousands of years. The ways in which filial piety is presented are being modified and modernised as China undergoes social transitions. The study aims to understand the meaning of filial piety for people with dementia and family caregivers. Semi-structured interviews with people with dementia (n = 10) and family caregivers (n = 14) were conducted. Data were analysed using interpretative phenomenological analysis. Three themes emerged: (a) ‘Being filial is a cultural continuity and my future investment’. (b) ‘The changed perception and ways of being filial’. (c) ‘Filial responsibility is a social and cultural convention, but not my personal choice’. This study highlights the importance of cultural values in family care decision making and in shaping filial responsibilities. It indicates that filial obligation can be maintained through social support, even though the nature of filial piety has been changed by social transitions.

Keywords
dementia, family caregivers, filial piety, obligation, China

Corresponding author:
Xiubin Zhang, School of Health in Social Science, University of Edinburgh, Medical School (Doorway 6), Teviot Place, Edinburgh EH8 9AG, UK.
Email: x1366949@sms.ed.ac.uk
Introduction

China had 9.19 million people with dementia in 2012 – over 20% of the world’s dementia population (Chan et al., 2013). In China, family caregiving accounts for a significant proportion of the care provided for people with dementia (Yu et al., 2016) and it is a legal obligation for adult children to take care of their aged parents (Wu et al., 2005; Zhan, 2005). Caring for older parents in China has been viewed as a family’s responsibility for thousands of years, with roles and responsibilities between children and parents regulated by Confucius’s filial piety (Zhan, 2004). However, the capacity and availability of the traditional family care support system are influenced by social-cultural and demographical changes, such as the 4-2-1 family structure (four grandparents, two parents and one child) as a result of the One Child Policy, and increasing migration and urbanisation, which has decreased the care workforce, isolated older people in rural areas and may result in the family assuming less responsibility for older family members. Dementia care services have been particularly affected since dementia care requires complex physical and psychological input (Chen et al., 2013). Chinese family caregivers are, therefore, facing a great challenge fulfilling their filial responsibility to a family member with dementia (Chen et al., 2013).

The lived experiences of people with dementia and their family caregivers in Western countries have been studied intensively. A large volume of Western literature views caregiving as having a negative impact characterised by physical, psychological, social and financial burden. Despite the challenges of caregiving, some studies identified benefits through caring for a person with dementia (Peacock et al., 2010; Quinn et al., 2010; van Zadelhoff et al., 2011). However, these aspects of research have been rarely studied in Asian countries. Traditional cultures may have cultivated the caregiving experience differently from one population to another. For example, Iranians think their relative becoming ill is a punishment for their sins in the past (Navab et al., 2012); in a study of Hispanic caregivers, Simpson (2010) indicated that familialism and loyalty to family strongly influence caring roles. Traditions of filial piety demand that the Chinese take care of their parents when they get old. Thus, these pressures may modify the caregiving experience in a different way to other ethnic groups and it is important to understand how the belief of filial piety influences the lives of people with dementia and caregivers.

This study aims to understand the lived experiences of people with dementia and their family caregivers in China. It focuses on the impacts of changing socio-economic, demographic and cultural values from their perspectives of the meaning of living with and caring for people with dementia; the negative and positive impact of their lived experiences, their ability to cope with their ‘altered’ life and their expectations of health and social care support and impact on their quality of life and how they cope with their filial responsibility.

Methods

Methodology

This study used Interpretative phenomenological analysis (IPA) as the methodological approach. IPA aims to obtain and analyse the specific experiences of the individual in a specific context or environment (Smith, 2009, 2015). It is concerned with how individuals make sense of and report their subjective experiences, and how those data are interpreted by the researcher with personal and professional knowledge and beliefs. Thus, it draws on both
descriptive and hermeneutic phenomenology to identify meanings. IPA is based on idiographic analysis, which requires a small sample size and deep, detailed subjective accounts to understanding experiences (Smith, 2009).

Ethical issues

The research was approved by Edinburgh University and Shandong Mental Health Centre. In order to maintain confidentiality, participants’ details were anonymised and pseudonyms used. Consent forms were signed by participants before conducting the interviews. According to the 17th general principle of the civil law of the People’s Republic of China, for people who did not have capacity for decision making, the legal guardian or relative signed the consent form. The provisions of the Mental Capacity Act (2005) were followed to assess whether a person lacks capacity.

