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**Intersections between culture, sociodemographic change and
caring: a qualitative study of current and prospective family
caregivers in mainland China.**

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Publications generated from this PhD study

Below is the list of papers published in peer reviewed journals generated from this thesis and findings disseminated in conferences:

- 1) Bífárin, O., Quinn, C., Breen, L., Wu, C., Ke, M., Yu, L. and Oyeboode, J., 2021. Stressors and coping mechanisms of family caregivers of older relatives living with long-term conditions in mainland China: a scoping review of the evidence. *Ageing and Society*, pp.1-38.

Paper under review and incorporated into this thesis:

- 1) Intersections between the culture of Xiao (孝) and caring for older relatives in China: Perspectives of UK-based Chinese students on future care for their parents. *Ageing and Society* (in press)
- 2) Filial discrepancy: the exploration of meaning, motivation, and preparedness to care amongst the One-Child Policy (OCP) generation in China. Submitted to *International Journal of Geriatric Psychiatry*

Finally, my collaborative endeavour throughout the course of this PhD further produced one publication in a Chinese peer reviewed journal:

- 3) Bifarin O., Oliver E., Oyeboode J., & Liu Y. (2020). Supporting Family Caregivers to Care for Parents Living with Dementia: the Experience shared from United Kingdom on specialized dementia care. *Chinese Nursing Management*, 20(9): 1285-1291.

Conferences

- 1) Presented findings in Chapter 3 at the School of Nursing and Healthcare Leadership R&KT event – University of Bradford
- 2) Presented findings in Chapter 2 at the British Society of Gerontology, 2021 virtual conference – University of Lancaster
- 3) Presented findings from offspring affected by One Child Policy (OCP) at the Alzheimer's Disease international conference, 2022 – London

Abstract

Oladayo Olufemi BIFARIN

Intersections between culture, sociodemographic change and caring: a qualitative study of current and prospective family caregivers in mainland China

Key terms: Filial Piety - Xiao, Person-centred care, Self-construal, Caregiver identity, Caregiving process, Family caregivers, Value-based service design, Long-term care, Chinese, Older people

Aim: As the ageing population in China increases, support required from family caregivers for older relatives living with long-term health conditions also increases. **This being so**, this thesis explored the experiences and perceptions of current and prospective family caregivers, under the culture of *Xiao* (孝; filial piety).

Design and Methods: **Phase 1** was conducted with 19 Chinese students using 3 focus groups to gain greater familiarity with the culture and inform the main study (**Phase 2**). Adopting a social constructivist philosophical position, data for **Phase 2** were obtained from three **generational** sub-samples: only-children affected by **the One-Child Policy** (OCP), parents affected by OCP, and family caregivers in the workforce, **totaling 23 participants through virtual in-depth interviews with participants in mainland China**. Interviews were translated, transcribed, and analysed using reflective thematic analysis.

Findings and Conclusion: **Phase 1 confirmed the centrality of the concept of Xiao to attitudes and beliefs around future caregiving for parents**. **Phase 2 findings'** overarching theme was 'Competing pressures', **which comprised of three inextricably linked themes:** (i) Caregiving beliefs, (ii) Contextual factors,

and (iii) Caregiving conditions. Participants expressed meaningful desires to fulfil obligations, reflecting value-based convictions, stemming from their socio-cultural environment. Stressors experienced reveals structural and personal barriers to seeking support. Ultimately, extensive demands and limited coping strategies could diminish meaning in caregiving. This thesis makes a novel contribution on perceptions and experiences of family caregivers of older relatives within China as a collectivist society. Findings have implications for research, policy, and practice, highlighting the need for culturally attuned services to build resilience.

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I am full of thanks to the individuals and research participants who generously shared their time and experiences with me, as well as the nursing professionals who engaged in critical discourses around mental health service delivery. Without funding from Research England- Quality Related Global Challenge Research Fund (QR GCRF) and the Centre for Applied Dementia Studies (University of Bradford) this study would not have come to fruition and for this, I am grateful.

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Dedication

This thesis is dedicated to the memory of my late grandmother Chief (Mrs) Mary Babatola Bifarin (28th of January 1927 -15th of March 2010) and to my auntie, Dr Egun Ajibola for mothering me through difficult phases.

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Chapter 1: Introduction

Through this doctoral study I aim to explore and understand experiences, perceptions, undertakings, and challenges of family caregivers of older relatives living with long-term health conditions in mainland China. Humans need support across their lifespan and the nature of assistance should be relevant to individual needs. In the Chinese context, under the culture of *Xiao* (孝; filial piety), individuals expect family caregivers to play a central role in supporting and caring for older relatives. However, there are concerns about the sustainability of traditional family-based caregiving due to expected increases in the ageing population (Aldridge 2018; Stephan et al. 2018). Given that caregivers' perceptions of preparedness can influence negative and positive aspects of caregiving (Parveen et al. 2018), the family caregiver role significantly impacts individual experiences and the meanings derived. I aimed to capture the lived or witnessed experiences of family caregivers affected by the One-Child Policy (OCP), whereby couples in China were restricted to having one child, to understand the meaning and motivation behind caregiving responsibility. Therefore, I sought to engage a sample of young Chinese people, parents, and caregivers in employment, some of whom are playing a supporting role to family members with caregiving responsibilities, attending particularly to the influence of the socio-cultural environment.

This chapter introduces my thesis background. I will initially share my personal motivations for carrying out my research in this field. Following this, I will outline key concepts relevant to this doctoral study on the perceptions and experiences of caregivers of older relatives in mainland China and lastly, I will provide an overview of the thesis structure and a summary of subsequent chapters.

1.1 Personal context

Prior to relocating to the United Kingdom (UK), where I have lived for 12 years, I lived in Nigeria for 22 years. My grandmother required full-time care due to long-term health conditions like diabetes, hypertension and glaucoma, and my parents were in full-time employment. As the firstborn of four boys, I was given the most domestic responsibilities and whether consciously or unconsciously, through providing that familial support, I got accustomed to assisting my parents with their commitments regularly, which made a significant impact on me growing up. The experiences of caring for my grandmother are pivotal to who I am presently and sharing her invaluable experiences with me created a bond that we might not have had without her health challenges. Providing care from my teenage years to early adulthood, I personally witnessed the ripple effects of the resultant strain on my extended family's circumstances and dynamics. The positive experiences I had whilst caring for my grandmother were challenged by the imbalance created in my personal life. My academic performance suffered, and I was worn out by the daily activities. This challenging period was further complicated by the lack of resources for support and my inability to articulate my needs and experience within my cultural environment. Ultimately, the examples I had during childhood were individuals commonly and routinely discussing the need to support older relatives, however, with no solution in sight.

My move to the UK brought contrasting experiences, particularly in terms of a society driven by individualistic values (Triandis 2018). Caring for older relatives in Nigeria and the UK living with long-term health conditions exposed me to varied effects of strain resulting from distinct caregiving contexts on family relationships. My witnessed and experienced realities, while combining my caregiving

responsibilities with studying and being in employment, motivated me to change disciplines and complete my mental health nursing program to a Masters' degree level.

I have had over a decade's worth of experience working within the healthcare sector in England as a nursing assistant, mental health nurse and now a quality improvement partner within an NHS Foundation Trust. Given my personal experiences, when I saw an opportunity to pursue a PhD in social gerontology funded by Research England- Quality Related Global Challenge Research Fund (QR GCRF), I was keen to apply, and this took me into my PhD journey. Ultimately, these experiences drive my career as a clinical academic with a keen interest in quality improvement in healthcare and show the diverse experiences that informed the lens I bring to considering my research in the Chinese context.

1.2 Self-Construal: individualist and collectivist societies

Societies like Nigeria and China have collectivist value systems, where interdependent self-construal tends to prevail, and how we perceive or are perceived is influenced by the values of the society we live in. This is often contrasted with individualistic societies (Triandis 2018). The characterisation of individualism and collectivism can be overly simplistic; however, some distinctions can be drawn. In an individualistic society, there is an expectation that an independent self-construal should be accepted or tolerated; whereas, in a collectivist society where one's sense of self is contingent on others' perspective, interdependent self-construal is dominant and self-constructs tend to merge in social relationships, with different patterns in a different social milieu (Kunda 1999). Although the former tends to uphold individual rights, freedom and allow self-expression, which inform policies and practices within a society,

adverse social and psychological implications can result from individualism. For instance, the value placed on respecting individual privacy could impede society's capacity for developing nourishing social networks. Similarly, individuals might find self-regulation challenging, impeding the process of seeking support from others. The focus on allowing everyone to choose their own way of life could mean that responding to circumstances such as having a relative with support needs can leave people very uncertain about how to respond. Alternatively, there are benefits to a collectivist society that celebrates group achievements and holds members of society accountable to a mutually beneficial behavioural ethos and principles. However, despite the positives of a collectivist society, fulfilling culturally intrinsic expectations and obligations can be detrimental to the well-being of individuals affected.

This broad classification could suggest that individuals in individualistic societies have a stronger sense of self, as they likely have an internal locus of control compared to individuals with collectivistic values, and that individuals in collectivist societies have a weaker sense of self due to their interdependency with a preference for group achievement ahead of individual ones (Xiao et al. 2014). My experience and observations within individualist and collectivist societies lead to the idea that individual pursuits are generally discouraged within a collectivist society, where individual achievements are often underappreciated, unless they benefit the group. Arguably, individual freedoms in individualistic societies create inequalities that are detrimental to other members of the society or beyond. Particularly, these cultural factors may affect the rate of socioeconomic development of countries (Wu and Tam 2015) because human

capital is dependent on creating healthy, fair, and equitable practices. From my perspective, culture plays an integral role in the context of health and social care provision, as it influences how individuals and societies formulate possible and sustainable interventions.

1.3 Perception of ageing

Discourse about older people tends to focus on 'morbidity and mortality' narratives, although there are counter-narratives. For example, the role of agency in later life has received attention, with Hyde and Higgs (2017) positing a new socio-cultural 'third age', in which older people are controlling their narratives through consumerism, tourism and leisure. The authors suggest that having a sense of control plays a crucial role in enabling and empowering individuals, creating new images and perceptions of later life, hence, 'ageing is inevitable, but how we age is not' (Centre for Ageing Better 2019: 4). Recent studies show that those living with long-term conditions like dementia and cancer are using technological platforms, i.e., social media, to communicate their needs, receive support and commune, with emphasis placed on their lived experiences. Through these activities, they are raising awareness and challenging stereotypes (Talbot et al. 2018; Taylor and Pagliari 2018; Brunner et al. 2019; Talbot et al. 2020). Arguably, the healthy, active ageing and advocacy characteristics of the 'third age', alongside the energetic, proficient technology using and industrious younger generations, engender a social imaginary 'fourth age', characterised by poor health and heavy reliance on others - a "black hole" of ageing (Higgs and Gilleard 2015).

In China, there is an expected increase in the numbers of people aged 60 and above from 230 million to 490 million between 2019 and 2050. Similarly, for those

aged 80 years and above, the number is expected to rise from about 25 million this year to 121 million by 2050 (United Nations 2019). The relationship between ageing and long-term conditions is well established in contemporary literature. For instance, those who live into old age may experience a range of chronic health conditions, including hypertension, stroke, ischaemic heart disease, chronic obstructive pulmonary disease, lung cancer and Alzheimer's disease (Jia et al. 2019). In developing countries with collectivist societies, caring for older people is not prioritised by formal services and the traditional model of family care for older relatives is expected to take precedence. Hence, caregivers are unsupported, due to the lack of an inclusive healthcare system (Chen et al. 2010; Wu et al. 2016; Wang et al. 2018), which can add to the pressures experienced by family caregivers and lead to stress (Jenkins and Macken 2014). Thus, regarding ageing and the continual evolution of the social environment over time, the pertinent question to ask is 'how stable are the other coordinates such as health or familial relations?' (Hyde and Higgs 2017: 104).

1.4 Aged care in China: 'a collectivist culture.'

In this section, I begin by addressing how individuals living in mainland China rely on principles of a collectivist culture, in this instance, filial piety - **Xiao** (孝). The concept of Xiao is one of the main Chinese cultural tenets used to guide individual behaviours and I will explore how this central cultural influence impacts identity and social roles. Following this, I will examine the impacts of contemporary societal changes on patterns of care in China and the insecurity these cause regarding caring for older people. Finally, I will substantiate how the relationship between the importance of Xiao and **the** resulting tensions created by

incongruence between traditional expectations and realities of modern society, **highlights** the **significance of** preparedness of family caregivers.

Culture is “a learned, patterned behavioural response acquired over time that includes implicit versus explicit beliefs, attitudes, values, customs, norms, taboos, arts, and lifeways accepted by a community of individuals” (Purnell 2011: 528). As such, Xiao et al. (2013) asserted that the collectivist value system in the Chinese cultural context underpins the prominence placed on the group rather than individual gratification. Furthermore, the tradition of Xiao strongly influences Chinese society, through the obligation of offspring to meet their parents’ needs (Smith and Hung 2012). This obligation is a shared virtue that promotes a great sense of identity and family cohesiveness (Park and Chesla 2007). It plays a significant role in shaping parent-child relationships and informs the pattern of older people’s care (Simon et al. 2014). Therefore, China’s situation is unique, given the cultural influences on the caregiving process. As such, society influences individuals within the community to meet others’ needs (family and friends) ahead of their own, compared to countries where individuals are socialised to have the welfare state cater for those who need support.

Within the traditional patrilineal society of China, sons are expected to live with parents and provide them with financial support. These traditional expectations are still present in modern China amongst young men (Warmenhoven et al. 2018). Alongside obligations for sons, there remains an expectation that unmarried daughters and daughters-in-law should provide hands-on care with spouses becoming primary caregivers if there is no offspring (Tang 2020). Family members are, therefore, at the heart of care provision. In addition to the obligations of Xiao, China currently has a lack of formal services for older people

(Yang et al. 2021a) and is facing a major socio-demographic transition due to the OCP. Therefore, understanding care expectations around fulfilling Xiao is highly pertinent, especially with the increase in the numbers of women in employment (Tang 2020), rapid urbanisation (Li et al. 2012; Marvalová 2018), the consequences of the OCP and the ageing population.

Wang et al. (2021) found that women in employment provided a low level of informal care, compared to women **who are** not in employment. Socio-demographic and rapid economic transition implies that offspring are less likely to live near older relatives (Yang et al. 2021b), and those living farther from parents are likely to provide financial support in lieu of direct contact (Bao 2021). Given the extent of economic growth in China for almost four decades and the associated rapid urbanisation, family members have to leave older relatives behind, yet still have to find a way to support them with care needs, in a context of limited support from health care professionals, society and lack of social services (Xiuxiang et al. 2020). Therefore, there will be a differential distribution of support made available, dependent on geographical location and gender of offspring, which has implications for the psychological well-being of parents and offspring. There is a filial expectation for sons to provide financial support (Bao 2021) and for daughters to maintain close physical or virtual contact with parents. Using virtual contact, offspring can mitigate against challenges ascribed to geographical distance (Bao 2021). However, offspring might feel immensely pressured, particularly when living in other countries or urban cities. They might not be in the position to obey, show respect or provide emotional and financial support accordingly. Culture characterised by strong family bonds with legal implications (Serrano et al. 2017) emphasises families' responsibility to care for

their older relatives. Therefore, in the absence of adequate support for family caregivers of older relatives, various stressors associated with trying to provide care from a distance occur (Shen et al. 2019a), resulting in extensive demands being placed on primary healthcare workers (Wang et al. 2018). Perhaps the underdevelopment of statutory services can help explain why majority of care of older people continue to take place at home (Wu and Lam 2016).

1.5 Family caregiving

In the section above, I highlighted how collective reliance on Xiao influences social roles and potentially could lead to tensions. I will focus this section on the sociocultural dynamics around caregiving expectations across generations and the desire to uphold tradition alongside the implications of societal perception on patterns of care. Lastly, I will explore the potential barriers or consequences concerning relationships as they pertain to motivations and willingness of family caregivers and the older people being supported.

1.5.1 Sociocultural dynamics across generations

This doctoral study focused on offspring supporting older relatives who are recipients of care, with emphasis placed on the Baby boomers, ‘Sandwich Generation (Generation X)’, Millennials (Generation Y), and Generation Z (Gen Z) (See Table 1.1 Generational Cohorts and Characterisations).

Table 1.1 Generational Cohorts and Characterisations

Generation Name	Characterisation	Birth start	Birth End	Youngest age now	Oldest age now
Baby Boomer	Post WWII optimism, The cold war	1946	1964	58	76
Sandwich Generation (Gen X)	End of cold war Rise of computing Lost between two huge generations	1965	1980	42	57
Millennial (Gen Y)	Great recession Explosion of internet 9/11	1981	1996	26	41
Generation Z (Gen Z)	Smart phones, social media, Avoiding financial struggles of Gen X and Y	1997	2000+	12	25

Focusing on these generations in this study is primarily because of the implications of family planning policy in China over the years. This policy has significantly impacted the number of younger people available to meet the demands of the ageing population in the future (Zhang 2017). In a European context, cross-generational (G1- grandparents, G2- parent G3- college students) differences in parental practices have been found with second generation and third generation showing more affection and less indifference when compared to first generation, and also a declining parental strictness from G3 to G1 (Garcia et

al. 2020). Arguably, the baby boomer generation, born 1946-1964, and Generation X (Gen X) struggled with different pressures. Older caregivers belonging to baby boomers were not as pressured to work compared to Gen X, who were more expected to manage paid employment and caring for their immediate family in addition to their family of origin. Further, as Gen X's societal climate was characterised by the rise of computing, compared to the boomer generation, a heightened focus was on the expectation of active engagement with their children whilst continuing the tradition of caring for their parents (Castrén et al. 2021). The proliferation of high parental expectations in raising their children could arguably prove even more burdensome for this group of caregivers in their midlife. For instance, millennials are considered the most diverse and global generation due to growing up with the internet (Bannon et al. 2011; Harmel and Yeh 2019), which has increased awareness of and access to issues globally. Hence, the increased duty of care required from Generation X by the boomer generation coincides with millennials' increased advocacy for sustainable care for older relatives (Roots 2021). Consequently, caregivers could experience caring for an older family member as a career within the context of ageing and socio-demographic transitions, as the intricacies of the role required caregivers to continually adapt to changing sociocultural dynamics (Pearlin and Aneshensel 1994).

1.5.2 Wider societal perception of caregiving patterns

Culture significantly influences the care of older people in a multi-dimensional way. Chinese older people tend to attach a sense of psychological safety to being cared for by offspring (Wang et al. 2009). Consequently, society views not subscribing to the values of Xiao as moral decadency (Wu et al. 2018; Yang and

Wen 2021). In addition, perceived stigma for older people and their families is strongly associated with moving into nursing homes (Luo et al. 2018), so this makes continuing care in the community the preferred option. In a study conducted with older people in Zhejiang Province in China (Ma et al. 2019), the authors advocated a multi-layered old age care system, rather than one that depends on family care alone, because the younger generation is under much pressure and cannot stop working because they are breadwinners for their respective families. Although traditional domiciliary care is considered the most viable option by caregivers and older relatives (Tang 2020), the lack of adequate social security in China might predispose both older people and caregivers to significant risks that come with a lack of financial autonomy (Johansson and Cheng 2016). These risks could become stressors in urban centres where the need for intergenerational support could aggravate strains in family relationships (Yang et al. 2021b).

Family members experience various challenges in their caregiving roles as people 'who provide unpaid, on-going assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with chronic illness or disability' (Roth et al. 2015: 310). In the UK, there is legislation such as the Care Act 2014 (England) and the Carers Act 2016 (Scotland) which is essential to recognising caregivers' needs. In contrast, there is no equivalent legislation in place in China, where caregivers are obliged to meet older relatives' needs regardless of personal circumstances. Not acknowledging the daily responsibilities of family caregivers in legislation carries adverse implications for family caregivers. For instance, relatives have to reach a caregiving threshold of

72 hours for women and 112 hours for men, weekly, before employers or businesses consider adjusting their working hours (Chai et al. 2021).

1.5.3 Motivation and willingness

For family caregivers, it has been found in the UK that lack of adequate support can result in reduced motivation to continue providing care (Quinn et al. 2015; Al-Janabi et al. 2018). Considering caregivers' personal or professional lives, lack of support in meeting older relatives' needs could be overwhelming, resulting in viewing filial responsibilities as chores they are obligated to perform. This lack of support or awareness of their support needs, and willingness to care can result in self-neglect (Oliveira et al. 2019) and poor health outcomes (Sherman 2019). In China's collectivist culture, individuals likely have external control of self and tend to oblige roles and responsibilities while figuring out others' perceptions, to meet their expectations better (Kunda 1999). If they are unable to fulfil the filial expectations instilled in offspring from childhood (Ho et al. 2012), this could predispose individuals to guilt and shame, leading to more critical thoughts of themselves. In some cases, family relationships can become strained due to incongruences in care preferences (Kristanti et al. 2018). For instance, lacking alternatives, an offspring residing far away from their ageing parents could employ a paid carer, yet feel embittered about being absent in their time of need. Conversely, despite tolerating the circumstances, their older relative could harbour resentments about being cared for formally. In this example, this incongruence can result in stress and strain i.e. caregiving burden (Shen et al. 2019b). Within the principles of Xiao, not meeting the responsibility that caregivers believe they owe society can be associated with family disputes over the years (Chou 2011). Therefore, for family caregivers seeking respite, and to

reduce tensions, it is understandable that there is recent clamour for developing long-term care, integrated care, and other stress alleviating interventions, essentially to support those caring for older relatives (Shen et al. 2019b).

Arguably, negative connotations can be ascribed to the caregiving role, but this narrative is simplistic as caregivers can have altruistic motivations behind their actions, their sense of duty notwithstanding (Greenwood and Smith 2019). As such, a detailed understanding of the concepts of caregiving burden and positive aspects of care is crucial for support purposes (Shea 2020). There are indeed positive aspects to caregiving, which are associated with better outcomes (Quinn and Toms 2018), however, many caregivers of older relatives feel obligated to fulfil the role, irrespective of their own choice (Parveen et al. 2019). In a Norwegian study, Carlsen and Lundberg (2018) explored positive and negative aspects of caregiving concerning caregivers' motivations. They found that family caregivers perceived their role as dutiful and meaningful because they bridged significant gaps between statutory services and older relatives' needs. Findings in the Carlsen and Lundberg study suggested that gaps in formal services may be the compelling factor that led to caregivers' engagement in care. In their study, due to the shortcomings of professional services, the choice family caregivers had made improved the health and well-being of their relatives. However, the efforts of these caregivers often went unrecognised by professionals, and it was particularly interesting to note that despite the caregivers' choice to participate in caregiving actively, their choice was still a source of stress which left them in the doldrums.

A systematic review that investigated the implications of motivations and meanings on the well-being of caregivers of people living with dementia found that cultural values and the relationship of caregivers to care recipients impacted caregivers' inclination to provide care (Quinn et al. 2010). Similarly, research showed the influence of relationships on motivation to provide care in a study that explored the lived experiences of family caregivers of people living with dementia and cancer (Kristanti et al. 2018). Study participants were commonly motivated to provide care by the high value placed on their relationships. Some caregivers exceeded the expectations of their relatives, especially when healthcare services were not readily available. They reported a strong sense of accomplishment as their actions brought smiles to the faces of care recipients. Some caregivers believed their contributions would guarantee a spiritual reward, which exemplifies the relevance of meanings to family caregivers while indicating the need to pay close attention to the construct of care obligation, as some caregivers might not complain even if they are miserable.

Caregiving burden amongst caregivers of older people can be linked to ethnicity (Aman et al. 2019). Aman and colleagues found caregiving burdensome for caregivers who were Chinese and Indian, compared to Malay caregivers. Amongst the two highly burdened groups of caregivers in this study, Chinese were more impacted by caregiving burden. This may be due to the complexities associated with Xiao, which values making sacrifices and providing care to parents even in challenging circumstances (Zhang et al. 2018). In Zhang and colleagues' study, Xiao was a coping style, as filial obligation was a priority for caregivers. The value attached to meaning or motivation when choosing to provide care for older relatives, makes it crucial to introduce two conceptual

models of stress and coping that I used as a lens to explore the phenomenon of interest of this doctoral study.

1.6 Models for understanding stress and coping

As established in the previous section, caregiving experiences differ according to the meanings associated with the role. Attention has been drawn to the importance of recognising the dynamic interaction between individuals and their environment for over three decades (Lazarus and Folkman 1984; Moos 2002). In the paradigm of stress and coping, individual or collective values, norms and beliefs are commonly used to capture the influence of cultural systems due to their pervasive nature (Chun et al. 2006). Therefore cultural values can influence the appraisal of stressful events because individuals guided by collectivist values are inclined to meet others' expectations, especially family members and friends, due to the need to belong and for protective reasons (Rothbaum et al. 1982; Weisz et al. 1984). Within the context of this doctoral study, this generalisation could be problematic when bearing in mind the attributes of interdependent self-construal as mentioned in section 1.2. For example, it could minimise the transitional nature of caring for older relatives and the individual coping efforts of caregivers or lead to the assumption that families within a collectivist socio-cultural environment are typically resourceful because the whole family is obligated to contribute to caregiving responsibilities. Irrespective of ones' cultural values and circumstance, self-construal is pertinent to coping efforts that individuals adopt during stressful periods (Chun et al. 2006).

Parveen et al. (2014) suggested that familism (i.e. strong identification and attachment of individuals with their nuclear or extended families, and strong feelings of loyalty, reciprocity and solidarity among members of the same family

(Sabogal et al. 1987)), might have a direct impact on caregiver health outcomes rather than being only a moderating factor. In a longitudinal study, Parveen and Morrison (2012) found that familism was a predictive factor of short-term gains in caregiving but with increased demands placed on caregivers, familism was not a predictive factor for gains over a more extended period. These findings suggest that people give meanings to experiences that transpire within individual contexts and those meanings change over time. As such, it is inappropriate to assume that the caregiving arrangements between older people and their offspring, within Asian cultures (Beard and Kunharibowo 2001; Zimmer and Kim 2001) for example, are a reflection of social competence and a strong support network.

1.7 Key conceptual frameworks

Stress and coping as a function of the social environment is deeply embedded in an individual's cultural environment (Aldwin 2007). Aldwin's model (see Figure 1.1: Stress, Coping and Adaptation Model below) emphasised that due to variations in individuals' appraisal of stress, efforts directed at coping, social support, cultural expectations, resources, and the reaction of others in a social context, individuals cope differently. In this premise, individual appraisal of stressors and available resources (situational demands) are influenced by experiences of cultural expectations and resources. Concurrently, in the model, individual values and beliefs are directly impacted by the broader cultural value and belief system, which shapes the individual and the reaction of others, thereby influencing individual appraisal of stress. Consequently, social support and coping efforts (coping responses) serve as a mediator, which impacts individuals and their environments, resulting in cultural, social, situational, and psychological outcomes.

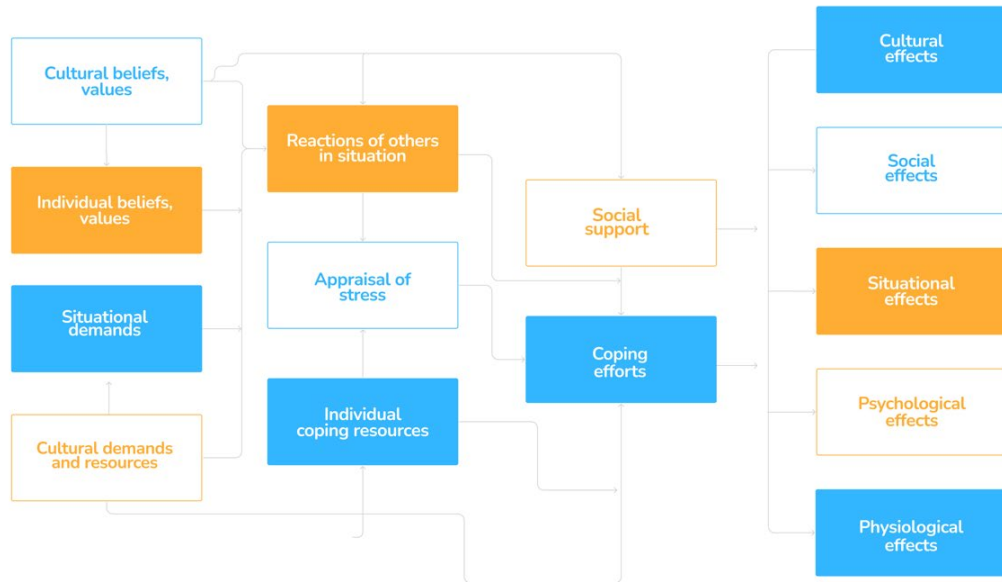


Figure 1.1: Stress, Coping and Adaptation Model

Source: Aldwin (2007)

Cultural values such as Xiao can act in the dual capacity of a protective as well as a risk factor. As such, Knight and Sayegh (2010) asserted that cultural values influence mediators such as social support and coping mechanisms but not necessarily the appraisal of burden, as research has found connections between stressors of caregiving (such as behavioural problems), burden and health outcomes consistently across cultural groups (see Figure 1.2: The Updated Socio-cultural Stress and Coping Model below).

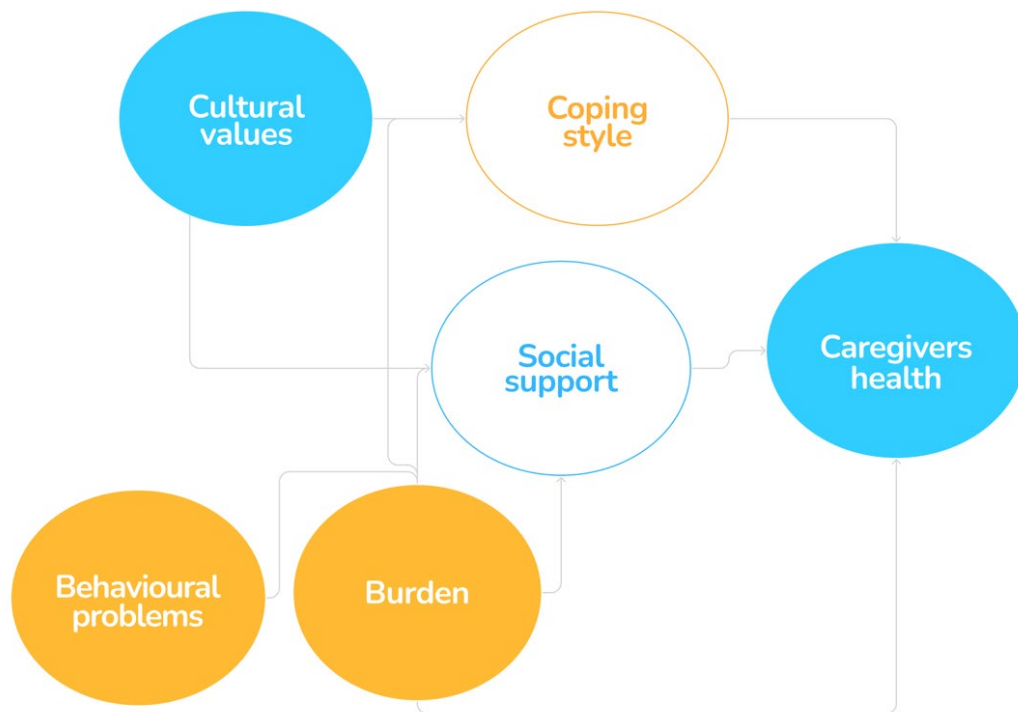


Figure 1.2: The Updated Socio-cultural Stress and Coping Model

Source: Knight and Sayegh (2010)

According to the Knight and Sayegh model, incongruity between an individual and their relationship with their socio-cultural environment can be stressful. Also, coping efforts will vary, considering the inevitable nature of individual involvement in a plethora of distinctive social settings. Aranda and Knight (1997) provided substantial evidence showing that ethnicity affects many aspects of caregiving, such as caregivers' appraisal of stressful events, the use of specific coping strategies and the nature of the social support systems used. Knight and Sayegh (2010) advanced this general approach and reinforced the notion of taking a step back from generalising the implications of ethnicity on stress appraisals and coping responses, under the umbrella of individualism and collectivism. Using studies conducted with Koreans and Korean American participants, it was evident that coping efforts may differ from one cultural group to another, stemming from

varied approaches to appraising stressors. Knight and Sayegh (2010) propounded that more attention should be paid to indigenous cultural values because this may yield a better contextualised understanding of individual coping styles and social support.

Both models (Aldwin 2007; Knight and Sayegh 2010) are complimentary, emphasising individual appraisal of stress and coping efforts, acknowledging that cultural groups are not homogenous, and suggesting that attitudes, beliefs, and cultural norms greatly influence how people adapt and learn. The models also indicate that individuals within apparently similar socio-cultural environments might respond differently to caregiving responsibilities. Therefore, to apply this knowledge within the context of this doctoral study, it is crucial to contextualise discourses since people ascribe meanings to cultural values on a personal basis. It is usual now for information to travel from one continent (e.g., Europe) to another (e.g., Asia) due to globalisation, via products of science and technology. For example, caregivers with online access might read information about caring for older relatives on the internet. Hence, continuous exposure to alternative ideas, for a person in mainland China, could alter the person's threshold of obligation. In a case like this, cultural values impact role appraisal, stress appraisals, coping styles and social support differently than their impact on an individual within a completely closed society.

Parveen et al. (2014) noted that empirical evidence relating to familism's influence on the outcome of caregivers varied. As such, the socio-cultural environment is integral to the caregiving process as it helps in understanding the implications of stressors and coping efforts for caregivers, and helps tailor support to meet individual needs (Parveen and Oyebode 2018). In essence,

focus needs to be on understanding meanings associated with specific indigenous cultural values, especially in China, where filial obligation is pertinent to family caregiving. Bearing in mind the rapidly increasing ageing population, the absence of adequate support for caregivers, and the value ascribed to Xiao, there are different layers to stressors influencing how people respond to stressful events. Therefore, it is important to focus on caregivers' subjective burden to understand specific stressors and coping mechanisms.

1.8 Summary and purpose of study

Providing care for older people who need support due to chronic health conditions that affect their ability to care for themselves is multi-dimensional in nature, being strongly influenced by both the socio-cultural context and demographic factors. Despite the rapid growth of the ageing population in China and the shifting demographics, there is still a widespread acceptance that family care is the default mode for supporting older people. Within formal services in China, older people's services are not well developed, and there is a lack of adequate support for caregivers. The dependence of older people on younger family members when care is required, makes it essential to focus on the needs of caregivers across generations to become more attuned to both family and cultural values. This in turn could provide a comprehensive understanding of the unmet needs of caregivers in China.

Underpinning the focus of this PhD research is the third goal of the Sustainability Development Goals (SDG) (United Nations 2015a), which advocates for good health and well-being for everyone irrespective of age. In my thesis, I employed an empathy-exploratory approach to comprehend individual caregiving context and used my judgement constructively with the aim of bettering the future. This

thesis makes a unique contribution to the existing literature by giving a deeper understanding of how current caregivers are faring within their socio-cultural environment in China and what prospective caregivers could face within similar caregiving contexts. As such, I considered how my lived experiences impacted my research and demonstrated the significance of being true to qualitative research, i.e., “qualitative sensibility” (Braun and Clarke 2013: 9). The skills and orientations adopted for this study included key interest in the meanings individuals associate with their caregiving roles whilst probing how their knowledge came to be and exploring the implications of cultural beliefs on caregiving processes. Reflexivity aided my wrestle with both relational (researched) and personal (researcher) dimensions within the context of this study (see section 8.5 Reflexive Juncture: Situating myself in relation to data), an effort directed at ensuring that I developed double consciousness to produce a credible answer to the proposed research question and proffer collaborative recommendations to aid a healthily ageing society in China.

1.9 Structure of the thesis

My thesis is organised into eight chapters:

Chapter 1: Introduction provided an overview of the critical concepts of ageing, broader literature on family caregiving and a critical discussion relating to stress and coping. Furthermore, I explored the implications of demographic transition and culture in mainland China on the phenomenon of caring for older relatives. Drawing on sociocultural models of caregiving, I showed how these factors are intertwined and highlighted their implications for caregivers who might primarily find themselves in a liminal position yet need to find meanings within their caregiving roles.

Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China provides a scoping review of existing evidence regarding the stressors and coping mechanisms of caregivers in mainland China. It highlights the dearth of evidence linked with the need for an in-depth understanding of the needs of families caring for older relatives in China.

Chapter 3: Phase 1: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents. provides the findings from a qualitative study using focus groups with young Chinese students residing in the UK, which gave insight into the culture and phenomenon of caring for older relatives in the Chinese cultural context. This study highlighted the significance of Xiao (孝) and presents an overview of the implications for future caregivers who belong to Generation Z and Millennials. This chapter aided in selecting an appropriate methodology and concludes with the aims and objectives of this thesis.

Chapter 4: Methodology and Methods clarifies my research stance, describes the methodological approach used and the underpinning philosophical stance guiding this research work. This chapter also provides details of methods used for data collection and analysis.

Phase 2, which is comprised of Chapter 5: Caregiving Beliefs- Xiao: the lifestyle, Chapter 6: Contextual Factors: Intersections of Xiao, work, and care and Chapter 7: Caregiving Conditions – Caregiving responsibility present the findings in relation to the aim of the thesis. *Chapter 5: Caregiving Beliefs- Xiao: the lifestyle* focuses on the meaning of Xiao to participants and their examples of experiences illustrating Xiao principles in daily life; how it motivates them to care and provides the foundation for societal expectations. *Chapter 6: Contextual Factors: Intersections of Xiao, work, and care* explores the contextual factors frustrating caregivers' efforts, such as the dilemma between having traditional expectations yet understanding the implications of socio-demographic changes, and the effects of having inadequate support in the workplace or from formal services. The last set of findings, *Chapter 7: Caregiving Conditions – Caregiving responsibility*, explores how the daily requirements of family caregivers utilise various human capacities, how demands become stressors and the ways in which they interact with each other. The chapter delves into various ways family caregivers sought to resolve caregiving challenges and the overall impact of the caregiving process.

Chapter 8: Discussion, conclusions, and key recommendations discusses findings **and** how they relate to the existing literature and socio-cultural models, and what they add to the current knowledge on family caregiving. The strengths and limitations of this study are then discussed. Lastly, the implications of the findings are discussed in relation to policy, practice, and research to provide recommendations and concludes with a summary of the study findings.

Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China.

2.1 Introduction

This literature review was published: *Bífarín, O., Quinn, C., Breen, L., Wu, C., Ke, M., Yu, L., & Oyebode, J. (2021). Stressors and coping mechanisms of family caregivers of older relatives living with long-term conditions in mainland China – A scoping review of the evidence. Ageing & Society.* As the original searches were made in November 2019, this chapter presents an updated version of this publication, incorporating papers published from searches made in August 2021. Socio-demographic transitions in Asian countries have distinct implications for caregivers and the appraisal of their role as Burhanullah and Munro (2020) propounded. Thus, it is particularly timely to focus on understanding individual appraisal of stressors and coping within a specific cultural context. In this chapter, I engaged with literature critically through a social constructivist lens. Reflecting on my experiences, and in the context of a collectivist society, individuals may feel pressure to demonstrate a willingness to care for their parents and may suppress feelings of stress or struggle (Au 2017). In this context, it seems plausible that caregivers of older relatives may be performing caregiving duties that potentially cause them to struggle with personal identities or role proficiency. Therefore, it is important to understand the impact of continuing care provision within the context of care obligation.

This chapter provides a systematic, narrative, and critical analysis of existing literature regarding the needs of older relatives' caregivers living with long-term health conditions in China and identifies the knowledge gap. In this chapter I describe the purpose of the literature review and the review method before presenting and critiquing the relevant literature. The chapter concludes with a summary of key findings.

2.1 Purpose of Review

The objective of this review was to systematically identify existing knowledge about stressors and coping mechanisms. Adopting the iterative approach outlined by Tricco et al. (2018), I designed two review questions while considering relevant key concepts: What are the stressors experienced by caregivers of older relatives living in the community with long-term health conditions?; What coping and/or support mechanisms did they use? Drawing on the socio-cultural models of stress and coping (Aldwin 2007; Knight and Sayegh 2010) (see section 1.7), it may be that the socio-demographic changes, in context of the value placed on Xiao, negatively affected the well-being of those caring for older relatives. Therefore, the imperative was for me to understand specific stressors and coping mechanisms.

2.2 Review Method

After exploring several review types and associated methodologies (Grant and Booth 2009), I mainly considered systematic review (SR) and critical review (CR) as alternative approaches alongside scoping review, which could aid the development of conceptual ideas from existing gaps in literature and synthesise evidence according to guidelines with a clear process that would allow replication. SR appraises evidence through a quality assessment process with emphasis on

providing insights into effectiveness rather than answering ambiguous research questions. CR does not require making searches, synthesis and analysis procedure explicit (Grant and Booth 2009), therefore, I decided to adopt a methodology that accommodated my lived experiences as a resource. Bearing this in mind, scoping review methodology rejects the notion that nature of knowledge of individuals can be captured as a single objective truth, making it the perfect approach. As a researcher, it allowed me to offer a subjective interpretation of what is known concerning the subject of interest (Thomas et al. 2020). Furthermore, by using my preconceptions constructively instead of concealing them, it was important to have measures in place to aid reflexivity while emphasising and synthesising to give a comprehensive overview of existing evidence (Peters et al. 2015).

Bearing in mind my positionality, it followed that social constructivism guided my review methodology. I aimed to conduct an inclusive synthesis of heterogeneous concepts and narratives to identify and analyse knowledge gaps. Hence, a scoping review was identified as the most appropriate method, systematically mapping out key concepts associated with the phenomena of interest and providing an in-depth synopsis of the evidence (Arksey and O'Malley 2005). This approach allows up-to-date, evidence-based research to be explored and provides a summary of findings from a range of methods or disciplines to facilitate future research work (Tricco et al. 2018). Thematic analysis and narrative reporting were used to synthesise and present the findings to accommodate the heterogeneity of the study designs and outcome measures, (Levac et al. 2010). Following data extraction, data retrieved from relevant studies were sorted and organised under themes. Close attention was paid to cultural nuances and novel

issues that related to the research questions. Chuntao Wu (CW), Ma Ke (MK) and I worked collaboratively to categorise the findings. Furthermore, the research team worked together to discuss developing themes. Themes were reconsidered on an iterative basis to establish consistency of interpretations. In the sections below, I go on to describe the iterative and systematic process of carrying out this scoping review.

2.2.1 Eligibility Criteria

To be included research papers had to meet the following inclusion criteria:

- Conducted with mainland Chinese caregivers of older relatives with a long-term health condition(s) residing in the community. Where the location of participants was not made explicit, researchers inferred studies to have taken place in the community.
- Data reported from primary research work.
- Caregivers' stressors or/and coping mechanisms were reported.
- Published in English or Chinese.
- No date restrictions applied

2.2.2 Information sources

Electronic databases were searched between October and November 2019, and updated searches was made in August 2021. UK databases included: Cumulative Index to Nursing and Applied Health Literature (CINAHL), Excerpta Medica dataBASE (EMBASE), Medical Literature and Retrieval System Online (MEDLINE), PsycINFO and SCOPUS; Chinese databases included: CNKI- China National Knowledge Infrastructure, WANFANG DATA, Chongqing VIP Database for Chinese Technical Periodicals, CBM- China Biology Medicine Disc. Forward

and backward citation searching was used to identify additional studies from eligible retrieved papers.

2.2.3 Search

The search protocol was discussed in depth between the UK and Chinese researchers to ensure mutual understanding. I developed key terms guided by the SPIDER search mnemonic (Cooke et al. 2012), where the letters refer to: S-sample PI-phenomenon of interest, D-design, E-evolution, R-research type. The terms were reviewed and discussed between co-authors. Two university librarians further critically reviewed the terms to ensure they addressed the research questions. Truncations, phrase search, wildcards and proximity searches were all used and tailored to the requirement of individual databases. For an example of the key terms in the Scopus database, see Appendix A: Scopus search term combination.

2.2.4 Selection of Sources of Evidence

I independently reviewed all titles using the eligibility criteria for the English papers, and selected studies eligible for further review. Following this, I checked all abstracts for eligibility alongside one of my supervisors, Dr Catherine Quinn (CQ), achieving an inter-rater agreement of 88 per cent. All disagreements were resolved through discussions and reaching a consensus. Similarly, the full text of 10 per cent of the eligible studies from the English databases was double screened by CQ and I. We found the inter-rater reliability to be 100 per cent. The Chinese studies were written in Mandarin, so I involved 2 Chinese MSc students who were fluent in the language. The titles and abstracts were screened independently by two master's students, CW and MK at China Medical University, School of Nursing. Following this, they each independently screened full texts for

eligibility and reviewed decisions jointly to ensure consistency. In cases of disagreement, the Chinese Principal collaborator for this project, Professor Liu Yu (LY), reviewed the studies independently and collaboratively with the other two master's students to reach a consensus (See Figure 2.1). References were managed using EndNote X9.

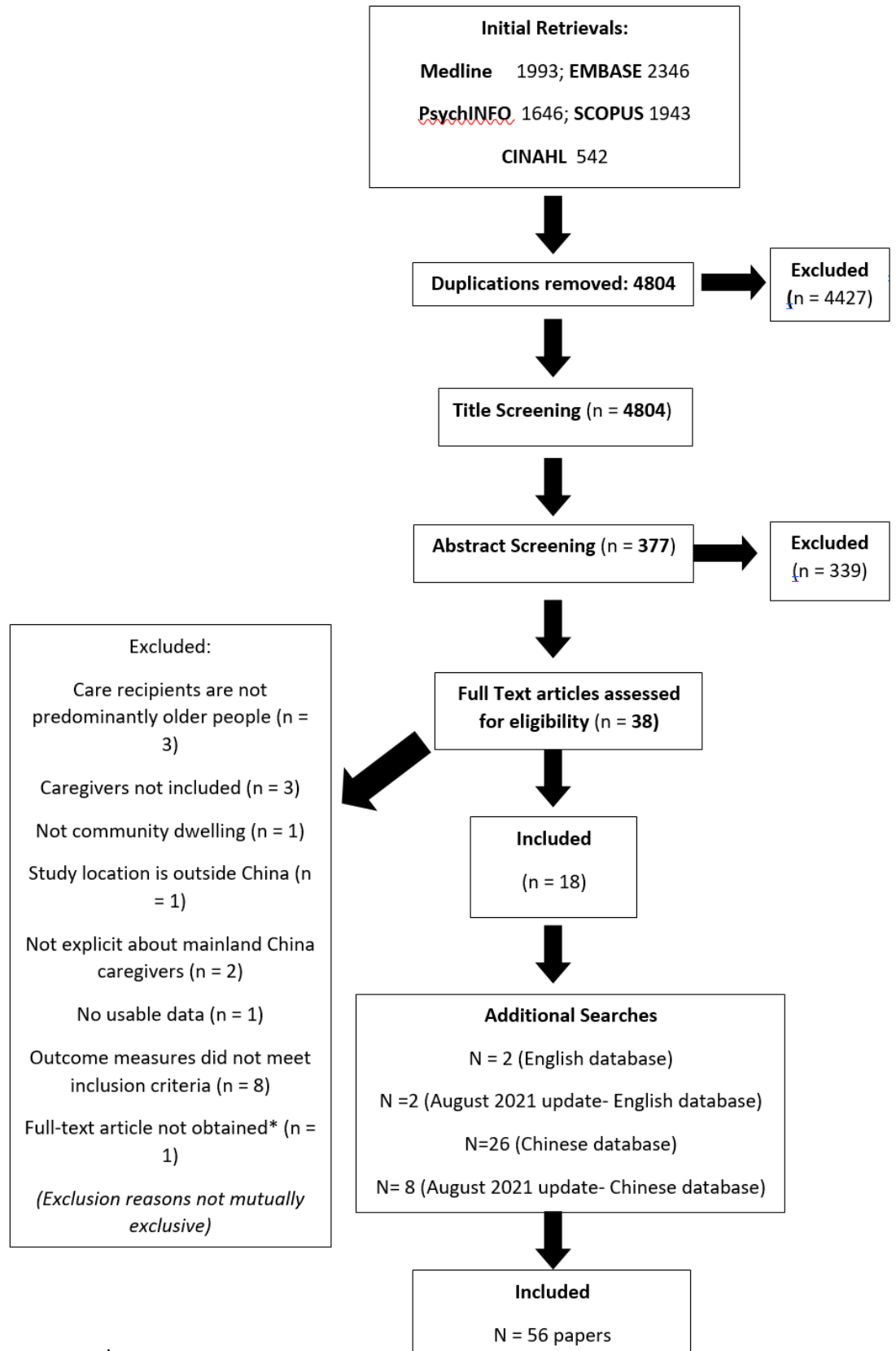


Figure 2.1: Flowchart of the search strategy

2.2.5 Data Charting Process

In line with the recommendation of Arksey and O'Malley (2005), the data extraction process was iterative. Charting tables were designed to extract key aspects of each study (country of origin, study design, number of participants, sources of stress and modes of coping). CQ checked my data extraction from two English papers and considered them satisfactory. For the Chinese papers, LY, who led a team charting relevant papers, conducted data extraction and translation into English. Finally, the extraction tables were sent to me for analysis and to inform write up.

2.3 Results

2.3.1 Selection of sources of evidence

Fifty-six papers were included: Twenty-two from UK databases, thirty-four from Chinese databases.

2.3.2 Characteristics of sources of evidence

Most of the studies were cross-sectional and focused on the burden and stress of caregiving, with a few capturing coping strategies. The majority were quantitative and employed a range of measures, such as the Caregiving Burden Inventory (CBI) (Chou et al. 2002) and Brief COPE Inventory (Carver 1997). Specific papers focused on caregivers of older relatives with a range of long-term conditions, including dementia, musculoskeletal conditions, visual and hearing conditions. Others generally focused on older people with disability and, in some cases, with co-morbidities or multi-morbidities. (See Table 2.1 below)

Table 2.1: Data charted from 56 papers included in the review

STUDY (PUBLICATION YEAR)	<ol style="list-style-type: none"> 1. STUDY DESIGN. 2. NO OF CAREGIVERS (CG) 3. CARE RECIPIENTS' LONG-TERM CONDITION (LTC) 4. LOCATION- CITIES OR PROVINCES 5. CHARACTERISTICS OF CAREGIVERS (CG). 	CAREGIVERS' STRESSORS AND COPING MECHANISMS.	MAIN FINDINGS
Davis et al. (1995)	<ol style="list-style-type: none"> 1. Qualitative study. 2. 75 3. Series of long-term conditions. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Lack of essential amenities</i></p> <p style="text-align: center;"><i>Lack of formal support</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Attributes of caregivers</i></p>	Women were the main carers of older people and experienced caregiving burden (physical, social, psychological, and financial). This was

	<p>4. Beijing, Tianjin and Guangzhou</p> <p>5. Age range: 23-89. Gender: Male: 39; Female: 36. 70 married, 5 widowed.</p>	<p><i>Finding practical solutions</i></p>	<p>attributed to meeting various needs of care recipients, as caregivers were spouses and older themselves. Caregivers primarily found psychological support through their moral qualities as they found strength in self-confidence, the sense of duty, responsibility and care obligation. Also, caregivers actively sought for practical solutions.</p>
<p>Chen et al. 2020</p>	<p>1. Qualitative study</p> <p>2. 12</p> <p>3. Alzheimer's disease</p>	<p>Stressors</p> <p><i>A lack of sufficient care knowledge</i></p>	<p>Caregivers struggled to cope with care recipients who presented with complex conditions as they lacked clinical knowledge.</p>

	<p>4. Hangzhou City-Zhejiang province</p>	<p><i>Social, emotional, physical burden and unappreciated care (hinging on filial piety)</i></p> <p>Coping</p> <p><i>Accepting and confronting difficulties, distraction techniques and social support. Neglecting needs of care recipients, surfing the internet for relevant information, consulting doctors or other dementia caregivers, adopting the use of tech.</i></p>	<p>Hence, they were often unable to adapt to change and had to endure caregiving demands. Also, having to always oversee care recipients, caregivers were constrained socially. Difficulties in communication created barriers, which caused caregivers great pain in their heart and resulted in depression, loneliness, and burnout. Over time, the adverse physiological consequences on their health meant caregivers struggled with meeting demands. Furthermore, caregiving efforts often</p>
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		<p>went unrecognised and unappreciated, and caregivers endured significant mental stress caused by relatives, friends, and neighbours. Under the influence of traditional Confucianism, most of the main caregivers adhered to the principles of filial piety, but it left them with regret as they want to provide support, but care recipients were unable to process this and consequently, had to provide care.</p> <p>Self-management strategies of caregivers</p>
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			<p>involved deliberate efforts to accept their situation, choosing to bravely confront difficulties.</p> <p>Caregivers mostly chose to rest and used hobbies to distract themselves.</p> <p>Caregivers sought support from relatives and friends by discussing their inner feelings to alleviate stressors. Family management strategies involved caregivers being selective about what they attend to and consequently, neglected deterioration in care recipients' health. Some caregivers resorted to</p>
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			surfing the internet for relevant information and consulting a doctor or other dementia caregivers, and the use of technology to prevent care recipients from being lost. Under the influence of traditional Confucianism, most of the main caregivers adhered to the principles of filial piety.
Hu et al. (2019)	<ol style="list-style-type: none"> 1. Qualitative study 2. 15 3. Disabled elderly 	<p style="text-align: center;">Stressors</p> <p>Caregiving time: <i>Role conflict,</i></p> <p>Role strain: <i>lack of freedom,</i></p> <p>Personal strain: <i>health impairment</i></p> <p>Preparedness: <i>knowledge deficiency, dealing with</i></p>	Eight overarching themes. Caregivers often had multiple roles, and long-term caregivers spent more time and energy. Long-term and continuous care

	<p>4. Hangzhou City Zhejiang province</p>	<p><i>accidents, burden, and appraisal of role</i></p> <p>Coping <i>Not reported</i></p>	<p>deprived caregivers of many opportunities for social engagement. Consequently, caregivers had no time to rest and adjust, which resulted in physical and mental exhaustion. Vast majority of caregivers were non-medical staff and had not received training on care management of health conditions of care recipients. Caregivers lacked the skills and awareness needed for their role. Caregivers who provided care alone mainly worried about accidents or unexpected situations.</p>
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			<p>Care recipients with communication disabilities were depressed as there was a generation gap between them and caregivers. Consequently, conflicts between them hindered effective communication between caregivers and care recipients, which reduced quality of care and increased caregivers' burden. Most caregivers were middle-aged and older and lived with long-term health conditions. Long-lasting and tedious care work threatened their health significantly. Some</p>
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			caregivers had to endure significant psychological pressure, due to a lack of social and psychological support.
Lian et al. (2017)	<ol style="list-style-type: none"> 1. Qualitative study. 2. 20 3. Dementia. 4. Chongqing 5. Caregivers had cared for older relative for at least 6 months. Age: Mean (SD) 58.0 (15.1), Gender: Male: 4; Female: 16. 19 Married, 1 Unmarried. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Lack of solution</i></p> <p style="text-align: center;"><i>Societal perception of condition</i></p> <p style="text-align: center;"><i>Early diagnosis</i></p> <p style="text-align: center;"><i>Behavioural management</i></p> <p style="text-align: center;"><i>Financial difficulties</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Social support and formal services</i></p>	Four themes were reported. 1. Capabilities to detect memory loss at an early stage. 2. Perceptions and beliefs about dementia in the community. 3. Different journeys toward the diagnosis. 4. Expectations of a smooth journey for others. Findings suggest that the transitioning period can be challenging for caregivers of people living with

			dementia. Caregivers found support through social support and seeking advice from relevant professionals.
Liu, (2016)	<ol style="list-style-type: none"> 1. Case study 2. 1 3. Disability 4. Hunan 5. Female family caregivers 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Financial stress</i></p> <p style="text-align: center;"><i>Health status of caregiver</i></p> <p style="text-align: center;"><i>Personality of care recipient</i></p> <p style="text-align: center;"><i>Caregiving role</i></p> <p style="text-align: center;"><i>Family conflict</i></p> <p style="text-align: center;"><i>Lack of care skills and knowledge</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Family support</i></p>	Significant pressure was associated with caring for an older relative. Family members continue to play a central role in providing support based on the values of filial piety. It would require additional support from the government, community services and professional support to reduce the pressure on family caregivers.