Research site

The research site was one of the mental health centres in Shandong province, China. This site was chosen because Shandong is the hometown of Confucius where the traditional culture of ‘Xiao’ (filial piety) originated. There are 98.47 million people in Shandong and 13.67% are over 65 years old. However, according to Alzheimer’s Disease International in China, there are no official statistics of people with dementia, no dementia care regulations and very limited support services for people with dementia and their family caregivers. The mental health centre is one of few authorised institutions for the diagnosis of dementia and treatment by professional psychiatrists in the province.

Participants

Patients from the Mental Health Centre’s outpatient and inpatient service (hospitals and Clinics) who met the inclusion criteria and were interested in the research were included in a ‘recommended patient list’ by the unit manager and participants were recruited from this list. Inclusion criteria were people with dementia who have been formally diagnosed with dementia ranging from mild-to-moderate severity so when conducting an interviewing their communication and comprehension skills would be less impaired (Lloyd et al., 2006), they must also have been cared for in the communities; family caregivers who are over 18 years old with over six months of caring experience so that they had enough subjective experience to reflect upon. The participants included 10 people with dementia and 14 family caregivers. The participants of the dementia group consisted of two females and eight males, whose ages ranged from 67 to 87. The family caregivers group consisted of nine females and five males, whose ages ranged from 39 to 78, with five spouses, eight children and one mother. All the family caregiver participants lived with the person with dementia in the same house. The participants were from urban and rural areas in Shandong province, 14 were urban residents and 10 were rural residents. All the participants were of Chinese origin and they had a range of social, geographical and educational backgrounds.

Data collection

Data were collected through individual semi-structured interviews and including open-ended questions to allow the participants to fully express their viewpoints (Turner,
2010). For example, in order to understand ‘what the meaning of filial piety is to them?’ We asked the questions: ‘What made you take the decision to look after your parents?’ ‘How would you feel if you were not able to care for your parents?’ Or ‘What are your expectations of your children?’ The interviews conducted in Mandarin (the official language of China), lasted between 30 and 60 minutes and were audio recorded for later transcription. Taking into consideration the impact of cognition and communication abilities of the person with dementia, the length of interviews with people with dementia was generally shorter than family caregivers and the interview questions were shorter and more concise. It was not always clear how much the participants knew about their condition, and so terms such as ‘dementia’ or ‘Alzheimer’s disease’ were avoided unless the participants mentioned them themselves. ‘Memory loss’ or ‘forgetting’ was used instead in the interviews. During the interviews, field notes were used to note any important non-verbal or emotional responses or any specific requirements that needed further actions. Half of the people with dementia indicated that they knew they had dementia, however, two of them said: ‘This is because I am old’. One family caregiver seemed to need emotional support and the village clinic physician was informed with the consent of the participant, and the caregiver was given the contact number of the China Association for Alzheimer’s Disease.

Data analysis

Nvivo 10 software was used for managing and assisting the data analysis. The process of analysis followed Smith’s six steps of IPA (Smith, 2009):

1. reading and rereading of each transcript allowed the researcher to actively engage with data analysis and to shift from generic explanations to the specifics of individual experiences;
2. examining the semantic content, language and context on an exploratory level with line-by-line coding;
3. listing all the key points and categorised them into initial themes;
4. analysing all the cases one by one;
5. following up with all the themes emerged;
6. identifying connections and patterns within and across the cases.

IPA aims to explore the participant’s experience and how the participant makes sense of that experience (Smith, 2009). As well as providing a description and interpretation of the individual experience, it involves the analyst’s belief and knowledge of the interpretation of the data. Therefore, during the data analysis, the researcher (XZ) reflected on her own pre-existing values, assumptions and beliefs that may affect the interpretation of data. A reflective diary was used to record the researcher’s experiences and responses to data collection and analysis. As the researcher had working experiences in both China and the UK, the different perceptions of health professionals in different social and cultural settings were an important focus of reflection. Translation took place after analysis in order to stay as close as possible to the cultural nuances of the interview data during analysis.

The findings

The findings include three themes: ‘Being filial is a cultural continuity and is my future investment’, which relates to traditional cultural value, customs and Confucius’ philosophy;
‘The changed perception and ways of being filial’ explains how a changing society affects the cultural value and the ways of being filial; ‘Filial responsibility is a sociocultural convention, but not my personal choice’ which reflects the impacts of the social and cultural expectations on personal life.