<p>Liu and Zhou (2009)</p>	<p>1. Qualitative study: (Descriptive), in-depth semi-structured interviews.</p> <p>2. 15</p> <p>3. Stroke (N= 9), Senile Dementia (N= 3), Parkinson's disease N=1), Coronary atherosclerotic heart disease (N= 1), Cancer (N= 1). <i>Most care recipients had comorbidity and multimorbidity.</i></p> <p>4. Shanghai</p> <p>5. Family caregivers</p>	<p>Stressors</p> <p><i>Physical status of caregivers</i></p> <p><i>Financial difficulties</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>Care recipients with stroke had the greatest care needs. Most caregivers had limited personal time; their physical health deteriorated due to caregiving, resulting in a significant psychological burden. Caregivers found medical expenses exorbitant, which contributed to stress. Relationships between caregivers and care recipients were strained.</p>
<p>Qiu et al. (2017)</p>	<p>1. Qualitative study</p> <p>2. 25</p> <p>3. Stroke</p>	<p>Stressors</p> <p><i>Standard of formal services</i></p> <p><i>Financial difficulties</i></p> <p><i>Accessibility of social support</i></p> <p><i>Demands of role</i></p>	<p>Three coping themes were reported:</p> <p>1. Caregiving role perception: the belief that caregiving was the 'right</p>

	<p>4. Nanjing</p> <p>5. Age range: 45-82. Gender: Male 6; Female: 19. Relationship with care recipient: Spouse 16, Child or Child-in-law 9. Education: Primary 4; Junior high 10; Postsecondary 9; University 2. Caregiving condition: Time spent (hr/day) 16hrs; Caregivers co-resident with care recipient 23.</p>	<p>Coping</p> <p><i>Sense of care obligations</i></p>	<p>and proper' thing to do, based on reciprocity and cultural/role expectations, influenced by role modelling of other family members. 2. Coping strategies: seeking practical support and assistance from family members. 3. Self-sacrifice: self-reliance and sacrifice of personal health to prioritise care recipients. Caregivers were also reluctant to use formal services due to concerns about quality and costs.</p>
<p>Sun, (2014)</p>	<p>1. Qualitative study</p> <p>2. 18</p>	<p>Stressors</p> <p><i>Attributes of care recipients</i></p> <p><i>Demands of the role</i></p>	<p>Limited physical, cognitive and behavioural abilities of care recipients were</p>

	<p>3. Dementia</p> <p>4. Shanghai.</p> <p>5. Age range: 53-82 years. Gender: Female: 11; Male</p> <p>7. Relationship with care recipient: Spouse 14; Adult-Child 3; Daughter in-law 1. Employment status: Employed 3; Retired 15.</p>	<p><i>Family conflict</i></p> <p><i>Societal pressure</i></p> <p>Coping</p> <p><i>Attributes of caregivers</i></p> <p><i>Personal and external resources</i></p>	<p>directly linked with the increase in the demands of the role. Salient stressors such as the role strain, family conflict and societal pressure were identified. Caregivers coped in various ways, which included some drawing on personal experiences, religion, technology and seeking support from doctors while others had to plan ahead.</p>
Tang Y. (2020)	<p>1 Qualitative study</p> <p>2 20</p> <p>3 Frail older relatives</p>	<p>Stressors</p> <p><i>Caregiving time</i></p> <p><i>Social role (being a son/daughter-in-law, meanings)</i></p>	<p>Three main themes were identified, namely: 'I am a traditional person': the impacts of Ren and Xiao, 'caring made me tired':</p>

	<p>4 Shenzhen</p> <p>5 Gender: Male (34%), Female (68%). Marital Status: Married (42%), Widowed (58%); Age: 65-75 (32%), 76-85 (48%), 86 or older (20%). Education: no formal education (24%), Primary school (31%), Junior high (18%), Senior high (16%), College (11%). Funding source: Pension (72%), Funded by adult children (21%), Social policy (7%)</p>	<p><i>Accessibility of services</i></p> <p>Coping</p> <p>Ren 'endure of injustice'</p> <p>Self-sacrifice</p> <p>Day care centres</p>	<p>mobility and environment, and 'I am not young': relaxation feelings of family caregivers. Caregivers were unable to take a break from caregiving and wondered how long it was going to last for as they were depleted of energy, felt helpless and were anxious, which resulted in being despondent but had to Ren "endurance of injustice". Some had lost their sense of self as they had to adjust their lifestyle to accommodate the needs of older relatives. Culture of Xiao made caregivers want to care for older relatives at</p>
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			<p>home as they considered nursing home as being unfilial. Similarly, sons had the responsibility to provide financial support and daughter-in-law to provide hands on care and some were tired of their care responsibilities.</p> <p>Accessibility to day care centre was a barrier to the services due to transportation and opening hour irregularities. Day care centre was an avenue for caregivers to reduce caregiving burden, which allowed them to attend to other priorities such as that of their immediate family.</p>
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<p>Wang et al. (2018)</p>	<p>1. Qualitative study</p> <p>2. 10</p> <p>3. Dementia</p> <p>4. Beijing</p> <p>5. Mean age 66.9 +/- 16.6. Gender: Female: 9; Male: 1. Marital status: Married 9; Widowed 1. Relationship with care recipient: Spouse 6; Adult children 3; Other relative 1.</p>	<p>Stressors</p> <p><i>Low or no level of preparedness</i></p> <p><i>Lack of support from both informal and formal services</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>Three themes related to caregiver stressors: care knowledge and skills, psychological counselling and collaborative management. Themes reflected lack of support. Participants had negative emotions related to the inability to provide adequate care. They considered caregiving as a burden, characterised by the lack of professional support and lack of socialising time.</p>
<p>Xiuxiang, Zhang and Hockley (2020)</p>	<p>1 Qualitative study</p> <p>2 14</p>	<p>Stressors</p>	<p>Cultural beliefs played a central role in the coping</p>

	<p>3 Dementia 4 Shandong 5 Gender: Male (5), Female (9). Age range: 39-78, Employment status: Retiree (4), unemployed (10).</p>	<p><i>Lack of adequate formal services</i></p> <p>Coping</p> <p><i>Filial responsibility and value placed on older relatives</i></p> <p><i>Self-sacrifice</i></p> <p><i>Activities of interest such as walking, singing</i></p> <p><i>Use of media-TV programmes</i></p> <p><i>Shared care within family members and neighbours</i></p> <p><i>Spiritual and emotional support via Buddhism</i></p>	<p>strategies adopted by caregivers. Four themes were used to represent these coping strategies namely: “Being filial”: acceptance and the intrinsic nature of cultural and social roles, which helped in regulating their roles and relationships. “Changing self and self-care”: caregivers having to fit into their roles which was in the form of self-sacrifice, disrupted night sleeps, enrolled in singing, dancing and fitness courses to avoid social isolation, played poker, went for walks to help manage the</p>
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			<p>stress of their role and resorted to healthcare programs on TV in the absence of formal training. “Seeking help”: family members rallied around one another, which was in line with the traditional culture in the absence of adequate health and social support services. “Having hope and continuing life”: caring for older relatives gave a sense of hope especially through beliefs in values of Buddhism, which showed a strong indication of value placed on older relatives.</p>
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<p>Yong, (2012)</p>	<ol style="list-style-type: none"> 1. Qualitative study 2. 10 3. Dementia 4. Not specified 5. Not specified 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Financial difficulties</i></p> <p style="text-align: center;"><i>Lack of respite</i></p> <p style="text-align: center;"><i>Lack of awareness</i></p> <p style="text-align: center;"><i>Physical health status of caregivers</i></p> <p style="text-align: center;"><i>Inability to balance work and care</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Family support</i></p>	<p>Three reported themes relate to the mental health status of caregivers of older relatives, feelings associated with caring for older relatives and the lack of long-term care services. Caregivers played an integral role in caring for older relatives including prioritizing the need of older relatives ahead of theirs. They were anxious about managing the health of older relatives due to the lack of adequate support and still had to provide a high-level of hands-on nursing care. Caregivers</p>

			experienced high levels of burden with negative health outcomes. Caregivers relied on family members for support.
Zhang et al. (2019)	<ol style="list-style-type: none"> 1. Qualitative study 2. 14 3. Dementia 4. Shandong 5. Age range: 39-78. Relationship status: Spouses, Parent and offspring. 	<p>Stressors <i>Caring at home</i> <i>Caregiving role</i></p> <p>Coping <i>Not reported</i></p>	Three overarching themes identified that caregivers felt that 'no one cares', as a result of changes in society, which highlights their state of disconnection. Thus, fearing that ' <i>home care may create a sense of social isolation</i> ', caregivers with lack of autonomy over their daily lives and caring duties, felt that ' <i>home care is a burden</i> ' and could be extremely demanding. Caregivers, when

			comparing ' <i>home care versus institutional care</i> ', highlighted the benefits to living at home; 'ageing in place' as well as the potential risks such as social isolation, depression and anxiety.
Chen, (2017)	<p>1. Cross-sectional study</p> <p>2. 208</p> <p>3. 52.8% 'disabled elderly', 47.2% 'semi-disabled elderly'.</p> <p>4. Shanghai</p> <p>5. Gender: Female: 62.1%; Male: 37.9%.</p> <p>Relationship status: daughters, spouses, sons, daughters-in-law, other family members, sons-in-law.</p>	<p>Stressors</p> <p><i>Lack of family support</i></p> <p><i>Duration of care</i></p> <p><i>Caregivers' physical health status</i></p> <p><i>Financial difficulties</i></p> <p><i>Lack of adequate skillset to provide care</i></p> <p>Coping</p> <p><i>Not reported</i></p>	The majority of care recipients lived with dementia. Family caregivers were mostly female, some caregivers were older people and they were spouses to care recipients. The poor physical health status of caregivers made it difficult for them to bear heavy burdens. The long hours

			<p>needed to provide care adversely contributed to the physical and psychological well-being of caregivers.</p> <p>Family caregivers reported being under great pressure, as they did not have enough people to share care responsibilities. Caregivers were subjected to financial stress and lacked the set skills needed to provide adequate care as some received little support from professionals.</p>
Chen et al. (2017)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 203 3. Disability 4. Zhejiang 	<p><i>Stressors</i></p> <p><i>Age of caregivers</i></p> <p><i>Care recipients' self-care ability</i></p>	<p>Caregivers were subjected to a caregiving burden. Compared with caregivers who cared for relatives</p>

	<p>5. Gender: Female: 123 (60.6%); Male:80 (39.4%). Relationship with care recipient: Children: 51; Spouses: 116; Other family members: 36.</p>	<p>Coping <i>Not reported</i></p>	<p>aged 75+ and above, caregivers who took care of relatives aged 60-74 presented with higher time-dependence, developmental and physical burden.</p>
Du et al. (2014)	<p>1. Cross-sectional study. 2. 744 3. Dementia: 112 (15.1%); Non-dementia: 632 (84.9%) 4. Beijing</p>	<p>Stressors <i>Lack of social support</i> <i>Financial difficulties</i> <i>Demands of caregiving</i> <i>Relationship status</i></p> <p>Coping <i>Not reported</i></p>	<p>Lack of self-efficacy and financial capability on the caregivers' part contributed to the adverse health outcome (depression). Caregivers with depressive symptoms lacked social support (subjective support and utilisation of support). Based on the relationship with care recipients,</p>

	<p>5. Gender: Male: 282(37.9%); Female: 462 (62.1%). Age: ≤40: 23 (3.1%); 41-59: 353 (47.4%); ≥60: 368 (49.5%). Relationship with care recipient: Spouse: 242 (32.5%); Child: 469 (63.0%); Other: 33 (4.5%).</p>		<p>spouses spent more time addressing the care recipients' needs.</p>
<p>Du et al. (2017)</p>	<p>1. A cross-sectional study.</p> <p>2. 766</p> <p>3. Older people living with long term conditions. Top five conditions are hypertension, stroke, coronary diseases, diabetes and osteoarthritis.</p>	<p>Stressors <i>Financial difficulties</i> <i>Subjective caregiving burden</i></p> <p>Coping <i>Not reported</i></p>	<p>Caregivers were subjected to moderate amounts of burden. Out of pocket money was negatively associated with the general well-being of caregivers. Time spent providing care, especially with care recipients living with co-morbidity, is associated</p>

	<p>Most had more than 4 chronic conditions.</p> <p>4. Beijing</p> <p>5. Gender: Male: 284 (37.1%); Female: 482 (62.1%). Marital status: Married 704 (91.9%); Others: 64 (8.1%). Relationship with care recipient: Spouse: 245 (32%); Children: 486 (63.4%); Others 35 (4.6%).</p>		<p>negatively with some aspects of caregivers' HRQoL. Subjective caregiving burden negatively correlated with caregivers HRQoL.</p>
Fu et al. (2007)	<p>1. Cross sectional study</p> <p>2. 42</p> <p>3. Dementia</p>	<p>Stressors</p> <p><i>Behavioural challenges</i></p> <p><i>Gender</i></p> <p>Coping</p>	<p>Care recipients' pathological behaviours were found to be a stressor and correlated with adverse health outcomes</p>

	<p>4. Beijing</p> <p>5. Gender: Male: 27(64.29%); Female: 15 (35.71%). Average age: 73±7.</p>	<i>Not reported</i>	<p>(depression and anxiety). Caregivers demonstrated a lack of knowledge around dementia. Some (26.2%) ascribed dementia to normal ageing or curable, 57.1% believed that dementia could improve or be maintained, and 61.9% could not understand the abnormal behaviour of care recipients. Women experienced more emotional burden in comparison to men.</p>
Guogui et al. (2017)	<p>1. Quantitative design</p> <p>2. 11331</p> <p>3. Not specified</p> <p>4. Nationwide</p>	<p>Stressors</p> <p><i>The health status of the caregiver</i></p> <p><i>Distance</i></p> <p><i>Lack of adequate skillset</i></p>	<p>Caregivers spent an average of 38.3 hours per week caring for care recipients. The main difficulties for caregivers</p>

	<p>5. Gender: 52% Male. Age: 31.5% were 60-64. Remainder were 65 years+. 64.9% Married. Education: 64.9% primary school and below.</p>	<p><i>Lack of time to provide care</i> <i>Financial difficulty</i></p> <p>Coping <i>Not reported</i></p>	<p>were physical exhaustion, distance, lack of time and dilemmas relating to finances. This partly contributed to the psychological pressure experienced by caregivers, whom were older people themselves.</p>
He et.al. (1995)	<p>1. Cross-sectional study</p> <p>2. 110</p> <p>3. Dementia</p> <p>4. Shanghai</p> <p>5. More female caregivers. Majority were married. About half were employed</p>	<p>Stressors <i>Demands of caregiving role and individual attributes</i></p> <p>Coping <i>Not reported</i></p>	<p>The magnitude of the role was associated with adverse caregiver health outcomes. Characteristics of the caregiver and recipient affected caregivers' mental health. Older caregivers had "other types" of work, distant relatives and care recipients with severe</p>

	and half retired. More than 50% of primary caregivers were children and spouses. More than 30% of spouses were older people themselves.		dementia. These caregivers experienced a higher psychosocial impairment index than other groups. Being female, un-educated, with care-recipient being male and over 85 years, affected caregivers' physical health.
Li et.al. (2009)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 568 3. Chronic diseases (hypertension, diabetes, coronary heart disease, emphysema, asthma, gallbladder and gastrointestinal disease, stroke, glaucoma or cataract, Parkinson's disease, prostatic 	<p style="text-align: center;">Stressors <i>Financial difficulties</i> <i>Co-morbidities/multi-morbidities</i></p> <p style="text-align: center;">Coping <i>Social support</i></p>	83.5 % of caregivers believed that there were different levels of family burden. Multivariate analysis showed that monthly medical expenses, self-care ability of care recipients, depressive symptoms, number of chronic diseases, living arrangement, caregivers'

	<p>hyperplasia, cancer, osteoarthritis, rheumatism).</p> <p>4. Fuzhou</p> <p>5. Gender: Female: 306 (53.9%); Male: 262 (46.1%).</p> <p>Relationship with care recipient: Children 111 (19.5%); Spouses: 434 (76.4%); Other family members: 23 (4.1 %).</p> <p>Age: ≥ 20:40 (7.0%); ≥40: 108 (19.1%); ≥60: 420 (73.9%).</p>		<p>education level and occupation were influencing factors relating to family burden.</p> <p>Caregivers of older relatives with decreased self-care ability and depressive symptoms had a higher burden than caregivers of older relatives with the ability to self-care and without depressive symptoms. Caregivers of older relatives with two or more chronic conditions had a higher burden.</p> <p>Caregivers found social support useful in terms of reducing caregiving burden on the family.</p>
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<p>Li et al. (2013)</p>	<p>1. Cross-sectional study 2. 418 3. Disability: Hypertension (60.3 %), Heart disease (47.8 %), Cervical and lumbar disease (21.1%), cerebrovascular disease (19.1 %), Diabetes (18.7%), tracheitis (17.2%). 4. Ji Nan 5. Gender: Female: 180; Male: 238. Age(years) : 20-40: 16; 40-60: 221; >60: 181. Relationship with care recipient: Spouse: 114; Child: 252; Other: 52. 345 caregivers resided with care recipient; 115 were in employment.</p>	<p>Stressors <i>Care recipients' characteristics and caregivers' self-efficacy</i> Coping <i>Not reported</i></p>	<p>The care recipients' Activity of Daily Living (ADL) score, health status, age, availability of spouse, the caring abilities of caregivers and the availability of helpers were associated with the burden of caregivers.</p>
<p>Li et.al. (2019)</p>	<p>1. Cross-sectional study 2. 291</p>	<p>Stressors <i>Demand of caregiving role</i></p>	<p>Caregivers experienced moderate to high levels of</p>

	<p>3. Disability: 175 cases (60%) of visual disturbance; 106 cases (36%) of hearing disorders; 91 cases (31%) of communication disorders ; 152 cases (52%) of cognitive ability injury; 121 cases (41%) of urinary and faecal incontinence; 107 cases (37%) of severe activity of daily living injury; 25 cases (9%) of pressure sore; 78 cases (27%) of fall in a year; 254 cases (87%) of chronic diseases for disabled older people.</p> <p>4. Zhejiang</p> <p>5. Not reported</p>	<p>Coping</p> <p><i>Not reported</i></p>	<p>caregiving burden on family members. The results of the multi-factor analysis showed that long-term caregivers of care recipients with low overall health perception contributed to caregiving burden.</p>
Li, Huang and Zhao (2019b)	<p>1 Survey study</p> <p>2 440</p>	<p>Stressors</p> <p><i>Age and physical health status</i></p>	<p>The anxiety score of caregivers was</p>

	<p>3 Disability (Specific health conditions not specified)</p> <p>4 Shanghai</p> <p>5 Gender: Male: 140 (31.8 %), Female: 300 (68.2 %). Age: < 50 years old: 105 (23.9%), 50-59 years old: 97 (22%), 60-79: 125 (28.4%), ≥80 years old: 113 (25.7%). Relationship with patients: children: 155 (35.2%), partners: 234 (53.2%), others: 51 (11.6%)</p>	<p><i>Employment status</i></p> <p><i>Relationship status</i></p> <p><i>Gender</i></p> <p><i>Financial circumstances</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>(46.63±6.74), the detection rate of anxiety was 29.55%, the depression score was (46.12 ±5.78), and the detection rate of depression was 27.73%. Univariate analysis showed that the distribution of anxiety and depression in the number of chronic diseases. Caregiver age, caregiver gender, being in full-time work, close relationship with the care recipient, their health status, family monthly income had statistical significance.</p>
<p>Liu et al. (2012)</p>	<p>1. Cross-sectional study.</p>	<p>Stressors</p>	<p>There were significant increases in CBI scores</p>

	<p>2. 90</p> <p>3. Diagnosis of dementia or non-dementia chronic diseases (hypertension, diabetes, chronic renal failure, osteoarthritis).</p> <p>4. Beijing.</p> <p>5. Mean age 77.02 +/- 3.66. Gender: Male: 13; Female: 77. Relationship with care recipient: Spouses: 48, offspring: 10. Co-residence: Yes: 86, No: 4. Employment status: Employed: 24, Unemployed: 13, Retired: 53. Education level: none:</p>	<p><i>Lack of information and guidance</i></p> <p>Coping</p> <p><i>Problems solving</i></p>	<p>between severe dementia and non-dementia (comparison group). In the dementia group, patients' CDR score was positively correlated with the measure of burden. There was a positive correlation between CBI scores and daily care time. There was a positive correlation between CBI scores and SAS and SDS. Carers of people with dementia reported insufficient involvement of GP in dementia care. Media was the most important source of knowledge and skills (newspaper 15%, tv 13%,</p>
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	7, Primary school: 17, Secondary school: 46, Tertiary school: 20.		radio 12% and book 12%). GPs guided only 11% of caregivers in the daily care of people with dementia.
Liu et al. (2013)	<ol style="list-style-type: none"> 1. Survey Study 2. 895 3. Oldest old in China (mean age of 90) 4. 31 provinces in China 5. Age: mean age= 55.8 (SD=7.3). Most caregivers were in their 50s (46.5 %) and 60s (33.4 %). Gender: 74.9 % of caregivers were 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Financial situation</i></p> <p style="text-align: center;"><i>Caregivers' health status</i></p> <p style="text-align: center;"><i>Societal expectations</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	<p>The income of adult children and the status of being the eldest son were related to economic stress. Economic stress was related to economic capability of caregivers (children of care recipients) as the oldest-old parents were financially dependent on their children due to rarity of pensions. Unmarried caregivers reported significant economic stress. Eldest sons were reported to</p>

	males. 58.9% lived in rural areas.		experience more economic stress in caring for older relatives than other siblings.
Liu et al. (2015)	<p>1. Cross-sectional study</p> <p>2. 124</p> <p>3. Disability</p> <p>4. Chong Qing</p> <p>5. Gender: Female: 89; Male: 35. Age: 18-35: 18; 36-45: 41; 46-60: 39; >60: 26. Retirement status: 59 retired; 65 not retired. Marital status: Married: 118; Not married: 4, Divorced: 1; Widow: 1. Relationship with care recipient: Spouse: 42; Siblings: 3; Offspring: 79.</p>	<p>Stressors</p> <p><i>Care recipient characteristics</i></p> <p><i>Time devoted to care</i></p> <p><i>Physical health status of caregivers</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>The highest score in terms of caregiving was time-dependent burden, followed by developmental burden and physical burden. Age of older relative, self-reported illness, general health status and health changes, daily caregiving time on the part of caregivers and self-reported illness status indicated that caregivers were subjected to a substantial amount of burden.</p>

<p>Liu et al. (2017)</p>	<p>1. Cross-sectional study 2 80 3 Dementia 4 Shanghai 5. Gender: Male: 28; Female: 52. Age range: 38-93. Education: Middle school or below: 67; College or above: 13. Family monthly income: <3000 Yuan: 31; 3000~ 4000 Yuan: 37; >4000 Yuan: 12. Relationship with care recipient: Spouse: 23; Others: 57.</p>	<p>Stressors <i>Nature of long-term condition</i> <i>Lack of training</i> <i>Demands of caregiving</i> <i>Monthly household income</i> <i>(per capita)</i></p> <p>Coping <i>Not reported</i></p>	<p>Per capita monthly income of families (caregivers), self-care ability and severity of dementia in older relatives, and the demand of care on caregivers were statistically significant. Thus a high care demand was placed on caregivers of older relatives with dementia, especially as they lacked the knowledge and skillsets.</p>
<p>Liu et al. (2018)</p>	<p>1. Cross-sectional study 2. 1000 3. Not specified 4. 10 cities in 5 provinces in East and Central China</p>	<p>Stressors <i>Age</i> <i>Caregivers' own health status:</i> <i>Older relatives' care need</i> <i>Lack of family support</i></p>	<p>Caregivers younger than 40; with chronic conditions; who slept for less than seven hours had significantly higher scores for depressive symptoms</p>

	<p>5. Average age of the main family caregivers was 42.7 ±12.7 years old. Female: 339, (48.9%). Education: 61.9% lower or middle school education. Hours of care per day: <2 hours: 25.5%; 2-5 hours: 50.5%; > 5 hrs: 24.0%.</p>	<p>Coping <i>Not reported</i></p>	<p>than those in the other groups. Caregivers that spent less than two hours a day caring for older relatives had significantly low scores for depressive symptoms. Likewise, caregivers of older relatives who did not need help with tasks such as housework and transportation had a significant low score for depressive symptoms compared to other groups. Caregivers of older people who often or always needed help with their health had a significant high depression score.</p>
Liu et al. (2019)	1. Cross-sectional study	Stressors	72 (22. 8%) caregivers of

	<p>2. 316</p> <p>3. Disability</p> <p>4. Ning Xia</p> <p>5. Gender: Female: 223; Male: 93. Age range: 40-49: 58; 50-59: 87; 60-69: 129; 70-75:42. Marital status: Married: 281; Not married: 1; Divorced: 26; Widowed: 8. Education: ≤Primary school: 75; Junior high school: 158; High school or technical secondary school: 61; College: 20; Higher education: 2. Relationship with care recipient: Spouse: 192; Offspring: 119; Sibling: 5. Daily care time (hrs) <6: 25; 6-12: 135; >12:156. Income (per month) :<1000 Yuan: 50; 1000-1999 Yuan: 35; 2000-</p>	<p><i>Age of caregivers</i></p> <p><i>Relationship with care recipient</i></p> <p><i>Health status of caregivers</i></p> <p><i>Low level of training</i></p> <p><i>Duration of care</i></p> <p><i>Financial difficulties and economic income.</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>older relatives had mild burdens, 189 (59. 8%) had moderate burdens, 55 (17. 4%) caregivers had severe burdens. Personal burden (30. 42 8. 82), role burden (17. 79 4. 35) and total burden (48. 32 ± 15. 19).</p> <p>There was a significant difference in the burden scores between different ages and caregivers with a disability, health statuses, whether they had received relevant care guidance or training, caregiving time, the number of assisted caregivers and other economic incomes (P<0.</p>
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	2999 Yuan: 169; 3000-3999 Yuan: 39; 4000-4999 Yuan: 21; ≥5000 Yuan: 2.		05). There was also a negative correlation between caregivers' burden and families' care quality, among which personal burden, role burden and total burden are more closely associated to caregivers and care recipients.
Liu and Klug (2016)	<ol style="list-style-type: none"> 1. Survey Study. 2. 895 3. Oldest Older parents. 4. 8 coastal provinces in China 	<p>Stressors <i>Self-efficacy</i></p> <p>Coping <i>Not reported</i></p>	Physical and cognitive function scores (ADL, IADL and MMSE) for care recipients indicated care needs were low. Caregivers reported high levels of concerns regarding their self-efficacy

	<p>5. Mean age (in years) 55.83. Gender: Female (daughter): 25.14%. Married: 89.61%. Living rural areas: 58.88%. Retired or not working: 38.97%; Part-time workers (18.19%); Full-time workers (42.84%).</p>		<p>(WAP) compared to items on <i>ZBI</i>. Linear regression showed: 1) Caregivers who provided long term care for older people with high IADL needs had a high level of WAP; 2) Emotional closeness and sibling support play a crucial role in predicting WAP; 3) Caregivers in full-time work reported a low level of WAP; 4) Full-time working status was not found to be significantly associated with WAP; 5) Higher living standard was significantly associated with higher WAP; 6) Higher WAP was</p>
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			reported by caregivers living with the oldest old; 7) Daughters were preferred to sons in terms of providing care.
Liu and Lou, (2012)	<ol style="list-style-type: none"> 1. Cross-sectional 2. 720 3. Disability 4. Shanghai City 5. Majority of caregivers were women, middle-aged, older people, retired, with average economic conditions, providing long periods of care. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Caregivers' poor health status</i></p> <p style="text-align: center;"><i>Financial difficulties</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	Health deterioration of caregivers was associated with caring for older relatives. In response to their financial circumstances in the last six months, 41.0% thought they had barely enough (295), 28.2% thought they had enough (203), 5.0% thought they had enough with spare (36), 19.3% thought they did not have enough (139), 6.4%

			practically had nothing (46).
Lu et al. (2015)	<ol style="list-style-type: none"> 1. Survey study. 2. 494 3. Frail elders with musculoskeletal conditions. 4. Shanghai 5. Gender: Male: 187; Female: 307. Relationship with care recipient: Spouse: 139; Children/son-in-law/daughter-in-law: 355. Married: 234; Other: 255. Age: >60: 250; 60-74: 134; 75-84: 83; 85 or above: 23. Education: Primary school or no formal education: 67; Secondary school or 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Care recipients' functional dependency (ADL), cognitive status and behavioural challenges.</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	<p>ADL was significantly associated with depressive symptoms. Depressive symptoms were associated with time dependence, physical and social burden. Both ADL and Life satisfaction were mediated by time dependence, and developmental burden. Time dependence fully mediated the association between cognitive status and depressive symptoms, the association between behavioural problems and depressive symptoms (also</p>

	<p>above: 426. Lived with care recipient: Yes: 335; No: 158.</p>		<p>mediated by physical and social burden). Income and informal care hours were significant predictors of time-dependence burden. Being younger, married, living with elders, higher income and shorter informal care hours were also associated with lower physical and developmental burden. Older caregivers were more likely to report higher levels of social burden. Caregivers with higher educational attainments were more likely to report higher levels of developmental burden.</p>
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<p>Lu et al. (2017)</p>	<p>1. Cross-sectional study 2. 375 3. Disability 4. He Nan 5. Gender: Male: 155; Female: 220. Age range: 27-87; Average age: 54.23 ±13.50. Relationship with care recipient: Spouse: 131; Offspring: 244.</p>	<p>Stressors <i>Gender</i> <i>Caregivers' attributes</i> <i>Care recipient's attributes</i></p> <p>Coping <i>Not reported</i></p>	<p>The burden of caregivers of older relatives in rural areas was found to be moderate. Gender, age, residential status, subjective support, level of management of care recipients' long-term conditions and emotional state of the caregiver were the main factors that influenced caregiving burden. Social support is negatively correlated with the caregiving burden.</p>
<p>Lv et.al. (2013)</p>	<p>1. Cross-sectional study 2. 119 3. Chronic disease, not specific.</p>	<p>Stressors <i>Financial difficulties</i> <i>Self-care ability of care recipient</i> <i>Caregiving time</i></p>	<p>Young and middle-aged caregivers in rural areas were under a relatively high economic distress as caregiving impacted their</p>

	<p>4. Zhejiang</p> <p>5. Gender: Male: 40; Female: 79. Relationship with care recipient: Spouse: 23; Offspring: 96.</p>	<p><i>Low income</i></p> <p><i>Caregivers' age</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>ability to work, which had implications on caregivers meeting care recipients' long-term medical expenses. Spouses of care recipients were under greater pressure due to their special roles and attitudes. Caregivers' occupation was associated with social pressure as caregivers in low paid jobs experienced a higher level of social pressure. This was further compounded by their persistent state of physical exhaustion and limited social opportunities. Other factors were the caregiver's age, education</p>
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			level, occupation, patient's self-care ability and mood.
Pan et al. (2018)	<p>1. Cross-sectional study</p> <p>2. 190</p> <p>3. Chronic obstructive pulmonary disease (COPD)</p> <p>4. Not specified</p> <p>5. Gender: Male: 93; Female: 97. Age: <60: 98; ≥60: 92.</p> <p>Relationship with care recipient: Spouse: 84; Offspring: 59; Others: 47.</p> <p>Marital status: Married: 124; Unmarried: 66. Education: ≤ Junior High school: 44; High school or technical secondary school: 96; ≥ Junior college: 50. Reside with care recipient: Yes: 121; No: 69. Monthly</p>	<p>Stressors</p> <p><i>Age of Caregivers</i></p> <p><i>Time of care</i></p> <p><i>Occupation</i></p> <p><i>Availability of formal services</i></p> <p>Coping</p> <p><i>Social support</i></p>	<p>The older the caregiver the more the reported burden. Caregivers in full-time employment reported a higher of burden compared to part time workers or those without a job. The longer the time of caregiving/ per day, the heavier the burden. Caregivers with better access of care reported less caregiving burden and the higher the level of social support received; the less care burden experienced by caregivers.</p>

	household income: <5000: 89; ≥5000: 101. Occupation: Full-time: 55; Part-time: 50; Retired or unemployed: 85. Daily time for patient care: <5hours: 75; 5-10 hours: 80; >10 hours: 35.		
Pei et al. (2017)	<ol style="list-style-type: none"> 1. Survey study 2. 214 3. Not specified 4. Central China 5. Gender: Male: 116; Female: 98. 8. Monthly income (Mean SD): Male: 2933.4(197.3); Female: 1996.0 (115.8); Types of employment %: 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Logistics of caregiving</i></p> <p style="text-align: center;"><i>Time and financial implications of caregiving</i></p> <p style="text-align: center;"><i>Gender</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	Lack of support for caregivers in employment was reported, as time and financial dependence on caregivers by care recipients were stressors. There was a 5% chance of experiencing negative employment consequences with an hour increase in care provision. As total care expenses moved up a

	Permanent: Male: 25.9; Female: 25.5; Contract: Male: 66.4; Female:70.4; Other: Male: 7.8; Female: 4.1.		level (from 1000 to 1999 or 2000 to 2999 Yuan), caregivers were 33% more likely to experience negative employment consequences. Women were reported to provide more hands-on care, which predisposed them to the caregiving burden.
Qian et al. (2014)	1. Cross-sectional survey 2. 243 3. Dementia and non- dementia. 4. Beijing	Stressors <i>Age of care recipient</i> <i>Caregivers' characteristics</i> <i>Low social support</i> Coping <i>Not reported</i>	The prevalence rate of anxiety was 29.2% reported by family caregivers. The average score of SAS was 35.6 ± 8.6. The risk factors of caregivers' anxiety included Barthel index score ≤ 20 (OR=1.51), SSRS score ≤ 33

	<p>5. Gender: Male: 88 (36.2%); Female: 155 (63.8%); Age: <60: 132 (54.3%); ≥60: 111 (45.7%). Relationship with care recipient: Spouse: 79; Children: 135; Other: 29.</p>		<p>(OR=4.56), no time to relax (OR=1.57) and poor health status (OR=3.48). Relative high levels of anxiety existed in family caregivers, which was found to be a complex process, influenced by diverse care recipients and caregivers' characteristics. Results showed that the older the caregiver was, the more time spent in providing daily care. The poorer their perceived health condition, the more the absence of daily exercises, relaxation time, and the higher the detection rate of anxiety</p>
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			among family caregivers with lower social support.
Qu et al. (2019)	<p>1. Survey Study</p> <p>2. 612</p> <p>3. Chronic and non-chronic health conditions not specified</p> <p>4. Heilongjiang Province</p> <p>5. Gender: Male: 276 (45.1%); Woman: 336 (54.9%). 307 persons (50.2%) were employed. Duration of care/day: <6hrs: 395 (64.5%), 7-12hrs: 144 (23.5%) and >13hrs: 73 (11.9%)</p>	<p>Stressors</p> <p><i>Caregivers' characteristics: poor health, balancing work, and family demands.</i></p> <p><i>Financial circumstance</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>Family caregivers reported a prevalence rate of 81.4% for depressive mood. The average score of SDS was (57.15±9.61). The influencing factors of depressive mood in caregivers (P<0.05) included balance of payments for older relatives' [balance of payments OR (95%CI) = 0.023 (1.106-3.766) , expenditure over income OR (95%CI)=1.773 (1.015-3.099)] , family caregivers rated themselves as having poor health OR</p>

			(95%CI)=5.612 (1.259-25.022) , caregiver burden status OR (95%CI) = 1.029 (1.009 - 1.050) , caregiver family and work demanding situation OR (95% CI) = 1.072 (1.026-1.119).
Shen et al. (2019a)	<ol style="list-style-type: none"> 1. Survey Study 2. 601 3. Older people with disability. 4. Nanjing 5. Mean age: 48.36 (SD 16.14); Gender: Male: 310; Female: 291. Relationship 	<p style="text-align: center;">Stressors <i>Caregiving role</i></p> <p style="text-align: center;">Coping <i>Family, market and governmental support.</i></p>	All participant groups experienced moderate stress levels, increasing with time with the highest level reported by spouses. Different relatives received different levels of support from the market, family members and the government with spouses receiving less support from the family members and

	<p>with care recipient: Spouse: 514; Offspring: 53; Other: 34</p>		<p>the market but more subsidy from government. All groups reported psychological stress > financial stress> physiological stress. Most caregivers received support from family members. Spouse (72.37%); Adult Children (78.72%); Relatives (73.44%). Smaller numbers sought support from businesses: Spouse (24.80%); Adult Children (40.66%); Relatives (39.47%). Where caregivers sought support from the public service over 75% were very unsatisfied</p>
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			or unsatisfied with the services.
Shen and Wang, (2016)	<p>1. Cross-sectional</p> <p>2. 605</p> <p>3. Over 60- disability</p> <p>4. Nanjing</p> <p>5. Gender: Male: 51.41%; Female: 48.59%. Average monthly economic income: 0-1999 Yuan: 11.2%; 2000-3999 Yuan: 42.2%; 4,000-5999 Yuan: 31.0%; 6,000-7999 Yuan: 8.7%; > 8000 Yuan: 7.0%.</p>	<p>Stressors</p> <p><i>Lack of care information</i></p> <p><i>The health status of the caregivers</i></p> <p><i>Health status of the care recipient: self-care ability</i></p> <p><i>Duration of care</i></p> <p>Coping</p> <p>Family support</p>	<p>Older caregivers with higher family economic income were willing to buy care services. Caregivers with children were more willing to buy care services. The lower the self-care ability of care recipients, the stronger the willingness of family caregivers to purchase care services. The longer family caregivers took care of care recipients”, the stronger their willingness to buy care services, but in cases where someone came to the assistance of</p>

			caregivers, there was a decline in their willingness to buy care services. With heavier physical and psychological burdens, the willingness to purchase care was greater.
Song, (2018)	<p>1. Cross-sectional study</p> <p>2. 219</p> <p>3. 24.5% of the older people can take care of themselves, 48.5% are semi-bedridden, and 27.0% are completely bedridden</p> <p>4. Shandong</p> <p>5. Gender: Female: 61.9 %.</p> <p>Age: ≤35: 9.1%; 36-44: 25.6%; 45-54: 47.5%; ≥55: 14.6%.</p>	<p>Stressors</p> <p><i>Time providing care</i></p> <p><i>Individual characteristics</i></p> <p><i>Family characteristics and cultural value</i></p> <p><i>Family support</i></p> <p><i>Financial pressure</i></p> <p>Coping</p> <p>Not reported</p>	Caregivers were mostly family members who were older people and were spouses. More than 60% of caregivers who provided long-term care were aged 45 and above. Caregivers' burden was influenced by individual characteristics of caregivers, family characteristics and the family support. These factors were found to have

			<p>had an important impact on caregivers' sense of burden. Caregivers living with long-term conditions associated care with a greater burden. As caregivers aged, awareness of their responsibilities for caring increased significantly, showing a greater recognition for caring activities, and a decrease in the sense of burden. Caregivers with better self-rated health, tended to have more negative attitudes towards caring for older people and felt more burdened.</p>
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<p>Tang, Y. (2006)</p>	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 300 3. Not specified 4. Chongqing 5. Gender: Male: 48.7%; Female: 51.3%. Education: 36.7% graduated from senior high school; 28.1% from junior college; 15.1% were college students or above. All caregivers were offspring (adult-children). 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Financial difficulties</i></p> <p style="text-align: center;"><i>Time of caregiving</i></p> <p style="text-align: center;"><i>Caregivers' psychological status</i></p> <p style="text-align: center;"><i>Caregivers' physical status</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	<p>Men and women showed statistically significant differences in economic, time and psychological stress. Married sons and unmarried sons felt more economic pressure, while daughter-in-law and married daughters felt more time and psychological pressure. Time was the most stressful aspect of care, followed by psychological and financial difficulties. Respondents stress scores were greater than three, which indicated that they faced a medium level of</p>
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			stress over a short duration of care.
Tong, (2018)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 90 3. Spinal cord injury 4. Shenyang 5. Gender: Female :67, Male: 23. Age range: 18 -70 years; Average age: 45.62± 4.19. Caregivers without help: 67. Caregivers with poor health status 51. Nursing time range: 4 -24 hours. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Health status of caregivers</i></p> <p style="text-align: center;"><i>Caregiving time</i></p> <p style="text-align: center;"><i>Lack of nursing care support</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	Caregivers had moderate nursing burdens. The health status contributed to the caregiving burden, as some care givers had their own long-term conditions, daily care time and lack of support in terms of nursing care.
Jiang et al. (2015)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 64 3. Alzheimer's disease 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Physical health status</i></p> <p style="text-align: center;"><i>Financial difficulties</i></p>	The SCL-90 total scores and the scores of somatisation, compulsion, interpersonal sensitivity, hostility, terror, paranoia

	<p>4. Chongqing</p> <p>5. Gender: Male: 28; Female: 36. Age: <50: 15; ≥50: 49. Relationship with care recipient: Spouse: 26; Child: 33; Other: 5.</p>	<p>Coping <i>Subjective social support</i></p>	<p>and psychosis of family caregivers of care recipients were significantly higher than those of the Chinese norm ($P < 0.05$ or $P < 0.01$). The SCL-90 scores of family caregivers with a somatic disease, high medical expenses and care for patients of mixed dementia were significantly higher than those with no disease, low medical expenses, and care for patients with a common type of dementia ($P < 0.01$). The total score of SCL-90 of family caregivers was significantly positively correlated with</p>
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			<p>the ZBI total scores (r=0.924, P < 0.01), and significantly negatively correlated with the SSRS total scores (r=-0.288, P <0.05), and significantly negatively correlated with the subjective support score (r=-0.355, P < 0.01). The main influence factors, according to the partial regression coefficient from large to small, were ZBI total score, MMSE score, the types of dementia, ADL scores, subjective support and the body disease (β) =0.831, 0.186, 0.145, 0.108, 0.089, 0.081, R²=0.892. Home</p>
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			caregivers of patients with AD had poor mental health.
Wang et al. (2015)	<ol style="list-style-type: none"> 1. Cross-sectional study. 2. 152 3. Dementia 4. A capital city of a province 5. Gender: Male: 43; Female: 109. Employment status: Employed: 39; Unemployed: 113. Relationship with care recipient: Spouse: 55; Non spouse: 97. Co-residence: No: 35; Yes: 117. Financial burden: No: 68; Yes 84. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Caregiving demands</i></p> <p style="text-align: center;"><i>Behavioural management</i></p> <p style="text-align: center;"><i>Gender</i></p> <p style="text-align: center;"><i>Family support</i></p> <p style="text-align: center;"><i>Time dependency</i></p> <p style="text-align: center;"><i>Financial difficulties</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	<p>Higher levels of stress and prevalence of Behavioural and Psychological Symptoms of Dementia (BPSD) was reported. Women reported higher levels of stress compared to male counterparts. The more helpers available to assist caregivers, the higher the level of distress experienced. This was attributed to lack of support for caregivers of people living with Dementia, i.e., lack of dementia education for caregivers and health care professionals to help</p>

			manage daily. Some caregivers reported having financial difficulties.
Wang et al. (2019)	<p>1. Cross-sectional study</p> <p>2. 208</p> <p>3. Chronic heart failure</p> <p>4. HaErbing</p> <p>5. Gender: Male: 51; Female: 157. Age: <60 years: 92; 60-70 years: 69; 70 years and above: 47. Marital status: Married: 173; Unmarried: 35. Education: Middle school and below: 89; High school and above: 119. Income: < 3000 Yuan: 73; > 3000 Yuan: 135. Employment</p>	<p>Stressors</p> <p><i>Financial difficulties</i></p> <p><i>Care recipient ability to self-care</i></p> <p><i>Age of caregivers and resident status</i></p> <p><i>Caregiving time</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>The age, residence, work and daily care hours of the carers were associated with level of caregivers' burden. Caregivers whose older relative had to self-fund their treatment experienced a higher level of caregiving burden compared to those who had access to public services. Care recipients who could barely attend to personal needs were highly dependent on caregivers, increasing their burden.</p>

	<p>status: Employed: 83; Not employed: 67; retired: 58.</p> <p>Relationship with care recipient: Spouse: 92, Offspring: 79, Others: 37.</p> <p>Caregiving time (hrs): < 3: 29; 3-6: 74; > 6: 105.</p>		<p>Older caregivers experienced higher levels of burden and caregivers who lived with care recipients showed a higher level of burden.</p>
<p>Wang et al (2020)</p>	<p>1 Survey</p> <p>2 212</p> <p>3 Dementia</p> <p>4 Jiangsu province</p> <p>5 Average age: 61.34±8.07, Gender: Male: 71 (33.49%), Female: 141 (66.51%).</p> <p>Relationship: Spouse: 104 (48.51%), Children: 93 (44.55%), Others: 15 (6.94%)</p>	<p>Stressors</p> <p><i>Caregivers' characteristics</i></p> <p><i>Relationship status</i></p> <p><i>Physical health status</i></p> <p><i>Financial circumstances</i></p> <p>Coping</p> <p><i>Social support – mitigated anxiety levels</i></p>	<p>Caregivers aged ≤59 years had lower anxiety levels than caregivers aged ≥60 years; Caregivers with the educational level of high school or above had the most serious anxiety, followed by junior high school. The anxiety level of caregivers with social support was lower than that of caregivers without social support; Caregivers who</p>

			<p>were spouses experienced the most anxiety compared to offspring. Longer duration of hands-on care caregiver resulted in high anxiety levels. The anxiety of caregivers in good health was lower than that of caregivers in poor health. Caregivers who had to pay by themselves experienced higher levels of anxiety compared to those with medical insurance and were reimbursed. Higher anxiety was associated with the severity of care recipients' health condition. The anxiety status of primary</p>
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			caregivers was positively correlated with their psychosis and neuroticism.
Wei et al. (2014)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 744 3. Disability (High blood pressure (72.7 %). Stroke (50.5%). Coronary heart disease (48.4%). Diabetes (41.3 %). Osteoarthritis (30.9%) 4. Beijing 5. Age range: 26 - 89 years. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Living arrangement</i></p> <p style="text-align: center;"><i>Caregiver's self-reported health status caregivers</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Social support</i></p>	The prevalence rate of anxiety was 29.2% reported by family caregivers. The average score of SAS was 35.6 ± 8.6. The risk factors of caregivers' anxiety included Barthel index score ≤ 20 (OR=1.51), SSRS score ≤ 33 (OR=4.56), no time to relax (OR=1.57) and poor health status (OR=3.48). A high level of anxiety exists in family caregivers for the disabled elderly. Caregiver anxiety was a complex

		<p>process. The results showed that the older the caregiver was, the more time spent in daily care, the poorer their perceived health condition, lack of daily exercise and relaxation time. There were higher detection rates of anxiety among family caretakers with lower social support.</p> <p>Regarding social support for family caregivers, difference between caregivers' older relatives with anxiety and those with no anxiety was found to be statistically significant.</p>
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<p>Yang and Hong (2019)</p>	<p>1 Survey 2 94 3 Dementia 4 Xiamen, Fujian province 5 Mean age of caregivers was (59.63± 10.75) years old. Gender: 52 Males (55.32%) and 42 Females (44.68%). Education: Primary school or below: 61, (64.89%); Middle school or above: 33, (35.11%). Relationships: children: 37 (39.36%), and spouse: 34 (36.17%), daughter-in-law: 18 (19.15%). Other :5(5.32%).</p>	<p>Stressors <i>Role appraisal</i> <i>Caregiving time</i> <i>Lack of adequate knowledge about dementia management</i></p> <p>Coping <i>Not reported</i></p>	<p>Role recognition was low, which was a function of willingness, acknowledgement of their role and duty to care, and taking responsibility to care. Most caregivers regarded care as an obligation and lacked adequate knowledge about dementia management. Caregivers with longer care hours per day had higher overall burden score.</p>
<p>Yang and Li (2019)</p>	<p>1 Survey 2 130</p>	<p>Stressors <i>Age of caregiver</i></p>	<p>The total score of burden feeling of caregivers was (19.47±9.92). The</p>

	<p>3 Chronic conditions (Not specified). One condition: 71, co-morbidity: 48, multi-morbidity: 11.</p> <p>4 Fujian province</p> <p>5 Average age (57.45±9.44). Gender: Male: 47 (36.2%), Female: 83 (63.8%).</p> <p>Relationship with care recipient: Spouse :22 (16.9%), Children: 59 (45.4%), Relatives :22(16.9%), Others: 27 (20.8%)</p>	<p><i>Self-care ability of care recipients</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>regression analysis results showed that age and patients' self-care ability were the influencing factors of caregivers' burden perception.</p>
<p>Yu et. al (2013)</p> <p>.</p>	<ol style="list-style-type: none"> 1. Cross sectional study. 2. 121 3. Stroke. 4. A city in central China 	<p>Stressors</p> <p><i>Time dependence</i></p> <p>Coping</p> <p><i>Problem solving coping</i></p> <p><i>Social support</i></p>	<p>MCS correlated with the Barthel index (BI) of care recipients, which showed that functional independence of care was associated with high MCS score. The Mental</p>

	<p>5. Age (years): <45: 5; 46–64: 38; >65: 78. Age range: 32-82. Gender: Male: 33; Female: 88. Marital Status: Single: 1, Married: 110, Divorced: 2, Widowed: 8. Relationship with care recipient: Spouse: 96; Offspring: 15. Employment status: Unemployed: 5; Retired: 101; Employed: 2; Other: 13.</p>		<p>Component Summary (MCS) sub-scale of HrQoL negatively associated with the number of caregiving hours per day, and the number of caregivers' long-term conditions. Problem focused coping strategies, active coping and planning were found to positively correlate with caregivers' mental health. Caregivers perceived social support mainly came from family members and neighbours and the least amount of support came from their friends.</p>
Yu et al. (2015)	1. Cross-sectional study	<p>Stressors <i>Attributes of care recipient</i></p>	Cognitive functioning in care recipients negatively

	<p>2. 168</p> <p>3. Alzheimer's</p> <p>4. Taiyuan</p> <p>5. Gender: Male: 53, Female: 115. Relationship with care recipient: Spouse: 71; Offspring: 77; Others: 20.</p>	<p><i>Time dependency</i></p> <p>Coping <i>Not reported</i></p>	<p>associated with caregiving burden Inventory (CBI) scores: with lower cognitive function in care recipients, higher CBI score was noted. Other sources of stress related to Activities of daily living (ADL) and behavioural challenges. Care recipients with impaired cognitive functioning reported higher level of dependency on caregivers with regards to ADL. Behavioural challenges predicted the cognitive status of care recipients. Hours of caregiving was reported to</p>
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			be directly proportional to reported CBI scores.
Zhang et al. (2013)	<ol style="list-style-type: none"> 1. Survey study 2. 58 3. Dementia 4. Wuhan 5. Gender: Male: 16; Female: 42. Age range (Years): 42–66. Average age: 49.8±9.2 years. 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Lack of adequate support</i></p> <p style="text-align: center;"><i>Lack of skillsets</i></p> <p style="text-align: center;">Coping</p> <p style="text-align: center;"><i>Not reported</i></p>	Psychiatric distress was found to be associated with a lack of adequate understanding, as caregivers lacked the skill set needed to provide care. Family functioning was low and had adverse implications on problem-solving and communication skills, affective responsiveness, behavioural control and general functioning.
Zhao, (2011)	<ol style="list-style-type: none"> 1. Cross-sectional study 2. 536 3. 157(29, 29%) cases of chronic cardiovascular 	<p style="text-align: center;">Stressors</p> <p style="text-align: center;"><i>Personal factors</i></p> <p style="text-align: center;"><i>Social pressure</i></p> <p style="text-align: center;"><i>Financial pressure</i></p>	Personal and social strains were the most important pressure faced by caregivers. This was

	<p>diseases; 209 (38.99%) cases of cerebrovascular diseases; 138(25.75%) cases of chronic respiratory diseases; 32(25.75%) cases of endocrine and immune system diseases.</p> <p>4. Shandong.</p> <p>5. Gender: Female: 297; Male :239. Age range: 60-80; Average: 69±4.23. Relationship with care recipient: Spouses.</p>	<p><i>Mental stress</i></p> <p>Coping</p> <p><i>Not reported</i></p>	<p>followed by work strain and financial strain. The psychological strain of spouses was relatively lower. The pressure associated with caring responsibilities was found to be responsible for caregivers' anxiety and depression symptoms and made caregivers' health self-evaluation worse. In terms of the needs of caregivers, among the 536 patients' spouses: 88.0% were eager to learn about how to nurse older relatives.91% wanted to communicate with nurses.27.6% wanted to</p>
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			<p>communicate with nurses generally. 57% wanted to communicate with nurses about patients' conditions. 66% wanted to communicate with nurses about nursing knowledge, as most caregivers struggled with the daily management of their loved ones.</p>
<p>Zhao, T., Li, J. and Xing, F (2021)</p>	<p>1 Survey study 2 284 3 Not specified 4 Tangshan, Hebei 5 Not specified</p>	<p>Stressors <i>Financial circumstance</i> <i>Social roles</i> <i>Health status of care recipient</i> Relationship status</p> <p>Coping <i>Not reported</i></p>	<p>The score of spouses' caregiving burden was (35.36 +/- 21.53), which indicated moderate burden; The family function score was (154.71 +/- 16.86), which indicated that the family function was normal.</p>

			Multiple linear regression showed that the monthly income of the care recipient, the number of chronic diseases, the relationship with the care recipient and family function were the main factors affecting the spouse's care burden.
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2.3.3 Synthesis of Results

Six themes were derived that related to caregiving stressors: Caregiving time, financial resources, role and personal strains, preparedness, social roles and lack of adequate formal support. Only one theme was identified that focused on coping. Each theme will now be discussed in turn.

2.3.3.1 Caregiving time

Twenty-eight papers referred to caregiver stress related to time spent performing caregiving duties. Across all the papers, a longer duration of caregiving was associated with higher levels of personal stress (Tang 2006; Liu et al. 2012; Guogui et al. 2017; Lu et al. 2017; Liu et al. 2018; Song 2018; Tong 2018; Liu et al. 2019), especially as the care recipients' ability to self-care decreased (Lv et al. 2013). Family members involved in caregiving were susceptible to low social functioning and reduced relaxation time (Yu et al. 2013; Qian et al. 2014; Guogui et al. 2017; Wang et al. 2018; Shen et al. 2019b). This resulted in physical and mental exhaustion (Hu et al. 2019), and ultimately, anxiety due to the long duration of care provision, which was contingent on the physical health status of caregivers as those with good physical health experienced less anxiety and vice versa (Wang et al. 2020b). This was partly due to the time needed to meet the increasing needs of care recipients (Liu et al. 2012; Du et al. 2014; Yu et al. 2015; Yang and Hong 2019). Consequently, caregivers tended to struggle to meet both care duties and work demands, which tended to impede caregivers' personal lives and social engagement (Liu and Zhou 2009; Liu et al. 2015; Hu et al. 2019) and career development (Pan et al. 2018). In addition, the difficulty of balancing full-time employment and relationship predisposed older caregivers to anxiety and depression (Li et al. 2019b; Qu et al. 2019). As the culture of Xiao

encouraged caregivers to care for older relatives at home, some caregivers questioned the duration of their caregiving role as they felt helpless, anxious and fatigued due to lack of respite (Tang 2020). More specifically, a study that explored the experiences of caregivers who were in work (Pei et al. 2017) reported an additional 5 per cent chance of losing a job with every one-hour/week increase in providing care. Care recipients who were dependent on public funding experienced higher levels of burdens compared with those who were able to fund care themselves (Yong 2012). This, in turn, had a ripple effect on poorer caregivers, who moved in with care recipients in order to meet their needs (Wei et al. 2014; Wang et al. 2019).

2.3.3.2 Financial resources

Twenty-one papers indicated that there were financial implications to providing care. Liu et al. (2013) found that widowed, unmarried, or divorced caregivers with poor health reported significant levels of economic stress. One female caregiver, for instance, took on care responsibilities with no financial support from siblings (Liu 2016b). In other cases, older caregivers living with long-term conditions had limited financial resources to meet personal needs and that of the care recipient (Lu et al. 2017; Wang et al. 2019). Over time, family caregivers faced financial pressure from the inevitable increase in the medical needs of older relatives (Chen 2017; Liu et al. 2017b). The high costs of health and social care could be challenging for low income families (Liu et al. 2019), especially where medical bills were concerned (Li et al. 2009; Liu and Zhou 2009; Lv et al. 2013). Many family caregivers were subjected to financial distress (Li et al. 2019b; Zhao et al. 2021) due to the exorbitant cost of medical expenses for the care recipients, which resulted in anxiety for those without medical insurance who had to make

out of pocket payments (Wang et al. 2020b). In some cases, this contributed to the psychological burden they experienced (Yong 2012; Liu et al. 2013; Du et al. 2014; Jiang et al. 2015; Liu 2016b; Du et al. 2017; Pei et al. 2017; Song 2018). As such, caregivers experienced relatively high social dissonance due to their inability to fulfil obligations well and persistent physical exhaustion, which curtailed opportunities to socialise (Lv et al. 2013) and was likely responsible for the depressive moods in older caregivers (Qu et al. 2019).