**Being filial is a cultural continuity and is my future investment**

This theme reflects the traditional concept of Confucius’ filial piety. During the interviews, the topic of ‘filial piety’ was mentioned without prompting by all of the participants in the study. For the participants, looking after parents is a child’s responsibility that is embedded in the traditional culture. For example, Ling, a family caregiver (FC) says:

*I will get older later, looking after my mum is not only my responsibility, but I am also a role model for my son. If I am not filial to my mum, my son might not be filial to me.* [FC5, Ling]

For Ling, looking after his mother is not only a task and an obligation, it is also a responsibility for him to carry on with the cultural continuity for the next generation and a potential investment for his own future. Caregiving responsibility has been interpreted as a cultural heritage and traditional value. Xue shared a similar view:

*The most important thing for me is the fact that I have played as a role model for my son, he will carry the culture of filial piety as he watches me do it.* [FC2, Xue]

When talking about whether there are effects on the family relationships as Yan takes care of her mother, she responds:

*Filial piety is the most important. Looking after parents is a priority for me, my child is also filial to his grandmother and he is a good kid. Parents are first, I’d rather sacrifice my job and…* [FC13, Yan]

In Yan’s opinion, being filial is not only a virtue, but is an indicator to judge a person’s character – describing her son as ‘a good kid’. From talking about herself to her son, the belief in filial has been treated as culture heritage in the whole family. Yan’s role of looking after her mother translates to the role as a carrier of the traditional culture value. For Yan, whatever is needed in order to complete this responsibility is worth doing. A strong feeling of willingness and pride that is related with cultural value can be identified here. Similarly, Guang says:

*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.* [FC1, Guang]

In this extract, Guang has raised a stronger feeling of willingness. The meaning of filial is not only a cultural belief and an important thing in her life, but it is inspiration and spiritual healing for her. For Mei, being filial is more like being a self-comfort – she says:

*It doesn’t affect my family relationship, because being filial is a priority in Chinese traditional culture… The only thing is that I had to sacrifice is many social activities and things which I am*
enjoying. I think that my life shouldn’t be like this. However, on the other hand, being filial is a self-confort for me as I am fulfilling my caring responsibility. [FC6, Mei]

Several meanings appear in the Mei’s quote. Firstly, it is a clear indicator of a sense of culture of continuity of filial piety by talking about the actions of the family. In addition, the participant’s self-sacrifice has emphasised the critical responsibility of taking care of her parents as a child. Thirdly, Mei refers to taking the caring responsibly as a ‘self-comfort’. She acknowledges that being filial is spiritually fulfilling and yet also a responsibility that cannot be avoided in Chinese culture.

The views about filial piety from the participants above revealed that being filial is not just about the action of looking after people with dementia, it is something very important that can be culturally and spiritually inherited. It is a moral and cultural duty, which increases the family caregivers’ willingness to look after their relative with dementia and enhances the relationship between people with dementia and their family as well the quality of care.

The changed perception and ways of being filial

In this theme, participants with dementia described how their children were being filial to them, which reflected the different perceptions of filial responsibility that they each hold. During the interviews, more than half of the participants with dementia held the view that being filial related to whether their children provide finance for them. For example, one people with dementia (PWD) says:

It is filial if they can provide the basic living material. Being filial can be in different ways. For me, they are filial as they provide food and drink to me. It is not filial if somebody wouldn’t provide the basic living material for their parents. [PWD7, Yin]

Even though Yin claims there are many ways of being filial, his experience of filial piety lies in his everyday life of what he needs for survival. Chuan said similar things:

I have one son, he is filial. He would send food and other stuff, whatever I need. I have no daughter. He buys clothes for me whenever he sees others wearing things that might suit me. [PWD5, Chuan]

In the above quotations, providing the physical materials is a foundational component of filial piety. This may be associated with the current social security system as many older people do not have a pension and so they are financially dependent on their children.

However, for Shao, being filial is more about having concern and respect towards parents. This may be because Shao and his wife are still able to work on the land and get income from it. Shao says:

What is filial piety? The first and most important thing is to listen to your parents and do whatever they say. Children must care about their parents and talk to them. [PWD10, Shao]

Shao, however, describes the meaning of filial piety as providing spiritual support rather than the material support such as food. This is consistent with one of the components of Confucius’s filial piety.
For Ye, the way of being filial is present in everyday life activities. Such as, doing house chores with children.