2.3.3.3 Role and personal strains

Fifty-one papers referred to either role or personal strains. Role strains arose when the caregiving role precluded the caregiver from fulfilling other obligations, as parent, spouse, or employee. Twenty-eight papers showed that caregivers felt trapped due to caregiving demands, especially those who had poor health status (Liu and Zhou 2009; Liu et al. 2015; Liu 2016b; Shen and Wang 2016; Chen 2017; Guogui et al. 2017; Tong 2018). The high dependency of care recipients on caregivers, characterised by the severity of their long-term conditions and poor communication skills, placed demands on caregivers (Li et al. 2009; Chen et al. 2017; Liu et al. 2017b; Song 2018; Li et al. 2019a). This may relate to the findings of Wei et al. (2014) and Wang et al. (2019), who found caregivers who were co-resident with care recipients were expected to meet the needs of their older relatives at any time, and this negatively impacted their well-being. Caregivers were left socially restrained and with no option but to meet the demands associated with their role, resulting in depression, loneliness, moral distress and adverse physical health (Chen et al. 2020) due to lack of freedom (Hu et al. 2019). Role assimilation for some caregivers was particularly difficult as they could not endure the demands of their role due to a lack of adequate knowledge about

dementia management (Yang and Hong 2019). Additionally, older caregivers experienced more stress as the care recipients' ability to self-care reduced (Lv et al., 2013). By contrast, Li et al. (2013) found that stress levels were lower in co-resident caregivers, especially those who were proficient in nursing care; the better the skills of caregivers, the better they were at coping with the demands of the role. Further, Qiu et al. (2017) noted that caregivers prioritised the well-being of care recipients at the expense of their own health and felt obliged to expend their energy before seeking help from others.

Due to competing demands of employment and caregiving, some caregivers gave up their jobs or reduced working hours to accommodate care responsibilities, which significantly increased caregiving burden (Pan et al. 2018). The demands or anticipation of providing hands-on care also gave caregivers the impression that they were not in control of their own lives (Davis et al. 1995; He et al. 1995; Liu 2016b). For instance, caregiving demands created a sense of isolation, leaving caregivers disconnected from others. Caregivers noted that 'no-one cares' about them; reflecting changes in society (Zhang et al. 2019a). Lack of control was also associated with the uncertainties of how to address the health condition of older relatives, ranging from the incurable nature of the condition to managing the implications of diagnosis, especially if society had negative perceptions of the condition (Lian et al. 2017). Role strain could also be a function of the cultural environment as caregivers had to manage the demands of their role, which predisposed them to a range of mental health conditions (Wang et al. 2020b). Family functioning was adversely affected (Zhao et al. 2021) for spouses who were caregivers dealing with personal co-morbidities and multi-morbidities. Also, societal pressures to hide the existence of dementia, coupled with negative

experiences of attempts to use social services and the lack of appropriate long-term care facilities, left families caring without outside help (Sun 2014). This could consequently place strain and cause conflict in family relationships.

Twenty-three papers highlighted issues relating to the personal strains of caregiving. These personal strains were associated with a range of factors. He et al. (1995) found that the physical and mental health of caregivers were adversely affected in cases where caregivers were older people (85 years and above), female, and uneducated, and the care recipient was male. Similarly, caregivers' age, education level, nature of social support and relationship status were all related to the anxiety levels of caregivers (Wang et al. 2020b). The age of caregivers and self-care capabilities of care recipients were associated with perceptions of caregiving demands (Yang and Li 2019). Reduction in physical, cognitive and behavioural capabilities of the care recipient (Qian et al. 2014; Sun 2014; Jiang et al. 2015), as well as older age and poorer health status of caregivers (Lu et al. 2017; Pan et al. 2018; Tong 2018; Liu et al. 2019; Qu et al. 2019; Wang et al. 2019), contributed to higher levels of personal caregiver stress (Shen and Wang 2016). Particular caregiving activities were found to be personally stressful, especially when caregivers had to manage the care recipient's behaviour (Fu et al. 2007; Lu et al. 2015; Wang et al. 2015; Yu et al. 2015) which disrupted caregivers' plans for social outings or hobbies (Zhao 2011; Liu et al. 2015). Caregiver stress could precipitate breakdown in family relationships (Liu 2016b), especially when caregivers perceived pressure from caring responsibilities (Chen 2017), had no time to consider personal preferences (Yong 2012) and further threatened the physical health of older caregivers (Hu et al. 2019; Li et al. 2019b).

2.3.3.4 Preparedness

Five papers identified the role of caregivers' preparedness. Caregivers felt unprepared for meeting the needs of care recipients (Liu and Bern-Klug 2016), as they were anxious, for instance, about post-diagnostic management, felt they lacked appropriate skills (Chen 2017; Lian et al. 2017), and were anxious about unexpected incidents (Hu et al. 2019). Most caregivers were non-medical personnel and lacked training and awareness about their role (Hu et al. 2019), particularly as the younger generation of caregivers struggled to meet care recipients' needs compared to the previous generation who were now care recipients; this resulted in burden and a reduced quality of care. Wang et al. (2018) suggested that caregivers would benefit from psychological counselling to address the consequences of lack of preparedness to ease some pressure.

2.3.3.5 Social roles

Twelve papers considered gender influence in the context of caregiving. Women were considered emotionally susceptible to the pressures of caregiving, especially as they were predominantly providing hands-on care (Tang 2006; Fu et al. 2007; Wang et al. 2015; Song 2018). Women were also found to experience more physical stress compared to men (Pei et al. 2017). Men, who did little or no hands-on care were considered privileged, with better opportunities to acquire health-related knowledge and social resources (Lu et al. 2017). In some cases, men also experienced negative aspects of caregiving (Song 2018). For example, 'eldest sons' were found to be more susceptible to stressors such as financial pressures (Tang 2006; Liu et al. 2013). Co-residents and daughters, who are societally expected to provide care, often had to provide care unfailingly, and this subjected these caregivers to stress (Liu and Bern-Klug 2016; Liu 2016b).

However, despite differing gendered expectations placed on caregivers by their environment, their efforts were not equally valued by their communities. Caregivers had to persevere through stressful situations, which outweighed their willingness to care (Chen et al. 2020), further compounded by social insensitivity, and this resulted in tiredness and exhaustion (Tang 2020).

2.3.3.6 Lack of adequate formal support

Twenty-six papers referred to the lack of adequate formal support from health and social care. There was copious evidence of caregivers lacking the knowledge and skills to meet the needs of care recipients, and this was associated with adverse health outcomes and negative experiences (Fu et al. 2007; Zhang et al. 2013; Wang et al. 2015; Liu 2016b; Guogui et al. 2017; Liu et al. 2017b; Liu et al. 2018; Wang et al. 2018; Liu et al. 2019). The absence of adequate formal support implies that relatives had to rally around primary caregivers for support. However, too little or too much relative input could equally be a source of stress (Chen 2017; Song 2018). In addition, caregivers expressed concerns about the societal rejection of people living with dementia due to stigma and misunderstanding.

The cultural environment did not necessarily afford caregivers adequate resources (Xiuxiang et al. 2020), mostly because dementia was considered incurable, and there was either lack of staff at community centres, lack of assessment tools or unaffordable costs for assessment. In these circumstances, caregivers sought advice within their social network, not from professionals (Lian et al. 2017). Similarly, caregivers lacked professional support from primary health workers (Liu et al. 2012; Chen et al. 2020). It was suggested that geographical distance between caregivers and care recipients could be a source of stress (Guogui et al. 2017) as the lack of local care services leaves caregivers with very

limited options for delegation of caregiving tasks. In some situations, where caregivers had to enrol older relatives in day-care centres, they found issues relating to transport and irregular opening times of services challenging (Tang 2020). Caregivers in one study expressed significant dissatisfaction with the comparatively low subsidy for care purposes and low levels of public service provided by the government (Shen et al. 2019a). This was further compounded by the lack of long-term care facilities (Du et al. 2017). In addition, the absence of services to signpost caregivers to available community resources (Yong 2012; Shen and Wang 2016) could perhaps explain the negative impacts of caregiving on health and finances (Liu and Lou 2012).

Depressive symptoms were significantly associated with time dependence, physical burden, and social burden (Lu et al. 2015). Lu and colleagues found that being younger, living with older relatives, having a higher income and shorter informal care hours were also associated with lower levels of physical burden i.e., moving and handling of care recipients and supporting activities of daily living. This suggests that higher physical burden in caregivers could result in low levels of satisfaction, which could result in conflict between family members, and manifest as a low level of support (Zhang et al. 2013). In support, Qiu et al. (2017) study found that poor social support services and limited access to information tended to impede caregivers from using formal services, resulting in caregivers feeling despondent and isolated. Moreover, in cases where caregivers had access to community services, health key workers were perceived to be unempathetic and inconsiderate (Yong 2012), and consequently, some had to endure significant hardship due to lack of social and psychological support (Hu et al. 2019).

2.3.3.7 Coping

Only eighteen papers explored how caregivers were coping. Studies indicated a range of sources of external support was used. Shen et al. (2019a) found that caregivers sought support from family members, professional care services and care-related government subsidies. Only 5% of their study respondents found the Government subsidy package somewhat useful. As most caregivers did not engage with professional services (Wei et al., 2004), Pan et al. (2018) and Chen et al. (2020) found that most caregivers sought support from relatives, friends and society and that the level of social support was moderate. In some cases, caregivers over 65 years of age had to rely on their family members and neighbours as they had only a few close friends to assist further (Yu et al. 2013).

Caregivers' provided assistance as an act of being filial to parents (Liu 2016b). Practical family and social support reduced caregiving burden by reducing the time caregivers devoted to caring and providing some respite (Li et al. 2009; Shen and Wang 2016; Wang et al. 2020b). In other cases, family members took the caregiving role in turn (Yong 2012). Some adopted distraction techniques and chose to rest (Chen et al. 2020). Conversely, Wang et al. (2015) reported that increased numbers of social support 'helpers' were associated with higher levels of caregiver distress. In the absence of social support, however, Liu et al. (2018) found that some caregivers became sleep-deprived, which was associated with higher levels of depressive symptoms, and social support was protective with regards to the depressive symptoms experienced by caregivers.

In terms of emotion-focused coping, caregivers generally accepted their situation (Qiu et al. 2017) and used emotion-focused strategies such as dancing, singing, listening to music and gardening, to cope with anxieties and frustrations

associated with their role (Sun 2014). They coped with social pressures through avoidance, escapism and providing justifications for actions. In addition, they coped with the demands of their role and developed self-confidence by drawing upon their moral qualities, including their sense of duty and responsibility (Davis et al. 1995; Qiu et al. 2017). Qiu et al. (2017) further stated that caregivers coped by drawing on their inner strength, which is an influence of the principles of traditional Confucianism such as Ren (endurance of suffering). Many had to sacrifice 'self' (Tang 2020) and sought for hope through beliefs of the value of Buddhism (Xiuxiang et al. 2020). Despite the resilience that could be gained, some caregivers were unable to cope and were filled with regret (Chen et al. 2020). Offspring of older people were found to need more support compared to spouses and other relatives. Emotional support from their social network reduced the level of burden they experienced (Wei et al. 2014). Caregivers believed that providing care for older relatives was the right thing to do based on their cultural values, and as a result, they coped by making self-sacrifices (Liu 2016b; Qiu et al. 2017; Xiuxiang et al. 2020). There was an expectation for immediate family members to provide care for their older relatives, regardless of receiving substantial support or not.

In terms of problem-focused coping, caregivers planned, actively sought care knowledge, mastered care skills, and positively reframed their experiences (Yu et al. 2013; Sun 2014; Qiu et al. 2017). For example, some caregivers sought advice from social networks and engaged with formal services (Lian et al. 2017; Chen et al. 2020) by seeking information to ground decisions and explore options, as they adopted the use of technology for safeguarding reasons (Chen et al. 2020). Liu et al. (2012) and Xiuxiang et al. (2020) found that in the absence

of general practitioners, caregivers made use of media such as books, television, radio, and newspapers as sources for knowledge, acquired skills via TV programmes, walked, sang and enrolled in fitness courses. In addition, some caregivers utilised a distinctive coping strategy, namely, a 'family-connected strategy' (Qiu et al. 2017). More specifically, Sun (2014) stated that caregivers coped with family challenges by planning ahead and engaging in direct confrontations as they perhaps had no option but to choose to accept challenging situations and persevere with their responsibilities. To cope with financial difficulties, caregivers actively searched for jobs and sought assistance through governmental agencies. Some combatted social isolation by playing games at home (Chen et al. 2020).

2.4 Summary and conclusion

Even though caring responsibilities are culturally ingrained as paramount, the results of this scoping review indicate that little is known about the holistic needs of the caregivers whose role is fundamental to sustaining the society. As such, it can be inferred that little attention has been paid to the intricacies of their burden. Areas relating to selfhood (implications of the process of caregiving on social identity), sociality (implications of caregiving process on relations with others), embodiment (implications of the process of caregiving for gender, body sensations and "disability"), temporality (implications of the process of caregiving for time) and spatiality (implications of the caregiving process for place) have not yet been captured adequately (Ashworth 2006). The association between caregiving and stress implies that caregivers feel excessively taxed. Consequently, this could progress to caregivers suppressing their emotions and limit their ability to exercise agency. In the absence of holistic consideration of

the needs of caregivers, this scoping review showed that a significant number of papers pertained to personal and role strains. Some caregivers felt trapped by their role, in the sense that although they were not particularly unhappy with providing care for their older relative, they resented their inability to pursue their personal goals and ambitions. Even though they were fulfilling Xiao and their legal responsibilities to meet their older relative's financial, emotional, and physical needs (Xu et al. 2018), within the context of role captivity, the lack of change for caregivers could be detrimental to their well-being. More specifically, with the socio-demographic transitions in China, Generation X and Millennials (those born from the year 1965 – 2000) must reconcile the key messages about Xiao from their childhood with the need to capitalise on economic opportunities, taking opportunities that life presents alongside managing being solely responsible for their ageing parents.

Continuously adapting to the changing needs of care recipients to manage this reconciliation can further exacerbate psychological stress, which can have adverse implications for self-efficacy and role appraisal (Montgomery and Karl 2009). More specifically, in situations where caregivers are no longer able to cope with increased demands and having in mind transitions regarding traditional values, Fang et al. (2018) showed that highly dependent Chinese older people are more susceptible to physical and psychological abuse at the hands of family caregivers when compared to their counterparts in Western societies. Despite the association between stressors, coping, care provision and the cultural context, only a few papers discussed how prepared caregivers were to take on caring. The lack of preparedness of caregivers, found in this review, reinforces

the point that caregivers of older relatives are simply expected to get on with their responsibilities. This highlights a gap between care provision and education.

Therefore, there is a need to develop and evaluate appropriate educational interventions to support caregivers and address their lack of preparedness. Such interventions would need to acknowledge that caring for older relatives in China is multidimensional and pay attention to the influence of the individual's socio-cultural environment on the process of caregiving, which has implications for caregivers' appraisal of their roles. As such, instead of focusing solely on families' obligations to care, the pertinent question is, how can families be supported to fulfil this responsibility?

Although the papers reviewed cover a span of 26 years during which socio-economic and cultural environments in China have evolved rapidly, it was not possible to extract a definite sense of how care practices and meanings attached to care-giving have changed over this period. However, I noted that only three papers in this review were published between 1995 and 2006, all focusing on whether there was caregiver stress. In the period from 2007 to 2021, there have been increasing numbers of publications (2007–2011: 4 papers; 2012–2016: 20 papers; 2017–2021: 29 papers) focused on a wider range of facets of caregiving. Given that the country had very limited time to prepare for transition into an ageing society, an explanation for the increase in the numbers of papers published could be researchers' response to the increasing prominence of the implications of socio-economic and cultural transitions on the role of caregiving over time. Quantitative measures of caregiving burden and coping, as employed by most papers in this review, can provide researchers or policymakers with a baseline and help identify unmet needs, but they do not provide insight into the

complexities underlying caregiving processes. Less than a quarter of the total number of studies (13) reviewed utilised qualitative methodologies, yet such methodologies potentially could provide a deeper insight into issues such as coping, particularly as so few studies have explored this. In the absence of sufficient evidence to determine the types of care services that will best serve older peoples' needs (Yang et al. 2021a), qualitative methodologies would be useful in providing a contextualised understanding of caregiving that could inform policy for future service development as nature of intergenerational supports have implications on older relatives' well-being (Yang et al. 2021b).

In the context of the pressure of an ageing society, major healthcare and societal challenges, questions persist over whose interest filial piety (Xiao) serves. Therefore, it is important to understand how current and future caregivers are thinking, feeling, and dealing with their care responsibility, which is firmly situated within a socio-cultural context. Given the recent clamour for a value-based resource allocation model in China (Fang et al. 2020), understanding individuals' nuanced relationships with their socio-cultural environment would aid the understanding of the actions of family caregivers as individuals might enthrone Xiao distinctively (Miao 2015).

Chapter 3: Phase 1: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents.

3.1 Introduction

This chapter has been adapted from the publication: *Bífárìn, O., Zhang, B., Quinn, C., Breen, L., & Oyebode, J. (in press) Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents.* In this chapter, I will describe the rationale for undertaking **this phase of** study and conclude with the aims and objectives of my doctoral work.

Due to the collectivist culture in China as noted in Chapter 1: Introduction, individuals typically prioritise others' needs and are therefore strongly affected by their socio-cultural environment. In the absence of holistic consideration for the needs of caregivers, as existing research showed in

Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China, showed that there is a dearth of research regarding the intersections between stressors, coping and culture (Xiao). Current caregivers are unprepared for their role and to support the call in the literature for a pre-emptive role in research on ageing (Fang et al. 2015), it is crucial to pay close attention to future generations of family caregivers.

The review I undertook helped inform this doctoral research but there were gaps in my knowledge. I needed to learn more about how Millennials and Generation Z (born 1980-2002) viewed their potential future caregiving obligations to their

parents and the role of *Xiao* (孝) in this to further my understanding of caring in China. Additionally, it addressed a gap in the literature pertaining to perspectives and preparedness for future care roles of well-educated offspring, born during the One-Child Policy, who may settle abroad or at a distance from their parents. Therefore, I decided to conduct this **phase 1** study with the aim of familiarising myself with the culture as an attempt at understanding more about my phenomenon of interest. At the time of collecting data, I had never visited China and did not speak or understand Mandarin. **Phase 1** study provided insight that help to form my main study objectives.

3.2 Design and Methods

A focus group method was adopted using semi-structured topic guides for data collection. Instead of individual interviews, focus groups were specifically chosen to generate discussions and debate among participants (Flowers et al. 2001; Love et al. 2020), as the study aimed to capture wide-ranging opinions around caregiving and produced an in-depth analysis of the account of small groups rather than a representative sample. Ethics approval was granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford (Appendix B: Ethics Application approval for **phase 1** (Preliminary study)).

3.3 Focus group considerations

Beyond my pragmatic considerations, I was concerned about the potential level of engagement and openness of individuals, considering they would be sharing their perceptions and experiences with others paying close attention. I therefore kept numbers relatively low by conducting three focus groups each attended by six to eight participants. The rationale for this was to encourage in-depth

conversations among participants, and to be able to effectively facilitate the focus-groups while noting the dynamic in the group. Group size for focus group studies is not prescriptive (Krueger and Casey 2009; Krueger and Casey 2015). Studies like Githaiga (2014) and Love et al. (2020), designed to emphasise idiographic experiences, found two to three participants to be ideal. However, given the availability of my participants and bearing in mind academic pressures and issues concerning their acclimatisation to England, flexibility was important. Being “flexible”; open to participants coming with their groups of friends to aid in-depth conversations, I found my group size appropriate for the nature of this study, which was to get more insight into the phenomenon of interest. The depth of the findings as evidenced later in this chapter attests to the appropriateness of that choice.

3.4 Procedure and Participants

Participants had to be aged 18 years and above and be from mainland China, with or without caring responsibilities. A purposive sample was recruited from current students at the University of Bradford. Students were invited to participate via their university e-mail accounts and WEChat (the main Chinese mainland social media platform). A snowballing technique was adopted, whereby students who responded to the invitations were invited to link the researchers to other potential participants. Bing Zhang (BZ) and I facilitated the groups. BZ, a research assistant from mainland China, translated and helped capture cultural nuances. BZ and I met with all who expressed an interest to provide an information sheet in English and Mandarin and establish that they understood the study. Discussions were held with potential participants about, for example, study objectives, confidentiality, and data management. Participants were then given

at least seven days after receiving the information sheet to think about participating. Also, they were informed that they could withdraw at any time without any consequences. Informed consent and demographic information were obtained on the day of the focus group. Twenty-four potential participants expressed interest. Four declined for reasons such as time constraints, and one did not meet the nationality criteria. Therefore, the total number of participants was 19 and they were between the ages of 20 and 30 with the mean age being 22.05 years. Participants are referred to by pseudonyms and personal identifying information was changed. Participants' demographics is provided In Table 3.1 below.

Table 3.1: Participants' Demographics

Gender (n)	Province (n)	Years lived in England (n)	Only-Child status
Female (14) Male (5)	Beijing (2) Guangdong (1) Zhejiang (1) Shandong (1) Jiangxi (4) Shanghai (4) Ningxia (1) Henan (1) Guangxi (1) Hebei (1) Jiangsu (1) Liaoning (1)	< 12 months (16) 1-2 (2) 2 years or more (1)	Only Child (13) Not an only child (6)

I designed the topic guide with input from supervisors based on existing literature on Chinese culture and care provision for older relatives. I asked open-ended questions to probe what participants knew about the experiences of relatives or friends with caring responsibilities, participants' preparedness, and future

willingness to care for their parents, their personal understanding and enactment to date of filial piety and their experience, knowledge, and attitudes to long-term care services (See table below).

Table 3.2: Interview guide and some prompts

Questions	Prompts
How do you understand the notion of caring for older relatives in mainland China?	Can you share with us any experiences of your relatives or friends with older adult caring responsibilities?
	Imagine your parents or other older relatives start to need support or care, what do you imagine or expect to happen?
Tell me about a typical day of caring for relatives. Do you think you are prepared for potential future caregiving?	What do relatives or friends tell you about their experiences? How are they managing?
	How prepared do you feel about: providing personal care, providing emotional support, finding relevant information for yourself or relatives living with long term conditions, the care role in general.
What does filial piety (Xiao) mean to you and to what extent do you subscribe to the cultural value?	How have you seen filial piety xiao (孝) shown in your family? (e.g., by your parents to their parents? By you to your parents?)
	What does filial piety xiao (孝) mean to you? Of what importance is it to you? Is it important to your relatives? (Filial Piety Law)
In terms of available long-term services, what are the possible barriers and facilitators relating to caring for older relatives in mainland China?	Tell me about any older people health care services in China?
	Would you be eager for your older relatives to use any of these services and why?

Some questions focused on potential future care needs to enable participants to imagine possible future caregiving, for example, an older parent needing assistance with nursing care or the facilitation of medical appointments. The focus groups were held onsite at the university, the average duration was 100 minutes, and they were audio recorded. Participants often switched languages between English and Mandarin, and BZ translated. The first focus group was observed by PhD supervisor CQ, who gave BZ and I feedback. BZ and I debriefed before and after each focus group to raise reflexivity and inform the conduct of the focus groups. I transcribed the audio recordings, and BZ transcribed and translated the Mandarin passages. This allowed us, especially BZ to check that nuances were well captured during the discussions.

3.5 Data Analysis

After all data were collected, I commenced data analysis using reflexive thematic analysis to yield contextualised understanding (Braun and Clarke 2006; Braun and Clarke 2014). **Reflective thematic analysis** creates an avenue to accumulate knowledge, identify literal, pragmatic, experiential and existential meanings (Braun and Clarke 2013) relating to a specific phenomenon of interest, conceptualise human behaviour patterns, and creates opportunities for unexpected themes to be identified (Braun and Clarke 2006). All six iterative phases of **reflective thematic analysis** were followed: “familiarisation, coding-generation of preliminary themes, reviewing and developing themes, refining, defining and naming themes; and writing up” (Braun and Clarke 2021a: 3).

Consonant with RTA, I adopted both inductive and deductive approaches, as the process involved in identifying themes was not independent of my knowledge. Also, by involving BZ, a research assistant from mainland China, and PhD

supervisors JO, CQ and LB in the analysis they brought perspectives as clinical-academic psychologists, applied dementia researchers and knowledge of healthcare service design and delivery. Consequently, analysis was data and researcher driven (Braun and Clarke 2021a), and the collective expertise of my supervisors on the object of interest, enabled openness and reflexivity throughout the process. Data familiarisation involved reading and re-reading individual transcripts. Initial codes were generated to capture the descriptive content of meaningful segments of text and their made memos of interpretations of patterns and meanings. I discussed the codes and debated memos to raise reflexivity. Following descriptive coding, all codes were listed, and I began the active process of grouping these into meaningful subthemes and themes, assembling them into clusters according to shared or similar meanings (see Appendix C: A sample of the analytic procedure showing connections from data segments to codes, sub-themes, and theme.).

Preliminary sub-themes and themes were discussed with my supervisors over a period of time and this allowed analytic insights to improve (Braun and Clarke 2022). For example, an early version of analysis in January 2020 included many sub-themes, but several iterations took place to deconstruct meanings within initial themes and sub-themes to best capture the data. In Appendix D: Process of identifying sub-themes and themes (**Phase 1: Preliminary Study**), I provided some examples to demonstrate how patterns of meaning evolved and became apparent over a period of ten months. The analysis was reviewed by BZ, who read through the final themes and considered the plausibility of the findings. To ensure the results were grounded in the text, quotes from participants were used to illustrate the themes, which equally influenced the title of the themes.

Generally, by adopting **reflective thematic analysis**, remarks, analytic resolutions, and personal reactions to data were continuously reflected upon, exposing any personal assumptions. In doing so, the grouping of participants' descriptions of the meaning of Xiao for instance, were replaced with sensitive expressions that encapsulated participants' choice of words.

3.6 Findings

Six themes were identified and encompassed under an overarching theme, namely Culture of Duty (See Figure 3.1 below). The prominence of family obligation and expectations within Chinese mainland society appeared to leave future caregivers in a dilemma about how to balance their own personal needs with the care needs of their parents. Despite Xiao holding various meanings for participants, the common thread discovered was that caregiving was strongly underpinned by altruistic motivations. Therefore, the overarching theme of 'Culture of Duty' reflects the significant role of family within mainland Chinese society and equally shows the relational tensions therein.

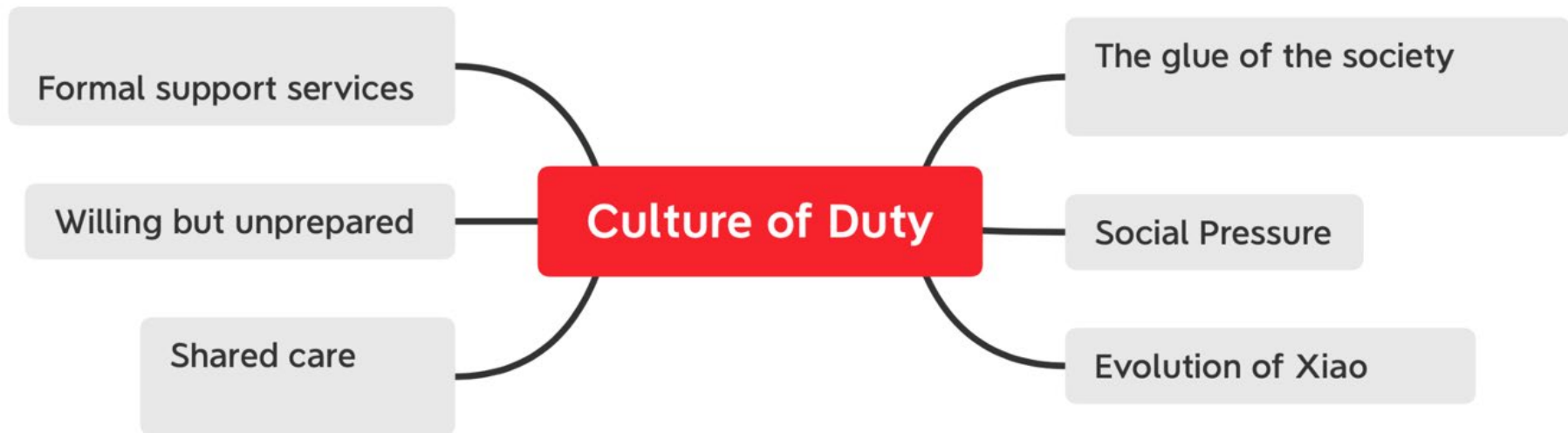


Figure 3.1: Overview of themes

3.6.1 The Glue of the Society

Most participants described *Xiao* as a cultural value which acted as the glue of both society and family. It was seen as a virtue of reciprocity with karmic-like consequences. *Xiao* was seen as being transmitted by example, from one generation to the next. In the following excerpt the participant suggests that if a good example is not set, a person might find themselves not cared for in turn by their own children:

Not all the people are good people. Some people are saying they cannot support their parents and relatives like the others do. If you don't take care of your parents, and when you get old your children will do the same. So, it is kind of rule to keep the society going well [...] in Chinese society, I think Xiao is basic for like family relationships at least, to keep it well.