*Children are good to me. I have five children. They often help me with cooking, they like to listen to me.* [PWD6, Ye]

Cooking together does not mean just helping with a chore for Ye. The process of sharing the task with children is more important. For Ye, being filial is reflected in the actions between parents and children. Liang expresses the same perspective as Ye.

*Coming and visiting me, helping me to do some stuff. I don’t want them to spend money on me, just come and help with washing and tidying.* [PWD4, Liang]

In these two quotes, the meaning of being filial links to the family connection and being together that lies in daily life activities.

As a family caregiver, Xue thinks that there are many ways of being filial but, for her, physically looking after her father is ‘paying’ filial piety:

*I think if someone can (physically) look after their parents it would be Xiao filial piety. We can’t value Xiao by money, it isn’t Xiao if one only gives lots of money to parents, and we do need to consider the person’s income. It is better to look after parents, take care of them in daily life. Err… we must consider the situation of everybody. For my situation, I can look after my father which is Xiao.* [FC2, Xue]

In the quote above, Xue interprets the concept of filial piety in two different ways: a spiritual way and a realistic way. *We can’t value Xiao by money* reflects the spiritual world of being filial as a cultural value which is personally significant. Providing physical care is reflected in real life, in which physical materials and daily tasks are important too.

For Yin, filial piety seems to be a safety net and a backup resource which brought a sense of security for him:

*I am not afraid of the financial problem. I don’t need to worry about the difficulties, it is not my problem to borrow money, is it? I have children, the children will shoulder it up.* [PWD7, Yin]

The quote reflects Yin’s feelings of security as he knows he would get support from his children if necessary which helped him adapt to his new life quickly and easily. However, Yi has a different view of filial piety, saying:

*I cannot say that whether my children are being filial to me currently…but remember it, if parents are wealthy and useful, children would be filial; otherwise, if parents lose the ability to be useful, the children would be not being filial to the parents.* [PWD8, Yi]

Yi lives in a rural area and his family has a large debt. This situation has led him to have different experiences of filial responsibility. He seems afraid to be discarded by his children and has judged filial piety by the value of the parents to their children. Yi’s perception of filial responsibility may reflect the weakness of the older family support care system, as this family care model requires considerable emotional and financial burden on family members.
Once this burden exceeds their ability to cope, being filial may not happen and, the person may not be supported by family.

Some family caregiver participants described the sacrifice of their jobs, social activities or time to take care a person with dementia. In the following quote, Yan emphasised the cost of taking care of her mother and the sense of self-sacrifice, illustrating filial as both the fulfilment of her responsibility and her self-sacrifice:

In fact, I have given up a lot… I gave up marriage and gave up my job as well. [FC13, Yan]

Similarly, the sense of having no alternative option to taking care of her mother is evident in Mei’s contribution:

because being filial is a priority in Chinese traditional culture… The only thing is that I had to sacrifice many social activities and things which I am enjoying. I think that my life shouldn’t be like this. [FC 6, Mei]

A query about the relationship between the meaning of filial piety and caring responsibility appears in Mei’s description. It reflects doubt about the traditional family care model as Mei had to sacrifice her social activities and free time. In China, following the rapid social change and economic development, many adults cannot look after their older parents because they must invest their time in a fiercely competitive society to earn a living. This has challenged the traditional culture of filial piety and may suggest that an alternative model of care in China is required.

Across the interviews, being filial has been interpreted by the participants in different ways, and the meaning of filial piety seems to become more realistic but less spiritual. However, under the current health care and social welfare systems in China, family provided care is still expected by both family caregivers and people with dementia, such as, Yu says:

I never think about it [sending mother to care home], she is my mother, it is not reasonable to let a care home to take the caring responsibility, is it? [FC9, Yu]

Filial responsibility is a sociocultural convention, but is not my personal choice

This theme reflects the changing value of filial piety and the changing sense of filial responsibility evident in the participant’s interviews. Comparing the traditional norms of filial piety and social obligation with understandings from contemporary society suggests that the meaning of filial piety should be redefined. In the study, filial piety has been interpreted by some participants as a social obligation rather than a cultural and moral belief. For instance,

Err, this won’t take many years, I have to do it, what can I do? She is my mother, who would look after her if I don’t look after her? [FC9, Yu]

In this extract, the meaning of looking after his mother is not based on the traditional value of filial piety. It is a task that Yu has to do as a child. Therefore, the caring
responsibility here reflects an obligation or principle that requires him to fulfil caring responsibilities. Shou also raises the similar sense, saying:

*What my thoughts are on being filial? I have no choice, it just happened (his mother has Alzheimer's). I have no way. Sometimes I get stressed, because of the situation, I cannot do anything, so how can I not get stressed? [FC10, Shou]*

In this quote, the meaning of taking filial responsibility did not reach the standard of the traditional value of filial piety as Shou expressed a strong sense of unwillingness. Shou was stressed because of the daily tasks and no free time for himself. The caring responsibility that has been carried out is not because of his belief of being filial, it is forced and regulated by social and cultural convention. Mei says:

*The government focuses on developing the economy, therefore leaving the responsibility of education, medical, housing and older care for individuals and family. Thus, the generation of 50s, 60s and 70s have to sacrifice their personal interests to cooperate with the state on construction. [FC6, Mei]*

In this extract, the sense of caring responsibility has been interpreted as an obligation rather than a cultural belief. By not regarding filial responsibility as a cultural belief, Mei is able to consider that the government should take responsibility of older people with dementia. Ling manifests a similar perspective:

*Although children have responsibility to look after their parents, but I think that the state should give children some compensation for doing it. [FC5, Ling]*

In the quote, filial responsibility has been taken out as a component of filial piety – taking care of parents becomes a job that needs to be paid for. If we take this idea into account, the value of filial piety will reduce. Although filial piety has been reiterated by the current authority in China, the data from some participants suggest that the cultural value is reducing. Shou illustrates this:

*Nowadays, not many children are listening to their parents. It would be filial if children can often visit their parents, and sometimes buy stuff for their parents. Someone who is not filial to their parents when their parents are still alive, but after they die, they offer a big funeral. I don't approve it. [FC10, Shou]*

In the extract, Shou indicates that the value of filial piety has collapsed. The episodes of visiting parents, buying presents and holding a funeral reflects the way in which being filial has changed from the traditional way, instead reflecting a more material form rather than in a belief. Caring responsibility became an obligation which is bound by law or custom, rather than being filial. Mei says:

*Less people can be filial like in the past. There are not many people doing it, being filial has become a formalism. There are less and less people sacrificing themselves to do it. [FC6, Mei]*

With social conditions changing, acts and understandings of filial piety have also changed. Even though the current Chinese authority tries to promote the culture of filial
piety in order to enhance the children’s responsibility to their older parents (Chou, 2011), the value of being filial still declines in the younger generation. People have become more focused on personal rights and identity – as Mei said, there are fewer children who are willing to sacrifice their time to take responsibility of their parents.

In addition, as migration is occurring in China, many adults move away from their older parents which reduces the possibility of adult children providing physical care. For example,

*It is only me who looks after my father, I have one brother who lives in Shanghai, sometimes he will visit, and then he can give a little bit help, however, it is only occasionally.* [FC2, Xue]

**Discussion**

The findings highlight the complexity of the participants’ attitudes towards filial piety. In this section, we discuss whether filial piety is an obligation or affection from the participants’ point of view and whether filial piety is a coping strategy or burden for them.

**Filial piety as an obligation or affection**

The participants interpreted filial piety through two different perspectives: filial piety is very important and is culturally and spiritually inherited; and filial piety is a principle or obligation that is constrained by social convention and law. In a Chinese family, reciprocity is one of the important characteristics of supporting filial piety in family life (Hsu & Tseng, 1985; Leung et al., 2010). Another specific characteristic is hierarchy, in which family members have prescribed roles and authority is determined by age. This characteristic of hierarchy manifests in the form of authority in which children listen to and obey their parents. It is similar to Hsu and Tseng’s (1985) study as well as Sung’s theory of the Two Dimensions of Filial Piety (Sung, 1999). The first perspective is behaviourally oriented filial piety, which manifests in sacrifice, responsibility and repayment. It is focused on accomplishing duty and compliance rather than satisfaction. This dimension is more likely to be reflected in the children’s sense of obligation to their parents and filial piety is measured by the degree of repayment and sacrifice that the children give to their parents. The second perspective is emotionally oriented filial piety, which manifests in harmony, love, affection and respect, and in which filial piety is measured by the children’s emotional inputs. This relationship of tension between obligation and affection means children can be responsible for their parents but without being affectionate with respect and love or they view their caring role from the point of caring and love. Very often, individual carers experience both of these perspectives simultaneously.