Fangfang

Some participants attached moral value to acting virtuously in fulfilling *Xiao*, with those who could not support their parents being viewed negatively. Participants expressed a view that the power with which *Xiao* was imbued could lead to it sometimes being used as a threat by parents. The example was given that parents were able to call on *Xiao* to make their children comply with their expectations of being cared for, even if only to avoid future consequences of being abandoned in turn by their own children. Participants' accounts suggested that *Xiao* would continue to act as a glue for families and society whether through intrinsic values or as a manipulative tool. By preceding this description of karma with the phrase 'Not all the people are good people', she highlights the moral value she attaches to acting virtuously in fulfilling *Xiao*, with those who could not

support their parents being viewed negatively. Participants expressed a view that the power with which *Xiao* was imbued could lead to it sometimes being used as a threat by parents. In this example, **Limin's** description of *Xiao* simultaneously implies closeness and a chain or tie:

Xiao is that it is like a bond between parent and children. With this bond, it kind of determines the relationship between parent and children, [...] Sometimes it can be a tool, which parent can use to threaten children.

Limin

The end of this quote from **Limin** conveys the view that *Xiao* can be weaponised by parents to make their children comply with their expectations of being cared for. Overall, this theme reflects the crucial role *Xiao* plays within Chinese society. Participants' accounts suggested that *Xiao* would continue to act as a binding force for families and society whether through intrinsic values or as a manipulative tool. It was evident that *Xiao* still held great relevance for our participants, and most importantly, it underlined the significance of family in the wider culture.

3.6.2 Evolution of filial piety, *Xiao* (孝)

Participants understood the traditional meaning of *Xiao* as embodying unquestioning obedience. It was recognised that the power of *Xiao* was waning, as stated in this extract:

The scope of Xiao is reduced, for example, the scope is just contrast, because in the past, if you cut your hair, you disobeyed Xiao, because your hair, your skin is given by your parents, but now it is totally depends on ourselves. Junkai

In this example, **Junkai** describes that even something as personal as having your hair cut without your parents' permission would have been seen as infringing *Xiao*. His comment *'now it totally depends on ourselves'* emphasises change through the term *'now'* and the expression that *'it totally depends on ourselves'* shows a view that there is now a sense of self-determination and self-preservation. Most participants spoke about the changing nature of *Xiao*. They appeared to interpret the concept as staying out of trouble and not placing pressure on parents: *"Health wise, we don't create any troubles for our parents. That is Xiao because we are not bringing more pressure to the parents"*. Some participants suggested their parents were also going through a phase of change. The quotation above continues: *"[...] but the parents think that once they keep themselves healthy, make sure everything is OK, they are decreasing the pressure for young people's lives. They are reversing their way of thinking"* **Ying**. These consecutive excerpts, which both use terms about reducing pressure, demonstrate that **Ying** felt there was a new reciprocity whereby both parents and children wanted to decrease pressure on each other. Consequently, some participants expected government to provide formal services as a viable alternative: *"I think the government should think about how to promote the retirement lifestyle and care services that will meet the needs of people in this era"* **Zhao**.

Overall, this theme reflects changes in *Xiao* from one generation to the next and shows a loosening of the ties of obligation between generations. It reflects the sense of independence for younger generations, but with this still hinging on parents' happiness.

3.6.3 Social pressure

Several participants had witnessed how the importance given to obedience can lead to society overlooking willingness to provide care in the way that tradition stipulates:

When my grandma was with us, she said to us that she wants to go back to where she was from and be buried in there. So, my dad followed her wailing and brought her back to Shanghai at the last few months of her life. However, he never provided any care to her all the time, he was just following what he was told to do apparently without the love. Zhao

Zhao's expression of "*followed her wailing*" describes the internalised defiance of her father's submission. This excerpt exemplifies how **Zhao's** father felt compelled to obey his mother's wishes regardless of his personal circumstances while suppressing his emotions, as that could be considered unfilial. Suppressing true emotions in favour of upholding tradition arguably results in outward acceptance of care responsibility but an inward indifference. We see this when **Zhao** recounts that "*he never provided any care to her all the time, he was just following what he was told to do apparently without the love*". From this statement we can consider the potential negative impact that emerges when society values obedience above willingness or capability to provide care.

Xiao made it crucial to ensure that harmony reigned amongst people, and its principles were expected to be adhered to by everyone. This concept is grounded in reciprocity, however, participants felt children might question the rationale behind "payback": "*If you were mistreated by your parents, or you were abandoned by them, but when they get old and want to find you back just for*

having your care because of Xiao, then what can you do for that?" Liu. These societal expectations were perceived by some participants as unfair.

You might provide care as Xiao required because of the social pressure.

But there was no care to you when you were a child, and then you might question yourself why do I need to care my parents now? Liu

Here, **Liu** explicitly attributes adherence to Xiao to societal pressure, particularly under circumstances where there are no common grounds for caregiving expectations. **Yanfei** shared an experience about her mother providing hands-on care for her grandmother who was living with a long-term health condition. Recalling the experience, her uncle's wife was caring for her own mother who also had a long-term health condition and their son. *"My uncle's wife has got a son, and their mother had experienced a very serious disease last year [...]"*. Her uncle assisted her mother in providing hands-on care and considering that provision of hands-on care was largely celebrated in society as upholding Xiao's principles, he was rewarded in their local community for visibly demonstrating Xiao.

As her (Yanfei's mother) brother did really good job in taking care of their parents, he was rewarded by the hospital and local community, as his story of taking care of parents was told by a nurse and was published in the local newspaper for others to take as a great example for promoting Xiao.

Yanfei

It is particularly interesting to note participants' examples of who is celebrated, and this example mirrors societal expectations, which tends not to put personal circumstances into consideration. Overall, this theme reflects the social

pressures within the cultural environment, as participants shared examples of how it tends to emanate from an appreciation of obedience, perhaps without regard for personal circumstances of family caregivers. These pressures to oblige parents without accounting for willingness, ability, or availability to provide care could consequently result, for some, in mechanical fulfilment of *Xiao*, bereft of emotional affection. It can also leave other family members feeling unappreciated or misrepresented.

3.6.4 Shared care

The consensus among participants was that circumstances dictated the type of support provided by family members. Illustrated by the following excerpt, those deemed to have fewer responsibilities in their personal lives (e.g., those unemployed) provided the hands-on care and those in employment sometimes provided financial assistance:

*My grandparents at my mom's side, they've got overall 6 children. If they split care; it is not a very big issue for everyone. [...] And my older auntie's child has got a newborn. It means there's a double-care responsibility for her; taking care of older parents, and a newborn. It means the care responsibility for the older parents comes to my younger auntie. In this case, those who work will take less face-to-face care responsibility than unemployed (younger auntie meeting grandparents daily) but the employed children will sometimes support with finance. **Liu***

When organising care and supporting older relatives, dividing responsibilities between siblings was feasible for past generations but with demographic changes in China, most participants had no (or few) siblings and envisaged that

future care responsibilities might be overwhelming: *“Nowadays we have a lot of single child families. In the past people split the Xiao as multi-children families do, but for more single child families there will be more Xiao responsibilities”* **Haoran**. Referring to only-children whose parents might develop long-term health conditions, **Junkai** subsequently expressed that such situations could be unbearable and inflict pain: *“[...] determined by the health conditions of the elderly. For those who keep healthy till they die, their children could easily manage it with Xiao, but in opposite conditions, their children can be suffering in applying Xiao”* **Junkai**.

With awareness of the compounding pressures that only-children will face in caring alone for ageing parents with health conditions, participants raised concerns about the difficulty of balancing work and care:

A lot of young people, they go to work in big cities, could be very far from the hometown, where the parents are living. So, sometimes it is just impossible to manage when the parents get ill [...] they have to go to the hospital and children have work to do in a very far city. **Xiaoming**

In this quote, **Xiaoming** reflects on how having to work far away from parents due to rapid urbanisation in China, makes it practically impossible to attend to parent’s health concerns in a timely manner. **Hongming** was studying abroad when his mother took ill. In hindsight, he reflected on his difficulty with aligning the desire to prioritise personal ambitions with the significance of being present to accompany his parents at a time of need.

I’m the only child, sometimes it’s a struggle to choose between your own life and your care for your parents. **Hongming**

This theme shows the significant role family members played in supporting one another as this was their duty and responsibility. Familial resources that were available to their parents' generation were not anticipated as an option for the younger generation who will inevitably be in the position of providing care alone. Consequently, where only-children might also live or work far away from parents, the difficulty of Xiao intensifies.

3.6.5 Formal support services

Perception of family members varied, but generally, in preparation for when their parents would require care, participants foresaw a need for formal care services. However, poor quality of care was concerning to some participants and was associated with formal caregivers' low literacy level, low socio-economic status, poor training and consequently lead to attitudes that stripped older relatives of respect and dignity:

*They are not very professional, a lot of the carers you get there. They couldn't cook [...] And a lot of them are from poor families, so they are not educated. They can't read, can't write, and they have really strong accents. So, communication is a problem. Giving the elderly medication is a problem and just basic moving, handling. **Meina***

*[...] With my other gran, this person was trying to give her a bath. The door was wide open, and she was using a really rough cloths, just like she was scrubbing a pig basically. They don't treat them like humans because they don't really think about them from their family perspective. It is just a job. They've got the money and that is it. **Meina***

Due to the poor treatment witnessed, which was viewed as a consequence of the formal caregiver's inability to see the older person as their own family, **Meina**, perhaps unknowingly, reinforces the mandate of traditional Xiao on family members as primary caregivers. The assertion that formal caregivers appraise their profession as *"just a job"* with financial security being the primary motivation could imply the rejection of a transactional relationship, opposed to the relationship between parents and offspring based on a motivation of re-paying past help.

Lack of trust in external influences or involvement emerged quite frequently in the focus group discussions. The following example highlights that on one hand, government-mandated Xiao could encourage individuals to meet their filial obligations, on the other hand, there is a potential for individuals to experience dissonance when individuals raised to uphold Xiao, as a rule of society, do not see Xiao enacted: *"Xiao is something that is the responsibility, forced by the country, because in China we actually have a lot of people who are not supporting their older parents and this concept of Xiao makes people to take more responsibility, which will take pressure off the government"* **Haoran**. The approach adopted by the government, alluded to by being *"forced by the country"* and the statement *"which will take pressure off the government"* could be down to the perceived inadequate governmental responses to the challenges of an ageing population, leaving family members unsupported in their caregiving role. Furthermore, some participants asserted there was the potential for business owners to exploit offsprings' desire to have the best for their parents, using Xiao to make excessive profits:

Apart from the luxury decoration of the room, most [of] the services provided are also for making money from people. They are utilising the initiative of our Xiao to our parents, and then making profit on it. Zhao

This theme overall highlights that even if offspring were willing to explore options for care outside the traditional family-based system, there were several barriers to securing the adequate public (governmental) and private services needed to provide support for the family caregivers of older relatives.

3.6.6 Willing but unprepared

Most participants believed in self-sacrifice to fulfil *Xiao* for their parents and easily expressed this. **Qiuyue** was enthusiastic when sharing: *“I think I really love my parents, I really do. I can stay with them all the time. I can give up my future”*. However, she goes on to express her concerns about whether she would be able to adjust to providing intimate care:

But something here, I just need time to adapt, like toileting, like bathing, because I never see my parents naked. If I am required to do all these now, I may need more time to get there. But I think I will do all these, and it is very difficult. Qiuyue

Her hesitation comes through in her use of ‘I think’ which she uses to temper the complete commitment she had expressed just beforehand. There were many participants like her who expressed willingness, yet shared concerns about providing care. **Liu** expressed a general lack of confidence due to fear of being financially or emotionally overextended: *“I don’t have any confidence about it [...] I think not just financial support, but more about emotional support. You will need to share more emotions with your own family, your wife, your children, once you*

become an adult person, which means less emotions you can share with your parents. So, I think emotional side is an important challenge for me” Liu. These examples uncover some nuances surrounding the physiological and psychological demands associated with anticipating being wholly responsible for older relatives’ well-being, which comes with additional cultural and societal pressures. Drawing from his personal experiences, **Hongming** illustrates the challenge he had of being an only-child who is geographically distant from his parents:

I was visiting [a large UK city], for 3 months, and my mum got serious illness. It was urgent. She had surgery in Beijing... and they didn’t tell me, because I was in [a large UK city]. I was overseas, and afterwards, maybe a month later my dad told me this happened, and I didn’t know that. I feel very disappointed. I feel like you didn’t do your job as a son. Hongming

On reflection, he felt guilty for not meeting certain societal expectations, hence, *“I feel like you didn’t do your job as a son”*.

This theme reflects the participants’ feelings regarding their sense of responsibility and their ability to fulfil several demands against all odds. Despite their willingness and motivation to take up the responsibility of selflessly caring for their parents, the participants did not feel they had enough preparation or support to meet either short or longer-term needs.

3.7 Summary and conclusion

Since its inception, the conceptualisation of filial piety (Xiao) has had a potential duality within its functions and how individuals construct their meanings, reflecting ancient social norms plus contextual and cultural factors (Bedford and Yeh 2019). Xiao focuses on reciprocity *and* authoritarianism and as these play distinct key roles in parent-child relationships, they are not mutually exclusive (Yeh and Bedford 2003). This indigenous psychology approach appears to still be relevant in contemporary China as participants expressed views that pertained to both the authority and reciprocity of Xiao. Cultural values have implications for individual coping responses (Knight and Sayegh 2010). As such, it is important to understand that Xiao expectations, the reactions of others in the social context, and the systems of support afforded individuals by their culture, influence perception of stressors (Aldwin 2007).

Considering this, coping efforts from participants' perspectives could potentially illustrate an attempt to re-interpret tradition to fit better with the current reality, in an endeavour to achieve cognitive consonance and reduce tension. The result of this attempt at balance appeared to shape Millennials and Generation-Z's thoughts about their future caregiving decision-making processes. The findings indicate that the practice of traditional filial piety, found among some of the younger generations could leave future caregivers susceptible to adverse experiences, making the study of willingness and preparedness to provide care pertinent. Even though Chinese culture stipulates that people should demonstrate reciprocity, the extent of the influence of family circumstances on caregiving process remains unclear, as most participants in **the phase 1 of this study** (preliminary study) were not providing care. Nevertheless, one major issue

found in this study that is consistent with existing literature (Wang et al. 2018; Shen et al. 2019b), was participant's concerns about the poor quality of formal care. Furthermore, by studying in the UK, Western influences might be ingrained in this group of participants, hence, these influences could further create tensions between individual right to autonomy and responsibility to family by upholding their cultural values.

3.8 Research aims and objectives

Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China demonstrated how the position of caregivers within the socio-cultural environment might adversely impact their wellbeing and that of the older relatives depending on them. Subsequently, at the heart of the themes identified in this chapter, are major concerns about supporting family caregivers, who are most likely left to fend for themselves. Findings in Chapter 3: **Phase 1: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents.** raised the question of how family caregivers' interests or issues of concern are known and understood within the wider society and clarified the qualitative approach as the most suitable for **phase 2** of this thesis. Due to limited qualitative studies, especially focussed on understanding intricacies of stressors and coping, it became evident that I needed to be innovative with my approach to add to existing knowledge, which I shall return to in *Chapter 4: Methodology and Methods*. As such, I decided to use descriptive phenomenology to capture main experiential features of 'being a caregiver', and interpretative phenomenology to understand how caregivers manage or cope with their role,

focusing on sense-making within the sociocultural context, drawing on a homogenous sample (Smith et al. 2022). With this, I propounded a sole aim for this thesis, which is to understand the experiences, views, and perceptions of current and future caregivers of older relatives across generations. Exploring the influences of societal and cultural factors would have the potential to inform adequate support, which is needed during the process of caregiving.

To achieve this, I identified four research objectives:

1. To understand current and prospective family caregivers' perceptions or experiences, or the experiences of their relatives or friends with caring responsibilities for older relatives in China.
2. To explore the meanings of filial piety (Xiao) to current and prospective family caregivers, i.e., to what extent do participants subscribe to these cultural values.
3. To understand current and prospective family caregivers' attitudes about balancing work and other areas of life when caring for an older relative, particularly the influences of social support, Xiao, and perceived barriers to providing care.
4. To explore the attitudes of current or prospective caregivers, and the preparedness of family caregivers to manage caring responsibilities for older relatives with needs for on-going daily care and support

In this thesis therefore, I aimed to carry out studies that would explore the role and influence of the socio-cultural environment on caregivers' experiences. I aimed to find out how current caregivers are responding to caregiving expectations and how future caregivers are thinking about intricacies of caregiving, with the view of producing recommendations informed by findings

from my participants. Prior to presenting **findings from phase 2 of this** thesis in *Chapter 5: Caregiving Beliefs- Xiao: the lifestyle*, *Chapter 6: Contextual Factors: Intersections of Xiao, work, and care* and *Chapter 7: Caregiving Conditions – Caregiving responsibility*, I will turn to theoretical underpinnings of my study by presenting the methodology and methods that guided the research perspective.

Chapter 4: Methodology and Methods

4.1 Introduction

The literature review in Chapter 2 examined the experiences of current caregivers of older relatives living with long-term health conditions in China. Through this review I identified some gaps in the evidence-base, that I started to explore in **Phase 1** in Chapter 3, to better understand perceptions and preparedness of potential future caregivers. It was essential to ensure personally that my research was ethical, sensitive, and respected family and cultural values. The experience I had while conducting my review in Chapter 2 and **Phase 1** in Chapter 3, enabled me to select the most appropriate research paradigm for my research objectives. In this chapter, I will expand on and explain my research positionality, articulate the philosophical stances underpinning my methodological position and provide explanations and justifications for my choice of methodology and methods. Further, I will highlight the implication of COVID-19 on my study, provide details associated with ethical considerations to harness trustworthiness and detail the procedure of recruitment and data collection.

4.2 Researcher's positionality

The positionality of this research includes the value placed on caring for older family members in mainland China, together with my belief that the perception of caregiving is a function of individual experiences that can influence the way family caregivers learn and act. Taking this position, I aim to lay a foundation to redressing the paucity of research in this area. As an outsider, to become familiar with the Chinese culture, I was able to conduct **phase 1**; a preliminary study in Chapter 3, prior to my main data collection. Following the data collection phase for the focus groups, I had an opportunity to visit China in 2019, which provided

a lot of insight that informed and shaped my methodology going forward in this doctoral study. My experiences whilst conducting **phase 1 drew** my attention to my role as a researcher being, to some extent, that of an insider who understood some implications of a collectivist society on individuals, i.e., shared values and stances. However, I was also an outsider, as I did not share characteristics such as religion, gender, ethnicity, age, and social class status with most of my participants. While recent systematic reviews in ageing research (Roche et al. 2020) and setting research priorities (Iqbal et al. 2021) suggested strongly that insider perspectives are needed to advocate adequately for people who are often marginalised and could generate rich data, the position could also be an impediment. Insider researchers might oversimplify participants' experiences based on the assumption that they have shared values (Kanuha 2000; Perry et al. 2004). On the other hand, the reality that outsider researchers might fail to capture nuances as well as insider researchers could lead an outsider researcher to pay more attention to the data and not taking anything for granted (LaSala 2003; Tang 2007). This shows that insider and outsider perspectives can be a complex phenomenon (Hayfield and Huxley 2015), and having both perspectives arguably gave me a distinctive advantage. I acknowledged my potential biases and expectations based on my experiences in Nigeria and the UK. However, to address this, the different perspectives of my supervisors were used to raise reflexivity.

4.3 Ontology and Epistemology

Ontology is a philosophical perspective that investigates the nature of reality and epistemology is a philosophical perspective interrogating knowledge i.e., what I know (nature of knowledge) and how I know what I know (how it can be known)

(Crotty 1998; Polit and Beck 2012). The phenomenon of interest for this study is caregiving for older relatives, which can be measured objectively using a quantitative approach as in most of the papers in the literature review in Chapter 2. I, however, decided to take a contrasting ontological stance as I believe that the phenomenon of caring for older family members is significantly constructed by the social and cultural space in which individuals live. Further, findings from the **phase 1** study in Chapter 3 strongly indicated that the participants' understanding of the phenomenon of interest was not a single narrative, i.e., a fact that can be transferred from parent to children, but an embodiment of narratives, depicting the dynamic nature of individuals' interactions with the phenomena of interest, which in turn, crafts their own understanding. The ontological perspective for this study, therefore, is not to do with caregiving for older relatives as a sole entity, neither is it about the family caregivers, but the relationship between the phenomena of interest and individual participants i.e., relativism. Epistemology is a philosophical perspective about exploring what knowledge is about and how it has come to be (Sharp 2009; Oliver 2010; Willig 2013). Knowledge can be constructed individually and collectively, via the process of socialisation. Socialisation in this context refers to the conscious or unconscious effort that people direct at developing their own interest; acquiring knowledge, skills, personal values and attributes (Dimitriadou et al. 2013). In essence, caregiving for older relatives can be viewed differently, depending on how family caregivers engage with the phenomenon being investigated. Therefore, it is feasible for caregivers to construct personal understandings of existing knowledge, i.e., this process embodies subjectivism. Conceptually, there is no exact definition ascribed to what caring for older relatives means. Due to

the dynamic nature and the demands placed on family members by the caregiving role, as 'family relationships are enduring and consequential for well-being across the life course' (Thomas et al. 2017: 1), informal caregiving has been described to be a career (Aneshensel et al. 1995; Quinn and Toms 2018). The transfer of knowledge regarding caring for older relatives can be done extemporaneously and evaluating this knowledge can be approached with the objective of gathering the facts by adopting relevant measures. These approaches, however, can be deemed to oversimplify the intricacies of providing care for older relatives, due to the possibility of reducing the relational and transactional viewpoint of family caregivers with the world they engage with.

4.4 Theoretical perspective

There are two main research paradigms, namely qualitative and quantitative (Creswell 2008). Each approach is an entity uniquely characterised and serves as the basis for formulating a research design to answer research questions (Crotty 1998). In essence, there was a need to carefully consider the conceptual background and philosophical stance regarding the ontological and epistemological perspectives (Jackson 2013). In enhancing rigour in research, the methodological and philosophical principles must align at the philosophical level. Furthermore, addressing questions relating to incommensurability (Mesel 2013) provides an opportunity for refining research methods, findings, and conclusions (Rudnick 2014). Considering this and to address the gap in literature articulated in Chapter 2, where a qualitative approach was deemed the most appropriate for this study, it was of great importance to contextualise individual experiences. Therefore, I sought to contribute novel knowledge to the literature by understanding the reasons and self-construal of caregivers that influenced

actions and reactions within socio-cultural contexts. Drawing on the work of the phenomenologist Merleau Ponty, it was important for me to understand my participants' actions by paying close attention to meanings associated with their realities based on their construal as individuals (Moran 2000). Similarly, I drew on Heidegger's early work, *Being and Time*, where he described human beings as "*Dasein*, finds 'itself' proximally in *what* it does, uses, expects, avoids- in those things environmentally ready-to-hand, with which it is proximally *concerned*" (Heidegger 1962: 155). Heidegger's stance aimed to address the question of authenticity, as *Dasein* tends to get stuck with the roller-coaster of life in the form of daily activities and relationships, which are considered innate, meaningful and often taken for granted (Heidegger 1962; Smith et al. 2012). As human beings, Heidegger made a clear distinction between '*it*' and '*they*', which could be everyone and no one and asserted that '*it*' is at a loss, when '*they*' fall apart i.e., *Dasein*'s world becomes less significant. Specifically, self is less prioritised due to a conscious or unconscious level of involvement with everydayness, as *Dasein* tends to give a false representation; when the state of the endlessness of *they*, suggests that something is amiss. What is pertinent with Heidegger's ontological question of existence is how *it* (participants) relates to *they* (caregiving) in this study.

4.5 Hermeneutic phenomenology

Having read specifically around different types of methodologies and relevant papers during the literature review process, choosing a qualitative research approach seemed the most appropriate method for addressing the study objectives. Edmund Husserl, Martin Heidegger and Gadamer were philosophers whose work focused on understanding lived experiences. As such,

phenomenology is an approach to inquiry, which was arguably brought to the limelight in the early twentieth century by Husserl, where he came up with the concept of “Lifeworld”. Lifeworld is often related to the notion that individual consciousness is intentional (Ashworth 2003; Husserl 2013) and can be described objectively (Moran 2000). Advancing on the work of Husserl, which offered a reductionist method of honing an epistemological stance that was more concerned to extrinsic factors and “series of temporal profiles” (Larkin et al. 2019: 193), is the work of Martin Heidegger. In *Being in Time*, Heidegger (1962) stated that meanings could be intuited from experiences as Husserl described. He however asserted that phenomenology is a method that offers interpretations of experiences and consequently provides the opportunity to see individuals as ontological *beings*, as defined in section 4.3. Even though these philosophers proposed different dimensions to understanding individual experiences of living in the world, Todres L, Holloway I cited in Gerrish et al. (2010), asserted that the commonality between these authors’ propositions is the desire to understand humans from their individual experiences. In modern terms, Smith and colleagues transformed the use of phenomenology within qualitative research by re-organising and conceptualising traditional approaches into what is called interpretative phenomenological analysis (IPA) (Smith et al. 2009). Since the philosophical underpinning for this doctoral study is that caregiving for older relatives is based on subjective individual experiences and that perceptions are constructed through individual interaction with the phenomena, a qualitative methodology adopting a hermeneutic phenomenological approach was identified to be the most appropriate (Smith et al. 2012).

Phenomenological research can be descriptive or interpretative (Gelling 2015). As the name implies, descriptive phenomenology describes participants' lived experiences, and an integral aspect of this is that the researcher is expected to 'bracket' their preconceptions as these are not allowed to intrude into the findings emerging from the data (Hamill 2010). On the other hand, an interpretative or 'hermeneutic' phenomenology aims to provide a comprehensive understanding of lived experiences (van Manen 2016) and allows use of preconceptions in a positive and self-aware manner (LeVasseur 2003). Since this study is about making sense of the relational world between the participants with the phenomena of interest, it is evident that interpretation will have to take place and having expressed my research positionality, I decided not to bracket my values and beliefs, but to use them constructively by engaging with reflexivity in research. This requires a researcher to be mindful of the integral role of context and the collaborative role in knowledge creation during interviews and data analysis, which contributed to rigour and trustworthiness of this study (van Hilten 2018; Dodgson 2019). As such, I aligned this study with the hermeneutics, existential and ontological perspectives associated with Heidegger's philosophical stance. More specifically, drawing on the fundamental concepts from Heidegger's work in terms of intentionality and consciousness, which are both imbued of meanings, I can articulate the distinctive phenomenological approach to my doctoral study in at least three ways.

First, I adopted a phenomenological approach to understanding experiences and perceptions, as individuals engage with caregiving contextually within their socio-cultural environment. Thus, the combination of both critical theory, which argues that rationality in a non-tangible sense can be retained and thoughts that might

result in emancipation can be recovered (Guba, 1990 cited in Alase 2017), and interpretative paradigms (Burrell and Morgan, 1979 cited in Alase 2017) were appropriate for this study. The two paradigms were operationalised separately but put together, helped articulate the research problem and helped to ground the interpretations of lived experiences and perceptions of participants. To explain further, a critical qualitative research paradigm was employed regarding participants' experiences and perceptions shared, which meant I could focus on and provide a holistic picture of the phenomenon of interest (Braun and Clarke 2013). Consequently, an interpretative paradigm was explicitly used to narrate the relationship between the phenomenon of interest that is being investigated and individual participants (Alase 2017). The processes involved in this type of qualitative research work are oriented towards attitudes and values which are deliberately directed at capturing participants' narratives that emerge from internality and thus disclose the nature of their caregiving experience.

Second, phenomenological research is also operationalised through methods adopted. With richness of data being contingent on a host of factors; including who is gathering the data, their expertise and circumstances of its collection, the context, mode and purpose of data collection was considered (Braun and Clarke 2013). Further, emphasis was placed on analysis of consciousness, intentionality, and essence of experience in consciousness. Choosing reflective thematic analysis allowed flexibility to place emphasis on subjectivity and meaning making. Finally, there is a phenomenological dimension to elucidating the research problem. Given that the study is about experiences and perceptions concerning caring for older relatives, it is about the existential problems associated with the enactment of caregiving and what the process means. This

process involved making sense of what participants were making sense of themselves.

4.6 Methodological position

In this study, I looked at the intersubjectivity between participants and the phenomenon of caring for older relatives as I needed to pay attention to what happened within persons and cultures. Broadly speaking, the socio-cultural environment places expectations on individuals, and consciously or unconsciously, individuals respond distinctively; a potentially complex process (Larkin et al. 2019). The methodological approach adopted was interpretative 'hermeneutic' phenomenology, as I am concerned with ordinary everyday experiences of caring for an older relative and aim to make sense of what participants are making sense of, as the phenomenon being investigated has both cognitive and affective effects on individuals (Smith et al. 2012). Thus, having established that reality is socially constructed, the associated research paradigm is that of an interpretivist, sometimes referred to as constructivist. In this paradigm, "a subjectivist epistemology, relativist ontology, a naturalist methodology, and a balanced axiology" is assumed (Kivunja and Kuyini 2017: 33). The characteristics of this paradigm are as follows: the viewpoint of an individual cannot be used to understand the social world, several realities do exist, and these realities are socially constructed; having the awareness that there is an unavoidable relationship between the researcher and the participants of the study; having the understanding that knowledge and knowing is context-dependent; individual values will influence perceptions (knowledge) and it is vital to make the values explicit to understand individuals rather than universal laws; cause and effect are mutually symbiotic; and lastly, to holistically consider the

phenomenon of caring for older relatives, I must consider circumstantial factors (Kivunja and Kuyini 2017).

The methodology needs to be suitable for capturing a rich account of participants' views of the phenomenon of interest, without making them feel uncomfortable either by feeling judged or by asking leading questions. The data collected must be genuine individual stories, and participants need to be free to express their understanding and lived experiences of caregiving for older relatives. A method of analysis, whereby the interpretation of participants' unique stories is adequately captured is important to help solidify the scope of understanding of participants and, as such, provide the study with credibility and trustworthiness.

In summary, following these philosophical considerations, with a focus on relationality between older relatives' caregivers and their world, the forming of individual subjective perceptions and creation of new knowledge through an interpretative analysis of subjective narratives, the decision-making process in relation to the methodology, and methods of data collection and analysis, were considered to have been well informed (Carter and Little 2007).

4.7 Alternative methods and methodologies

The focus of this thesis is the exploration of lived experiences of family caregiving in a specific context, underpinned by the theoretical model of the socio-cultural stress process model. Thus, aside from Reflective Thematic Analysis, I considered two methods, namely, discourse analysis and narrative analysis. Methodologies that were considered included Interpretative Phenomenological Analysis (IPA) and Constructivist grounded theory.

4.7.1 Discourse Analysis

Discourse Analysis (DA) could have potentially been used to generate overarching themes, capture nuances, and explore the lived experiences of the research participants just as **reflective thematic analysis** would do. However, it was not feasible to employ DA in my research as it is heavily dependent on linguistics, including the non-verbal component, as it is expected to de-code or interpret what participants did not verbalise (Smith et al. 2009). Furthermore, as an outsider researcher, who cannot speak Mandarin and has not lived close enough to any Chinese indigene, it became apparent that this could not be used. Also, as I intended to seek participants' understanding and lived experiences to produce knowledge, DA is an inappropriate methodology **for my own study** in the sense that it is particular about understanding the processes of how knowledge came into existence, i.e., co-construction of knowledge rather than seeking to understand a person's reflective lived experience which is the terrain of my study.

4.7.2 Narrative Analysis

There are commonalities between **interpretative phenomenological analysis**, **reflective thematic analysis**, and narrative analysis **in that they are** about exploring the lived experiences of individuals. In **narrative analysis**, the personal account of participants is the object as the storyteller recounts their own lived experience and the role, they play in it. The researcher accepts the narrative of individuals, and focus is later shifted **to understanding the knowledge of participants and** why the story was presented in a certain manner (Reissman 1993; Hyden 1997). Even though this approach was **an option**, I felt that the **slightly more structured approach of reflective thematic analysis** with its

emphasis on subjectivity and meaning making would be preferable to the very open approach of inviting participants' narratives.

4.7.3 Interpretative Phenomenological Analysis (IPA)

The flexible attributes and the potential of providing a better insight into complex entities (Smith et al. 2012) would identify IPA as an appropriate research method, given the relationship between the researcher, participants and the view of their world in the context of the phenomena of interest. Also, the phenomenology and the double hermeneutic characteristics of IPA would help capture participants' perceptions and understanding. Furthermore, the process is inductive. The researcher engages thoroughly with individual narratives from the data set and analysis is carried out through an iterative process, whereby the data set is reviewed back and forth, consequently encouraging a wide range of thinking and reflection. Lastly, IPA involves integrating existing psychological theory and literature to consolidate the findings (Smith et al. 2012). IPA was the methodology I originally proposed to analyse the interviews. Whilst the descriptive underpinnings of IPA would not have been a problem, I would have found the practicalities of linguistics and conceptual foundations needed to consolidate my interpretations challenging (Smith et al. 2009; Smith et al. 2012), therefore, I reconsidered my position and decided not to use IPA.

4.7.4 Constructivist Grounded Theory

Grounded theory (GT) was primarily designed to help the researcher in the development of theories, and due to its high standards of rigour as explained by Glaser and Strauss (1967), it could be seen as the main alternative to IPA. The enquiry method is inductive and the researcher must submerge him or herself in the data to generate the theory (Ng and Hase 2008). In terms of the development

of theory, Glaser and Strauss (1967) stated that the researcher should not have any preconceived ideas or notions during the process of data collecting and analysing, as it is expected that the data dictates the theory. Having said this, GT has moved on from the classic version to include constructivist grounded theory (CGT). This permits researchers to be explicit about their pre-conceptions, and in the same vein as IPA, it is process oriented and attaches importance to meanings and understanding (Charmaz 2006). However, given my particular interest in individual constructs (unique personal experiences with intention to 'make sense of what they are making sense of), a methodology with a more idiographic focus becomes more appropriate as it puts the person first and firmly within a cultural environment, i.e., CGT is less idiographic. Secondly, George (2003) argued that the aim of CGT to produce a GT involves lengthy iterative processes of data collection and theory generation sampling, which would have been extremely difficult to achieve given the impact of COVID-19 pandemic on my research process (explained later in the chapter). These processes need to operate continuously to achieve their aim which does not perfectly align with the aim of my study.

4.8 Ethical considerations

Aside from the ethical approval sought for **phase 1** in Chapter 3, a series of ethical considerations were considered for this doctoral study. As a result, ethical approval was granted by the Chair of Humanities, Social and Health Sciences Ethics panel at the University of Bradford on 06/04/20. Also, **phase 2, main study** research was granted ethical approval by the Institutional Review Board (IRB) on 27/03/2020 at China Medical University Shenyang, where the study was

conducted (See Appendix E: Ethics approval for Phase 2 (main study) - University of Bradford).

4.8.1 Informed consent

The consent form produced in English and subsequently translated into Mandarin, was completed when participants met with researchers at the agreed venue of the interview. During engagement prior to the study via email, phone call(s), WeChat messages and virtually, I ensured that potential participants demonstrated a good understanding of the focus of interest and their role in the study (e.g., by holding conversations that allowed potential participants to paraphrase our discussion, thereby showing their understanding). Participants were also informed about how to withdraw from the study, if they wished to do so. This prior engagement was also used to answer questions that participants had regarding the study, and potential participants were informed that written consent forms will be obtained prior to the start of the interview. Participants were given at least two days after receiving the information sheet to think about the pros and cons of participating in the study.

4.8.2 Distress

There was a very low risk that the interviews could have caused harm or distress to participants. However, I was conscious of the fact that the most innocuous question could trigger negative emotions. As such, potential participants had access to an information sheet (in both English and Mandarin languages (See Appendix F: Posters and Information sheet (English)), before obtaining consent. The information sheet highlighted the study's inherent risks and benefits and the support mechanisms that was available to participants, which included a de-

briefing session and an avenue to air complaints. In addition, if anyone got upset during the interview, the session would be stopped to see if the participant wished to continue, and the participant could take a break or stop the interview if they preferred. The approach adopted always considered my clear intentions to safeguard participants. For instance:

- ✓ General questions were asked, followed up with more specific prompts for adequate information collection.
- ✓ Participants had the option not to engage if they find any subject distressing.
- ✓ Participants had the option to take a break if need be.
- ✓ I watched for early warning signs of distress and modified interview sessions accordingly.

I considered the potential risks and benefits and the above plan ensured that participants' financial, physical, psychological, or social circumstances were not taken advantage of in anyway.

4.8.3 Confidentiality

All information collected was stored safely and securely on the university's Microsoft one-drive. In line with the General Data Protection Regulation (2018), only a "preferred provider of transcription and translation" of the University of Bradford was used. Only members of the research team had access to data collected. A password protected audio-recorder was used to capture the interviews.

4.9 Sampling

The study used purposive sampling techniques to conduct in-depth semi-structured interviews to engage with a sample comprising three sub-samples listed below. I focussed on current caregivers of older relatives who were also in employment and on parents and children affected by OCP to gain a rounded picture that was used to generate **robust** themes and valid recommendations, as these groups of people are most likely to feel the impact of the societal and contemporary demands. In addition, the homogeneity (in that all are concerned with caregiving for older relatives) and the small size of my sample (23 participants in total) enabled me to examine 'divergence and convergence in some detail' (Smith et al. 2009: 3), and as such, this helped to inform a rich, detailed descriptive and interpretative analysis.

The three sub-samples for this study were:

- a. Only Child (born between 1980-2002) – Generation Z & the Millennials; age range 18-40.
- b. Family caregivers who were also working – Generation X (born between 1965-1979) – age range 41-55. Baby Boomers (between 1946-1964)- age range 56- 74, would be included if I struggled to recruit Generation X for the study).
- c. Parent with one child- Generation X (those born between 1965-1979) – age range 41-55.

4.9.1 Inclusion criteria

Children affected by OCP (Generation Z & the Millennials).

- Participants needed to be age 18 and above, with or without responsibilities for caring for an older relative.
- Participants needed to be an only child because of the one-child policy.

Caregivers in employment (Generation X or Baby boomers).

- Participants needed to provide at least four hours of face-to-face care per week.
- Participants needed to be age 18 and above and provide care for an older relative living with at least one long-term medical condition(s).
- Participants needed to be in full-time or part-time employment.

Parents affected by OCP (Generation X or Baby boomers).

- Participants needed to be age 18 and above, with or without the responsibilities of caring for an older relative.
- Participants needed to be parents with only one child because of the one-child policy.

4.10 Procedure

From the outset, as neither I nor my supervisors understood Mandarin, I understood that I needed to collaborate with mainland Chinese academics with a shared interest in the care of older people living with long-term health conditions. Finding an appropriate person who would be keen to assist and advise was

therefore a priority. I blogged about my experience of finding a collaborator [here](#). Following various leads, I established a working relationship with Professor Liu Yu (LY), Professor of Nursing at China Medical University, who expressed interest in supporting me. A memorandum of understanding was established between China Medical University and University of Bradford, and I visited China with my principal supervisor in November 2019 to discuss the nature of the study and the support that would be needed.

LY agreed to support phase 2 of this doctoral study. She assisted with participant identification and recruitment. Additionally, LY acted as a translator in my online interviews. LY., Ph.D., RN is a Professor in the School of Nursing at China Medical University and a visiting scholar of the University of Pennsylvania School of Nursing. She acquired her Ph.D. from the University of Arizona College of Nursing in 2010 with a major in Gerontological Nursing. Her research interests are related to home care for community-dwelling older people living with dementia, and she has been working with communities and long-term care facilities to improve their quality of care. This relationship had implications for my research design and positionality. It meant that there were always three people in my phase 2 interviews (the participant, LY, and myself) and that I needed to manage the dynamics of this configuration. To do this, I needed to be clear about our respective roles as researcher (myself) and interpreter (LY) (see sections 4.5, 4.6 and 4.7). In the interviews, LY acted only as an interpreter, being a conduit to translate between myself and the participants. However, as a collaborator, during the process of analysis, LY enabled me to interpret nuances captured during interviews that I would have missed due to my lack of understanding of Mandarin and my outsider position with regard to Chinese society.

4.11 COVID-19 and research implications

On the 31st of December 2019, the first case of the novel Corona Virus (COVID-19) was announced in China. This was followed by the World Health Organisation reporting the first case of COVID-19 on the 11th of March 2020 (Giebel et al. 2021), which resulted in nations enacting various public health restrictive measures (Payne 2020). The initial plan was to spend some weeks pre- and post-data collection in China to absorb the environment and gain my participants' trust by disclosing my own experiences and why the study mattered to me. Due to COVID-19, I had to adapt my research, which mainly had to do with recruitment and data collection. I had no option but to conduct my study virtually and I considered using Skype and Zoom for data collection (Deakin and Wakefield 2014; Lo Iacono et al. 2016; Krouwel et al. 2019). This was advantageous on one hand, in the sense that I could conduct the interviews in the comfort of my room just like most of my participants did. Equally, participants were given control over the place of the interview (i.e., choice of going to the university to meet LY or staying at home). This provided participants and I some privacy in the sense that participants could choose where to be interviewed, what part of their house they wanted to sit in, and could use virtual backgrounds, as well as decide whether to turn on their video (Salmons 2016). On the other hand, it was somewhat mechanical, with limited emotional connections, especially when there was poor connectivity (Oliffe et al. 2021). In addition, participants might have felt that I was intruding into their personal space, especially if they were in their own homes and due to lack of technological knowledge, were unable to turn off their video or use virtual backgrounds or headphones (Sy et al. 2020) to prevent older relatives from hearing what they had to say when they might have been referring to sensitive

matters. To mitigate this, for the Phase 2 interviews, the collaborator was able to offer necessary practical support to participants.

Given the unprecedented nature of the pandemic, conducting virtual qualitative research complicated the research context (Roberts et al. 2021). However, the benefits of using Zoom outweighed the disadvantages, as participants appeared to have appreciated talking about the phenomenon of interest. In terms of methodological rigour, irrespective of the impact of the pandemic on my research, I still would have employed the support of LY to gain access to participants and interpret from Mandarin to English. As such, Covid-19 did not greatly interfere with my research design, purpose, and methods. Yet, I was mindful that if I had been able to travel to China as originally planned, I could have presented my research to a wider audience who might have been willing to partake in my research, especially those with low socio-economic status in the society, (Johnson et al. 2021). Bearing in mind, LY's role as stated in the preceding section and this section, I shall discuss the practicalities of organising and undertaking the interviews for my research.

4.11.1 Participant identification and recruitment

Potential participants were identified through LY's professional networks; mainly community nurses in Shenyang who approached people about the study. Potential participants were also identified through snowballing and were able to make direct contact with LY via various routes (email, text, message, WeChat, phone call) or via the professional network. Potential participants who were interested in taking part were screened using the inclusion criteria by the community nurses and LY. For instance, participants who were current

caregivers needed to provide care for a minimum of four hours weekly. This criterion was considered a substantial low entry and my rationale for this is to accommodate those combining caregiving with other responsibilities. Potential participants who were found to be ineligible for some reason, received an explanation, and they were thanked for their support and their time.

The process of identifying and contacting participants was as follows:

- (i) Community Health Care Centre nurses told potential participants about the study.
- (ii) If the potential participant was interested, the community nurse gave the person an information sheet and got the person's permission to pass on contact details to LY.
- (iii) We waited for at least 48 hours to give the person time to read the information sheet, then LY called them to answer any questions and messaged me via We Chat to ensure we agreed.
- (iv) If the person understood and was happy to take part, LY went ahead and arranged a time to meet for a virtual interview at a suitable venue of their choice, such as their home or a room at the university with LY.

4.11.2 Data collection

Given the questions that I intended to ask, I believed that having participants in groups could be counterproductive as they might not be willing to be vulnerable in the presence of others. From the **phase 1** focus groups in Chapter 3, I realised that some participants became guarded when other participants challenged personal views and practises. Thus, I decided to conduct one -on -one interviews

for data collection with the attendance of LY in the capacity of an interpreter. The interviews were conducted at the participant's convenience via the Zoom platform.

LY contacted me whenever potential participants showed interest. They were given the information sheet and a suitable time for the three parties was arranged, noting the eight hours' time difference between the United Kingdom and China. To avoid interrupting participants' working hours, most interviews commenced between 09.30-10.30hrs (UK time) / 17.30-18.30hrs (China time). I sent Zoom invitations a few minutes before the interviews, and I called in. Written consent was sought before commencing the interviews, and this was shared with me electronically at the start of the interview (see Appendix H: Blank consent form). Following this, participants were asked to provide some information about themselves (see Appendix I: Blank demographic forms). They were then asked to complete a family tree exercise, indicating three generations: G1 (grandparents), G2 (parents/uncles and aunts), G3 (participant and cousins) and G4, if this existed, which served as an ice breaker, and I found to be helpful as I had to collect data virtually. Additionally, demographics were gathered, such as age, gender, care recipient's long-term health diagnosis, employment status/occupation, relationship with care recipient, highest level of education/qualification, home province, ethnic background, hours of care provided to older relatives/day and whether participants were affected by one-child policy. I used this information to situate participants to inform the interview process and data gathering. Following these activities, which helped with building rapport with each other (Casey, 2006), participants were informed that recording was going to start, I reconfirmed consent verbally and the interview commenced.

I prompted participants when needed and kept the discussion on track to gain an in-depth understanding of the phenomena of interest. Questions focused around understanding the lived experiences of participants (See Appendix G: **Phase 2** (main study) interview guideline), including their motivations and cultural obligations towards caring for older relatives, inclination to care, knowledge and attitude were explored. **A typical opening question was “tell me about yourself?”.** **The interview process was a 3-way interaction as, although I gave all participants the opportunity to test out their English, this often did not go beyond introductions.** **Therefore, I asked my questions in English, LY translated to the participants, the participants replied mostly in Mandarin, then LY translated their Mandarin to me.** **I paid close attention to non-verbal aspects of interaction between the participants and LY and followed up on questions, if I felt my questions were not addressed or when I sensed that participants or LY might still have something to relay to me.** **At the start of the interviews, I reiterated that my expectation was for participants to only share what they were comfortable with as highlighted in the information sheet.** During the interviews, which did not last longer than 90 minutes, I **consistently** paraphrased key points and stated them back to participants to check for accuracy. Participants were asked to share personal encounters and experiences about caring for older relatives. As time went on, I was able to judge by facial expression whether my understanding of what they said was a true reflection of their experiences. **In a few cases, that led to further probing which enabled more insight into what participants had said.** There were no times where interviews had to be stopped because participants were distressed. At the end of the interviews, each participant was thanked for their involvement in the study

and a token gift of a maximum of £20.00 was given to participants in return for their involvement, in accordance with Chinese research practise.

Following each interview, LY and I stayed behind online to debrief. I was able to check that interviews were translated verbatim, and this also gave me the opportunity to get a sense of her reflections on participants' experiences. Often, she disclosed how much she had learnt from participants, with emphasis placed on her privileged position in the society, as she could not have imagined what people were going through to support older relatives. I found the process beneficial as it reinforced the trust that our working relationship was built upon. After every interview, I reflected on our deliberations and captured this in my reflective notebook, and this played a crucial role in data analysis, which I will return to in the next section.

Following interviews, audio files were downloaded and stored on a password protected computer as well as uploaded via the secure portal of the UK based transcription company. This company transcribed only the English language content of the interviews. At this point, audio files were deleted from the recorder. The transcription company returned transcripts via the same route (e-portal system), which I then stored on a password protected laptop computer. Pseudonyms were used for write-up purposes, to protect the participants' identities and personal identifying information was changed at the point of interview to ensure that scripts are anonymised. Personal information was only linked with the consent form using a participant identification number. Participants' demographics is presented below (See Table 4.1, Table 4.2 and Table 4.3 below). Participants' ethnic backgrounds are presented as (H) for Han and (M) for Manchu.

Table 4.1: Offspring affected by OCP characteristics

Participant pseudonym (Ethnic Background)	Age (years)	Gender	Older relative(s) long term health condition	Working status	Highest level of education	Caregiving status	Province	An only child?
Geyue (H)	23	Female	Not applicable	Student	MSc	Not a caregiver	Liao Ning	Yes
Elaine (H)	35	Female	Liver condition	Nurse and Academic	Msc	Caregiver	Liao Ning	Yes
Zijian (H)	24	Male	Not applicable	Student	Bsc	Not a caregiver	Liao Ning	Yes
Jie (H)	20	Female	Not applicable	Student	Bsc	Not a caregiver	Liao Ning	Yes
Yun (H)	30	Male	Stroke	Railway operator	Bsc	Caregiver	Liao Ning	Yes
Zhirui (H)	22	Female	Not applicable	Student	Bsc	Not a caregiver	Liao Ning	Yes
Yingyi (H)	35	Male	Not applicable	Sales merchant	Diploma	Supports mother who is the caregiver	Zhejiang	Yes
Feng (H)	23	Male	Not applicable	Teacher	Bsc	Supports mother who is the caregiver	Liao Ning	Yes

Table 4.2: Parents affected by OCP

Participant pseudonym	Age (years)	Gender (long-term health condition)	Older relative(s) long term health condition	Employment	Relationship with care recipient	Highest level of education	Hours of care/ day	Do they have a single child? (Gender)	Location of Child (Same city, country)
Andrea (H)	49	Female (health condition)	Stroke and Hypertension	Public service	Mother	Bsc	Four – five	Yes (F)	Yes
Xue (M)	49	Female	Stoke and Dementia	Domestic worker	Mother and Mother-in-law	Junior high school cert.	Had to quit her job to provide care.	Yes (M)	Yes
Wen (H)	53	Female	Diabetics and Mild Cognitive Impairment.	Academic	Father and Mother	Msc	Two	Yes (M)	Yes
Ruiying (H)	60	Female	Hypertension	Manager	Father	Diploma	One-two	Yes (M)	Same county, different cities

Shifan (M)	61	Female	Hypertension, mild dementia and Diabetes	Nurse	Mother	Msc	At least 4 hours.	Yes (M)	Yes
Yingceng (H)	47	Male	Dementia and Hypertension	Teacher	Father	Junior College	About an hour	Yes (M)	Yes
Dan (H)	62	Male	Dementia and Hypertension	Technician	Mother-in-law	Bsc	One	Yes (M)	Yes
Joanna (H)	57	Female	Dementia and Diabetes	Academic	Mother	Msc	About an hour	Yes (F)	Yes

N.B: All Participants were from Liao Ning province.

Table 4.3: Caregivers in employment

Participant pseudonym	Age (years)	Gender	Older relative(s) long term health condition	Employment	Relationship with care recipient	Highest level of education/qualification	Hours of care/day	Do they have a single child? (Gender)
Sutong (H)	50	Female	Chronic heart condition History of bladder cancer	Primary school teacher (FT)	Previously: Grandma, father, and mother-in-law. Currently- Father	Diploma	six – seven	Yes (M)
Niu (H)	47	Female	Stoke and reduced cognitive functioning	Teacher (FT)	Father	Bsc	Four	Yes (M)
Yan (H)	49	Female	Stoke	Sales trainer (FT)	Mother (Passed away in Feb 2021)	Associate degree	Three	No (no child)
Jerry (H)	42	Male	Hypertension, Chronic Renal condition, Brain haemorrhage (paralysis)	Taxi-driver	Father	Associate degree	Almost 24 hrs	No (No child)

			and visual impairment					
Xiang (M)	37	Female	Rectum Cancer	Purchasing manager (FT)	Father	Bsc	Three	Yes (M)
Tong (M)	43	Male	Rectum cancer	Train station ticket salesman (FT)	Mother	Associate degree	Six-seven	Yes (F)
Lisheng (H)	56	Female	Brest cancer and Dementia	Teacher	Mother-in-law	Msc	Four	Yes (M)

N.B: All Participants were from Liaoning province.

4.11.3 Data analysis

Given that inter-subjectivity between researcher(s) and study participants constitutes the process of developing meaningful knowledge production and to an extent, 'rejects the search for consensus' (Madill et al. 2000: 17), it was of great importance that I adhered to research values driven by the contextualist constructionist research paradigm. This meant I had to think critically about my analytic strategy, specifically, how I intended to apply my strong interests in the experiences of family caregivers as well as my common cultural assumptions with participants, as valuable analytic resources. As such, I chose to make "Big Q", which incorporates qualitative data, values, and practices, fundamental to my analytic processes. This made the choice of reflective thematic analysis a good fit in comparison to using *coding reliability* or *codebook* "small q", which are less interpretive approaches to analysis (Braun and Clarke 2021b). Considering these fundamental underpinnings, with emphasis placed on distinctiveness of reflective thematic analysis verbatim transcripts were analysed manually (Braun and Clarke 2020). I employed a latent level analysis (Braun and Clarke 2006; Braun and Clarke 2013), where shared/co-produced meanings were integrated into themes (Braun and Clarke 2019). Meanings were drawn inductively from multiple realities of participants within their socio-cultural environment. Central to this was my interpretative reflexive process, which was iterative and dynamic to adequately inform the process of theme identification (Braun and Clarke 2020). The six iterative phases of reflective thematic analysis adopted are as follows: Familiarisation: reading and rereading transcripts, which resulted in immersion and critical engagement with some imaginations of how. Code generation: coding data extracts several times to aid reflexivity, i.e., finding out the significance,

purpose, textual and pragmatic implications of data. Identifying themes: an active process where themes evolved. Developing and reviewing themes: where themes are refined and were clustered together based on their inter-connections to develop subthemes, simultaneously, subthemes were clustered to aid theme identification. Refining, defining, and naming themes: themes were reviewed and refined and finally, writing up the analysis. This iterative process enabled me to present my findings' diversity within a framework of convergence. In addition, to aid reflexivity, I employed 7 key questions proposed by (Braun and Clarke 2013) and further underpinned the work of Smith (2019) as it pertains to meaning-making between participants and me (See Table 4.4 and Appendix J: Typology of meaning and example demonstrating mechanisms aiding reflexivity.). The appendix shows examples of analysis in relation to the sub-sample of offspring affected by the OCP. A similar set of steps was followed for the other two groups.

Table 4.4: Six phases in reflexive thematic (latent) analysis and a description of the process involved

Phase	Description of process
<p style="text-align: center;">Data familiarisation</p>	<ul style="list-style-type: none"> • I reviewed reflection notes written at the end of each interview • Took notes and marked down ideas for coding. • Checked the transcript back against audio files for accuracy. • Had meetings with supervisors to compare and discuss our individual understanding of data.
<p style="text-align: center;">Initial code generation</p> <p><i>Exploratory process</i></p>	<ul style="list-style-type: none"> • I re-read transcripts, made notes focusing on making sense of what participants were making sense of, by using reflexive lines of questioning as recommended by Braun and Clarke, (2013)

	<ul style="list-style-type: none"> • I coded interviews using the review feature of Microsoft word. • Grouped together relevant coded data, which then led to codes evolving. • Being a data-derived and researcher driven analysis (Braun et al. 2019), all content of transcripts were coded against the research questions with emphasis on semantic and latent meanings. • I met with supervisors to discuss the initial codes and coded three from 2 sets of samples to aid internal validity. Consistently checked the feasibility of my interpretation with Chinese colleagues.
<p>Identifying themes</p> <p><i>An active process-means to an end and overlapped with phase below</i></p>	<ul style="list-style-type: none"> • an initial thematic map was developed. Through further engagement with data, themes evolved. • Supervisors reviewed the thematic map, asked questions and during series of deliberations, my awareness was raised around choice of words, connections between themes and clarity around the process of meaning creation i.e., making clear distinction between participants' narratives and interpretations.
<p>Developing and Reviewing themes</p> <p><i>Overlapped with phase below</i></p>	<ul style="list-style-type: none"> • I read through transcripts again. • Read through my reflections and field note memos, having in mind research questions and discussions previously had with supervisors. • I revisited codes and situated each participant, arranging and re-arranging codes to achieve data coherence within themes and clear distinctions between themes and developed another thematic map.