The current study captures this conflict and the complex relationship within the participants which influences care decision making, quality of care services and coping. In relation to the decision to care, some family caregiver participants perceived an obligation about their caring decision which was guided by social and cultural requirement rather than personal choice and willingness. ‘I had to’ and ‘it is my responsibility’ were phrases that were used frequent when the participants recalled the reason why they commenced caring. These clearly show that the filial responsibility has been defined by cultural expectation rather than the family caregivers’ willingness. In this case, there is a diminished sense of love and caring
in everyday care activities, which may have a detrimental effect on the quality of care and on the caregiver. For these participants, the outcome of caregiving is only to complete the duty, or obligation, of care. In comparison, participants who made the decision to care because of love, affection and respect were more likely to willingly give emotional support to their family member. As a result, harmony and satisfaction more often occurs for the people with dementia and their family caregiver, potentially resulting in better care. These findings showed the importance of caring motivation and how it can influence the quality of care.

The value of filial obligation that affects caregiving experiences is controversial. Sayegh and Knight (2011) identified that cultural obligation increases the level of care burden and leads to caregiver depression. On the contrary, some studies argue that caregivers with a stronger sense of filial piety would be more likely to perceive a positive and beneficial care outcome (Kim & Lee, 2003; Tang, 2011). The finding has been further supported by Lai’s (2010) research that identified filial piety as a protective factor to reduce stress and caregiving burden. It concurs with the finding of the study reported here of the value of filial obligation in maintaining the family responsibility to the role and securing the function of the family care model. In these ways, obligation-oriented filial piety helps caring responsibility to be established in the first place while affection-oriented filial piety enhances the quality of care during caregiving activities. The current findings further highlight the interrelationship of these two dimensions of filial piety reflecting the complexity of the participants’ attitudes towards filial responsibly. The current study indicates that whilst looking after a person with dementia can be stressful and needs personal sacrifice, the role of obliged filial plays a ‘regulator’ to fulfill the older care services within an unstable health care system and social security network society in China. However, family caregivers are starting to challenge the traditional view of family caregiving responsibility and to question whether they need to put aside their own needs to meet family obligations and care for family members. The findings show that individual responses to caring responsibilities are varied and complex – filial piety becomes contradictory and there is ambivalence towards filial responsibility. The research has shown that filial piety retains its place in the family care model even though its value is diminished. It requires Chinese society to consider whether caring should be the responsibility of individuals or the government.

Filial piety as coping strategy or barriers

Sacrifice is an expectation in Confucianism’s filial piety, which may explain why family caregivers are willing to provide care to their parents, even in extremely difficult situations. ‘She is my mother’ or ‘he is my father’ was frequently given as the reason why family members commenced caring responsibilities. The participants clearly believed that there is a cultural and social requirement that they must accept the responsibility to care for a parent. Consequently, accepting this filial expectation becomes a coping strategy for the family caregivers. Linking this back to Yeh’s (2003) authoritarian filial piety in which children must listen and obey parents, the authoritarian filial has enforced parent–children responsibility and secured the family care provision under the specific cultural and social contexts. This coping strategy of providing care for a parent with dementia is natural in the context of maintaining family harmony and practicing filial sacrifice in Confucianism countries (Lai, 2010; Sung, 1995). The implication of this authority filial was also understood by people with dementia who felt secure and safe because they expected their children to be a
supportive resource for their care. They regarded this cultural value or belief as a ‘hope’ of the utmost importance in coping with their ‘altered’ life. For example, regarding hospital expenditure, one participant with dementia said: ‘I don’t need to worry about debt, it is my children’s responsibility’. Thus the values of obliged filial piety support the informal care of older people. This new finding from the current study gives people with dementia a sense of ‘security’ because they know that their family would care for them. This new knowledge of the coping strategy for people with dementia can add to the existing literature about the effects of filial piety on the lived experience of people with dementia.

Reciprocal filial piety played a key role in the affection-focused coping strategies in the current study. Some participants thought that reciprocal filial piety contributes to continuing with a cultural belief by being filial to their parents. While others take the belief of filial piety as a cycle and believe that their children would be filial to them if they do so. This belief leads them to more easily accept their caring roles and adjust to daily caring duties. As caring for people with dementia can be a distressing time for caregivers, they must adjust to their caring roles and new life, and this close relationship is key for family caregivers. Indeed, this is one of the most commonly described coping strategies in early-stage Alzheimer’s disease (Clare, 2002; Clare et al., 2003; Pearce et al., 2002). In this study, people with dementia discussed the support they received from their children or other family members, which allowed them to cope with an ‘altered’ life. These accounts from the participants are significant for explaining the meaning and the concept of filial piety.

In the current study, filial piety was one of the coping strategies used by over half of the participants who are family caregivers and this has been found in other studies (Knight & Sayegh, 2010; Siu et al., 2001). The sociocultural stress and coping model proposed by Aranda and Knight (1997) suggested that the stress and burden of caregiving were influenced by the caregiver’s cognitive appraisals, which influenced physical and emotional health outcomes. In the current study, despite participants experiencing difficulties with adjusting to their caring roles, they still used the words, ‘I try my best’ to maintain their caring role because ‘filial is a priority’, ‘she is my mother’ and ‘he is my father’ to encourage themselves to cope with the new roles. In this case, the belief of filial piety is inspiring and motivating for the participants. In one previous study, Lai (2010) noted ‘filial piety as a protective function to reduce the negative effects of stressors and to enhance the positive effect of appraisal factors on caregiving burden’ (p. 200). Consistent with Lai’s finding, filial piety was an emotion-focused strategy for most of the caregiving participants – one participant, for example, described being filial to her mother as a self-comforter. For most of the participants with dementia, filial piety was the main coping resource, which was represented in either material or emotional support from their family. It is clear from these accounts of both participants with dementia and their family carers that filial piety plays a significant role in coping with an ‘altered’ life. Some of them view it as authoritarian whereas others draw more on reciprocal aspects.

The current study shows that the impact of filial piety is a very strong influence in supporting dementia care services. It is presented in two ways: filial obligation helps to maintain the function of family care services, which seems the only feasible care model under the current health care system in China; the belief of filial piety can be developed as one of coping strategies in dementia care service. Although its value is still in place, many factors influence its functions and it seems to have been negatively affected by the ongoing sociocultural and economic change in China, which highlights the need for social and political action.
Limitations of the study

There are a number of limitations of this study. The method of data collection relies heavily on the participants' ability to communicate and talk about their living experience. Thus, it would be difficult to use this approach to access to people who have communication problems or are in a severe stage of dementia. The sample in this study was recruited from hospital and health professionals and although it contributes to the homogeneous nature of a sample advocated in IPA, this may have some influence on the participants as the powerful position of health professionals may make it difficult for patients to refusing a doctor's request to take part in the research. This also necessarily excludes many people with dementia who do not use or cannot afford hospital services. It is possible that this may have distorted the findings as those recruited may not represent the wider body of people living with dementia. The researcher (XZ) had an established understanding of embodied interrelationship in Chinese families as well as an understanding of the Western emphasis on an individual's independence which influence and sensitize key issues in analysis. The research was conducted with a small group of the population and in a specific geographical area, and cannot, therefore, claim to necessarily reflect the situation in other regions where the economic development is different.

Conclusion

There are few research studies on the subjective views of people with dementia and family caregivers in China, and this study describes the particular meanings and influences of filial piety for people with dementia and their family caregivers in the development of an alternative care model for older people in China. The contribution that the different perspectives of filial piety have in influencing different experiences of caregiving and outcomes leads to a need to reconsider the concept of filial piety and its value in the family care model. We should not only consider discussions of care in informal care services found in Western studies but also aspects of obligation in the parent-child relationship and its value in practice in Eastern cultures, and these merit further study. This study highlights the importance of cultural values in family care decision making and in shaping filial responsibilities. It indicates that filial obligation can be maintained through social support, even though the nature of filial piety has been changed by social transitions. It suggests that while there may be continuing support for reciprocal filial piety, a family care model complemented by a stronger government welfare system is needed to support older people and their families in modern Chinese society.

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Xuabin Zhang, MPH, RN has a background in adult nursing in China and care of older people with dementia in England. She started her masters in public health in University of Edinburgh in 2013 and continuing with her PhD in nursing studies. She is in her third year of her PhD and her research interests are care for older people and improving life for people with dementia.

Charlotte L. Clarke, DSoCSe, PhD, MSc, PGCE, BA, RN is a professor and head of the School of Health in Social Science at the University of Edinburgh.

Sarah J. Rhynas, PhD, MSc, PGCAP, FHEA, RN is a teaching fellow in nursing studies, School of Health in Social Science at the University of Edinburgh.