	<ul style="list-style-type: none"> • With a good understanding of each participant's narrative i.e., experiential meaning (what does it mean?) (Braun and Clarke, 2013), I developed a thematic map. To develop this, emphasis was placed on creating a coherent pattern within coded data extracts and ensuring that the complete set of data were well presented in terms of meaning creation.
<p>Refining, defining, and naming themes</p>	<ul style="list-style-type: none"> • Quotes from transcripts relating to each theme were organised in a coherent and internally consistent fashion, with accompanying narratives. During this process, some codes were reworked to substantiate experiential meanings, showing convergence and divergence in manifesting themes. • The content of the themes was considered to ensure that there was not too much overlap between them. Each was considered in the context of the research question, and how this related to the overall narrative. Subthemes and themes evolved over time, reviewed by supervisors. We all read through transcripts again to ensure the experiences of participants were accurately reflected in the analysis.
<p>Report writing</p>	<ul style="list-style-type: none"> • Each theme was written up and quotes were used to substantiate discussions relating to identified themes. • The inextricable link between themes became very evident at this phase and I decided to focus my writing on the overarching theme “competing pressures” rather than individual themes per se.

	<ul style="list-style-type: none"> • Situated my findings in wider literature of family caregiving of older relatives and influence of culture on the process. • I engaged in an on-going consideration of the principles of ethics and reflexivity, aided by presenting to supervisors and colleagues, and the process helped deepen my understanding and confidence for my interpretations. Finally, synthesising the focal perspectives of 3 homogenous samples, I adopted the approach “lines of arguments”, which enabled me to situate my analysis <i>within</i> and <i>between</i> samples with emphasis placed on relational, intersubjective and microsocial dimensions of the phenomenon (Larkin et al. 2019).
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4.11.4 Rigour and trustworthiness

Reflecting on misconceptions and confusions around thematic analysis, Braun and Clarke (2019) concluded that rigour in **reflective thematic analysis** required that I am explicit, thoughtful, deliberate, and own my assumptions and position with regard to the typology of TA, as highlighted in the Data analysis section.

Being clear about the implications of my personal and cultural perspectives on the research design for Phase 2, it is important that I articulate my position.

One key aspect in my phase 2 research relates to trustworthiness in relation to the management of interpretation of the participants’ utterances. Back translation was not used as such. Instead, in keeping with the epistemological and constructionist foundations of the thesis, I placed emphasis on the quality of my relationship with LY as interpreter and on her understanding of qualitative

methodologies and the task at hand. Through these, I was confident that the English language portions of the interview transcripts reflected as much as possible, the meanings the participants were attempting to convey. More specifically, no one was employed to check for accuracy of LY's translations. In some contexts, adopting back translation is seen as vital to check that meanings are not lost in translation. This often dominates quantitative, positivist or post(positivist) research as it provides a direct control on quality of translations, especially where concepts need to be accurately translated into written materials, such as when producing questionnaires in different languages. However, in the qualitative research context, I realised that the quality of LY's interpretations would be very much dependent on background and skill set, quality of briefing with regards to role clarity as well as language competence (Behr and Braun 2022). As such, semantic equivalence of Mandarin to English language was less crucial than LY's ability to convey participants' meanings. Hence, the choice not to contrast LY's interpretation with that of another native Mandarin speaker (Behr and Braun 2022). LY's role as an interpreter was complex (Chen and Boore 2010) and was to bring meanings expressed in Mandarin into the English language as clearly as possible. This decision has been put into consideration and well-grounded in Chapter 4: Methodology and Methods, especially in the sections on Hermeneutic phenomenology and Methodological position.

In further considering what objectivity and reliability meant for this current study, my subjective experiences were used as a resource, anchoring on my epistemological and ontological foundations i.e., social constructivism (Braun and Clarke 2020). Hence, the analysis involved both descriptive and interpretative approaches (Braun and Clarke 2020). Even though **reflective thematic analysis**

could be carried out by a sole researcher (Braun and Clarke 2021b), I was conscious that only involving one person in the analysis might mean it would be influenced by my viewpoint. (Tong et al. 2007; Shaw 2010; Braun and Clarke 2020; Braun and Clarke 2021b; Braun and Clarke 2021c). I was also mindful that participants could have under reported socially undesirable attributes. My position as an international student and that of LY as a Professor could have made participants consciously or unconsciously portray themselves in a good light, in an effort to mitigate being embarrassed (Latkin et al. 2017). For instance, participants in phase 2 appeared to more readily express positive attributes regarding their role and identity, than to divulge their stressors. In phase 1 of the study conversation about stressors came about more organically with participants, whereas in phase 2, I needed to ask probing questions to find out about stressors. The awareness that social desirability may have influenced phase 2 participants' interviews and narratives, made it important that I drew on my experiences as a family caregiver, in a collectivist society, and as a mental health nurse, in an individualistic society, in conjunction with my supervisors at every stage of the phase 2 analysis during team discussions. Furthermore, JO and CQ brought perspectives as clinical-academic psychologists and applied dementia researchers. LB brought a healthcare service design and delivery perspective. LY is Chinese and brought cultural perspectives and clinical-academic (nursing) expertise. I endeavoured to reach a consensus regarding multiple points raised about the data set, leading to outcomes and development of themes that grounded participants' stories. Put together, our expertise was used to mitigate against bias, which aided reflexivity and reinforced the relationship between our accounts and our interpretations of the data. Hence, the

developed thematic map incorporated the participants' narratives and researchers' interpretation with concise and apt themes.

4.12 Summary

In this Chapter, I have discussed my research positionality. I have discussed justified my choice of hermeneutic qualitative research. More specifically, I made a case for employing hermeneutic phenomenology as I am interested in grasping lived or perceived experiential meanings mainly from an ontological viewpoint. I supported this by explaining the philosophical underpinnings of the study, which then informed my methodological position as a social constructivist. Lastly, I discussed considerations that guided and impacted decisions about my study design, to demonstrate rigour and research reflexivity. Having established the philosophical and theoretical underpinnings of this doctoral study, in the following 3 chapters, I will present the findings **from Phase 2 of my study**, which incorporate the views and perceptions of participants across the three purposive sub-samples.

Chapter 5: Caregiving Beliefs- Xiao: the lifestyle

The findings that will be shown in Chapters 5, 6 and 7 are detailed in Figure 5.1 below. They represent three themes encompassed under the overarching theme of 'Competing Pressures - Meanings, Motivation, and Preparedness'. Chapter 5 will address the first theme; Chapter 6 addresses the second and Chapter 7 addresses the final theme. Direct quotes from the interviews have been used to illustrate findings.

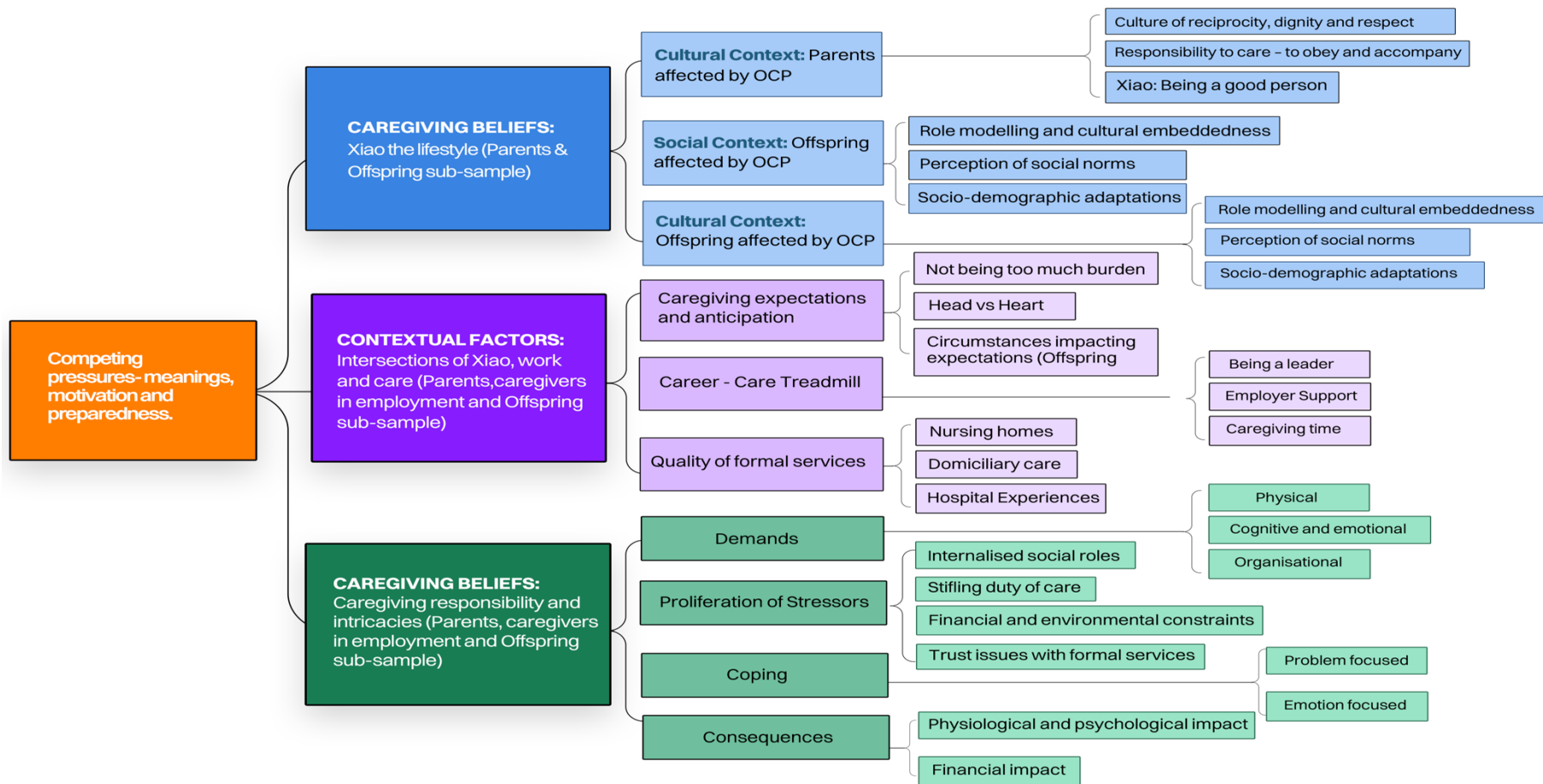


Figure 5.1: Overarching theme, themes, and sub-themes

Chapter 5: *Caregiving Beliefs*, looks at the meaning of filial piety to a sub-sample of parents and a sub-sample of offspring affected by the One-child Policy (OCP). The overarching theme; Xiao: the lifestyle, addresses objectives one and three of this thesis: 1) to understand participants' experiences, or that of their relatives or friends, of caregiving responsibilities for older relatives in China, and 3) to explore the meanings of filial piety (Xiao) to participants.

Participants provided experiences and descriptions detailing the significance of Xiao and the motivation to provide care, which appeared to be driven by cultural beliefs that were embedded in their social environment. However, a potential for incongruence was revealed between cultural beliefs and individual interpretations for performing Xiao. This theme, Xiao: the lifestyle, highlights how the cultural disposition of parents to invest in their offspring creates a powerful positive reverence that is the basis of their desire to reciprocate caregiving. Within the context of motivation, this obligation to care serves as a precursor for participants' duty of care. The socio-cultural environment presents family caregivers as an anchor for older relatives living with long-term health conditions. Hence, family caregivers face pressures to prioritise older relatives' needs and health above their own.

The findings show how society has been socialised across generations to regard Xiao as intrinsic and that participants learned the art of negotiating their beliefs about the enactment of Xiao as they became pertinent to individual circumstances. Their experiences and perceptions emphasised socio-cultural intricacies associated with caregiving responsibilities. Data suggest that reconciling the moral gratification derived from caregiving ideals attached to cultural beliefs, with navigating through the reality of caregiving challenges, will

present younger generations with both opportunities and challenges. Ultimately, the sociocultural beliefs encouraged perseverance in participants' attitudes. However, a cultural evolution is unfolding as participants are redefining how to fulfil Xiao because there are societal expectations to remain positive and empathetic while attempting to balance work with adversities associated with their responsibility under their family caregiving role. In the rest of this chapter, I present findings of my analysis thematically, adopting descriptive and interpretative approaches as highlighted in Chapter 4.

5.1 Cultural context- Parents affected by OCP

5.1.1 Xiao: Culture of reciprocity, respect, and dignity

Evident through the narratives of parents affected by the OCP is the reality that adhering to Xiao's principles requires self-abnegation. Participants highlighted the intrinsic nature of Xiao, expressed through an appreciation of parents as the source of life. This motivated them to provide care to their parents at all costs:

In my mind nothing is more important than taking care of my parents. And I feel very lucky and very gratified to be with my parents because I think my father and my mother gave birth to me and they gave me a living opportunity and that they raise me. So, I think I can give up anything to take care of my parents [...]. (Ruiying; 60; Female; Parent affected by OCP)

As family caregivers, all participants identified a desire to ensure a good quality of life for their parents. The sacrifice and devotion that is part of Xiao, as illustrated, grounded their desire for reciprocity. **Shifan's** example below

demonstrates the extent some parents would go to support their children to ensure a good future, which drives offspring to repay in kind:

[...] I really appreciate my mother's contributions to my professional achievement when I was young and it gave me a lot of personal responsibility, for example, looking after my child and my mum, and my parents at that time really helped me so much so that I can have today. So, when my son was just 28 days and I left my child and go to study English for about one year, at that time my parents helped me to look after my son. (Shifan; 61; Female; Parent affected by OCP sub-sample)

According to participants' interviews, the normative values of Xiao strengthened society and often kept individuals accountable to one another in upholding the shared virtues. The level of sacrifices illustrated by **Shifan's** example is common within Chinese society and leads to the assurance that future generations will care for the older generation. **Yingceng** substantiated this when he expressed that "*as they're getting older that's the time for us to return, to take care of them*". His description illuminated the inevitable sense of these deeply held beliefs about reciprocating caregiving as echoed by all participants:

Parents nurtured us and helped us grow up. [...] Taking care of our parents is the natural thing. (Yingceng; 47; Male; Parent affected by OCP sub-sample)

Cultural expectations naturally infused the responsibility to provide care for older relatives into familial and societal relations. More importantly, despite potential inconvenience, differing interests or routines, participants maintained their caregiving role as an avenue to show respect:

So, I think respect, you know for example I will cook some food which they love. For example, when we go to the shops, such as the supermarket, actually for me I don't go there but for my parents I will do that. I will bring them there even though it is not a place I like. (Wen; 53; Female; Parent affected by OCP sub-sample)

Endeavouring to create and sustain their parents' peace of mind is one example of how most participants fulfilled Xiao. Additionally, parents' dignity was preserved through shielding their parents from negative emotions. This could be covert in nature with some family caregivers self-regulating to sustain the quality of their relationship with their parents:

Respect them and not make them angry. As children we should not make trouble for the parents. Don't lie; don't like to think about bad, so try to let them know, do more things for them. (Andrea; 49, Female; Parent affected by OCP sub-sample)

5.1.2 Xiao: responsibility to care – to obey and accompany

The onus to sustain a good relationship with parents lies with offspring within the ethos of Xiao, and it seems justifiable to highlight that some participants perceived their ideal self (how they would like to be) and their ought self (how they are taught they ought to be) as one and the same. When expressing their prominently held views, most participants positively reinforced how “*you should be*”:

You know, like we say that when they (parent) grow up you should be accompanying them when they get older. So, it is kind of the way to express. So, when my parents get older it is my responsibility to take care

of them. So that's the way you should be. (Wen; 53; Female; Parent affected by OCP sub-sample)

Xue (49; Female; Parent affected by OCP sub-sample) expressed that to be Xiao is to be a role model to offspring. She stated, “*Xiao is the traditional Chinese culture. So, I think that's the culture we followed and the rules we follow. I think that being Xiào, if I was a Xiào person, I am kind of a model for my children [...].*” Other participants also shared how adhering to filial rules relied on those from younger generations being conversant with these cultural expectations. Some participants believed that providing the necessary foundation for offspring required a natural assimilation of Xiao's principles:

I educated my son on Xiao purposely, and not in some special way. I showed how to be Xiao to my son by asking him to go visit my parents every week before going to the university and asked him to talk, speak politely to the elders. (Yingceng; 47; Male; Parent affected by OCP sub-sample)

Being raised to be a role model with expectations of sustaining a good relationship with ageing parents carried a responsibility that went beyond providing hands-on care. It was of great importance to all participants for offspring to take full responsibility for the holistic needs of older relatives in their care. For instance, mitigating relational stressors between their parents was just as crucial as providing material needs:

And then we should, you know, pay more attention about them, for example to watch out for their physical condition and their food and to make sure they have good rest, and I make sure they have followed the

treatment, followed the therapy schedule. Persuade them to share their worries, and some confusion. I try to persuade them to talk with me, to communicate with me and then I can share their worries. I should spend more time to be around and when parents don't communicate between each other, you know, and as the children we should try to persuade them to help to solve the conflict. So, there is another Chinese culture. And we should do more household chores. (Andrea; 49, Female; Parent affected by OCP sub-sample)

Due to parents putting their needs on hold for their offspring's sake during early years, most participants agreed that enabling a good quality of life required that they should now put their needs on hold for their parents. For instance, for **Shifan** to be a filial person meant ideally ensuring her mother's happiness. Therefore, she altered their living arrangements. In striving for her mother to enjoy the same quality of life as herself, it was necessary to always endeavour to be understanding of "*shortcomings or drawbacks or behaviours that make us very unhappy or not understood*":

Xiao means I would like to help my mother to enjoy the same quality of life as me. So, this is why I'm living together with her and trying to get a home maid to care for her [...] If I just enjoy my life and I never think about my mother, so I think this is not Xiao. Even though my mother has this or that kind of shortcomings or drawbacks or behaviours that make us very unhappy or not understood and we need to understand try to let her feel happy. This is another way of Xiao. Yeah, making my mum very happy to live the life is my top aim. So, I need to balance all kinds of our relationships

so that my mum feels happy. (Shifan; 61, Female; Parent affected by OCP sub-sample)

This sub-sample of parents continued to express their conscious yet instinctive need to self-regulate daily living in the best interest of their older relatives. The level of support and compassion concerning caregiving was meaningful for some and allowed reframing an event positively to cope with requests that might be viewed as illogical. In relation to this, **Ruiying** described an experience where they accompanied her father on a physically challenging journey but failed to fulfil her father's demands, resulting in his unhappiness as illustrated in the excerpt below:

In our house we have many basins already, but my father still wanted to buy a basin, a pot. And firstly, we didn't meet him at that time. I told him we already have a lot of basins in your house. So, we just carried him to the supermarket and after visiting it we came back home but he became a little unhappy. So, after I visited my father's home I was outside the house and I just thought, "Maybe buying a basin will make him happy". So, in that time the supermarket opening up has an activity, that when you buy other things that means 200 Yuan, RMB. The supermarket will provide you a free basin. So, I bought 200 RMB, some things that my father might use in later days and took the free basin to him. And when he looked at the free basin, he became very happy and said, "What a beautiful basin" and he became very happy. (Ruiying; 60, Female; Parent affected by OCP sub-sample)

in the preceding excerpt, **Ruiying** paid more focus to the outcome of her father's satisfaction or demeanour than the rationale of already having enough basins. Further, as shown in the quotation below, the opening of the supermarket was cause for his interest and **Ruiying** and siblings were proactive in giving him that experience despite the challenge of the distance:

My siblings and I just become most truly filial piety to my father or become very obedient to him. I think that is our role [...] For example, some days earlier in our community a supermarket opened up and my father wanted to go to visit the supermarket. And we took him from our home to the supermarket; it is a very long distance, so we put him in the wheelchair to visit the supermarket. (Ruiying; 60, Female; Parent affected by OCP sub-sample)

Nevertheless, on this occasion, despite having several basins at home, the unhappiness that her father experienced made her feel like she was not being "truly filial". **Shifan** also gave an example of adjusting life around the older relative with care needs. In this excerpt below, terminating the maid's employment could be justified based on her difficulty in knowing how to respond as her mother's confusion developed, nevertheless, the focus was on maintaining the happiness of her mother regardless of any difficulty experienced:

So, for me I think making my mum happy is my main purpose to be Xiao [...] When my mum got confused more so sometimes her behaviour was not appropriate. So, the home maid tried to stop her or sometimes was very critical. And my mum was unhappy. So, we fired that home maid. So, we changed and got another new home maid. So, at that moment it was

very difficult, you know. So, we tried to figure out how to deal with my mum.

(Shifan; 61, Female; Parent affected by OCP sub-sample)

In other cases, the expectations for offspring to be present physically for older relatives, being responsible for creating a thriving environment to support the well-being of parents, could present difficult choices when adjusting their lifestyle to caregiving circumstances. In this example, travelling abroad was something **Ruiying** had envisioned doing in her life but when the opportunity came, she deliberately gave up the idea to be present to accompany her parents. The main reason she cited for not temporarily visiting abroad was her desire to live close to her parents and missing her mother; a decision she did not regret as she described feeling gratified to have made this decision:

*And I suddenly missed my mother very much and I think the main reason, important reason is that I cannot live very far away from my father. So, when my friends asked me to go travelling at that time, I even had the thought of going abroad, I give up the idea. I think I feel very gratified just to be accompanying my parents. **(Ruiying; 60, Female; Parent affected by OCP sub-sample)***

While historically, the traditional Chinese culture of Xiao expects younger generations to heed parents' needs verbatim, parents interviewed had to negotiate and reconcile their caregiving responsibilities with their identity as offspring. More so, they incorporated being Xiao into their identity as caregivers and tended to gain satisfaction or esteem from fulfilling it even at the cost of other aspects of life. Therefore, the responsibility of offspring to care appeared to be measured by the breadth of obedience and dedication to accompanying the older

relatives being cared for, which seemed to be accepted as evidence of personal commitment to filial values.

5.1.3 Xiao: being a good person

According to all participants, the traditional pre-eminence of Xiao dictated peoples' attitudes within the cultural environment. Therefore, with all participants expressing the prioritisation of older relatives' needs, prioritising others was seen as morally significant. Consequently, there was a moral and ethical imperative for participants to assimilate their caregiving role into their identity:

[...] I think it's the traditional Chinese culture. We usually say that if you want to be a good person, you need to be Xiào. (Wen; 53; Female; Parent affected by OCP sub-sample)

With this view, the positive connotations associated with prioritising older relatives' needs served as motivation to provide care. This motivation was experienced as an opportunity to demonstrate their devotion to Xiao to offspring. A representative example is **Dan**, who acknowledged how the “*small things*”, that is, daily caregiving tasks, can accumulate, making the role demanding. However, the inevitability of needing future care himself continued to fuel his motivation to model Xiao to offspring. As **Dan** explicitly stated, “*If you are not Xiao, the good Xiao, your children will not take good care of you as well*”:

Xiao is really important for being a person, for the human being. And the meaning of Xiao to me is I should, you know, take the responsibility to take care of the elders, all responsibility. So, I'm happy to do that. And regarding the responsibility it includes the daily care, you know, the small things, but every day you need to do it every day. And you need to take care, daily

care for your parents, so for the elders. And don't let them be hungry. Don't let them be, you know, catch cold. If you are going to travel you should bring the parents, bring the elders with you and be with you. And I also think about, you know, being Xiao is important for myself because everyone will be getting older and older. If you are not Xiao, the good Xiao and your children will not take good care to you as well. (Dan; 62; Male; Parent affected by OCP sub-sample)

Various examples were given of several overt or covert approaches to directing the younger generation to the principles of Xiao. Participants like **Dan** highlighted how the traditional teachings were interwoven into daily life to the extent where it did not need to be explicitly expressed:

*You know Xiao, being Xiao is Chinese culture. It is our tradition. And we don't need to say out loud. When the children, you know, they go to the school and the school will educate what is Xiao. But we show the children. We show the child how to be Xiao. So, I think it is really a natural thing and they learn from when they are very young. **Dan***

The commonalities between **Dan's** above quotation, and other participants' interviews in general, showcase the early socialisation around being a good person within Chinese culture. Parents would often use their relationship to demonstrate the principles of Xiao to their child, showing how intrinsic Xiao was within the cultural environment and social relationships. From a very young age, individuals were taught that being a good person in Chinese society meant to "live for others", as **Andrea's** example illustrates in the following excerpt. Parents' sacrifice, which is the basis of respect and reciprocity, justified the request for

obedience and self-restraint from the younger generation. In this context, because **Andrea** taught her daughter to live for others, arguing with the father was considered disrespectful and the act immoral and not filial:

*I taught my daughter to live for others, meaning no time for herself. She understands that we usually do more for her and she should respect parents. One day, daughter argued with her dad and I just cracked. I let her understand that it is not right and that she was in the wrong, which is not a good thing to do. Parents sacrifice their life for children and so the children should respect back for the parents. My daughter is growing up, so she is trying to understand more, how much we have sacrificed our lives for her – it is Chinese culture too. (**Andrea**; 49; Female; Parent affected by OCP sub-sample)*

In expressing how filial principles can be covertly taught, **Joanna** told of an instance when using her bare skin to warm her husband's cold feet impressed filial behaviour upon her daughter's mind. According to **Joanna**, this example was chosen to show that children will observe behaviours and from their observations, are expected to learn and internalise the principles. This example also serves as an illustration of the subtlety and level of discomfort one should endure on behalf of another's comfort under Xiao:

[...] One thing impressed her is one day is a big heavy snow day. They all said, you know, the heavy snow is so heavy. And my husband came in the house from the outside and his shoes were totally white. And his feet were so cold, and I just opened my clothes and put his feet into my body to warm the feet up. So, this behaviour impressed my daughter and my daughter

said, “That’s the thing, the most impressive thing she remembers”. So, I say this example because I want to say when you teach filial piety you are not teaching, you do not talk, you just do and your kids, your children will observe. They will learn from your behaviour. (Joanna; 57; Female; Parent affected by OCP sub-sample)

Elevating another’s needs above one’s own is the essence of Xiao and as Xue (49; Female; Parent affected by OCP sub-sample) expressed directly, “I think for a good person, especially for elders, it’s just being good to elders, putting their wishes first and making them happy. That’s what I think is a good person.” Wen’s example substantiates Xue’s statement about prioritising elders as it relates to the expected responsibility of offspring:

So, I think it’s similar, you know, from my father’s generation when they think of Xiao now it is, kind of, similar to mine. Mother’s family has 11 children, and my mum is the youngest one, but my mum took care of my grandma. And my grandma also took care of the children. So, I watched my mom taking care of my grandma. So that’s why I know how to take care of the elders. And also, I also had an aunt and my aunt also has her children, but my mum said the children of my aunt didn’t know about Xiao to my aunt. They didn’t know to be good children for my aunt. (Wen; 53; Female; Parent affected by OCP sub-sample)

Wen’s account also reinforced Dan’s (62; Male; Parent affected by OCP sub-sample) sentiments as it referenced the normative values regarding caregiving responsibilities. As such, the potential repercussions of societal perception surrounding the inability to uphold filial expectations would lead to perceiving

those who are not “*the good Xiao*” as unfilial offspring, irrespective of underlying barriers to meeting societal expectations. Therefore, fear of not being “the good Xiao”, which could lead to inadequate support from offspring in the future, might contribute to the idea of concealing negative emotions and limitations associated with providing care. However, the possibility that the younger generation could reinterpret how to “be good” was unsettling for participants like **Shifan**. Should offspring decide to prioritise their own needs, the resultant danger, from her perspective, was that younger generations could move towards self-indulgence, resulting in tensions or a source of conflict between family members. Such is the nature of some fears regarding changes to Xiao’s principles or how they might be enacted:

The meaning of Xiao is really similar between my mum’s generation and mine. But I believe there is a big difference between my generation and my son’s generation. For example, several times I changed the home maid to a new one and my son said, “Why are you getting another one?” I said, “The only expectation your mum expects you to do is this job, trying to find the right person to take care of your mother”. And my son said, “No you can’t expect that. I’m going to send you to a nursing home” Yeah “I will send you to the nursing home and then I will try and visit you once a week or twice and try to visit you, but you can’t expect me to take care, to provide care like you do to his grandma. I can’t expect that type of care”. Those were my son’s words to me: “and I will visit you once a week or twice a week”. (Shifan; 61; Female; Parent affected by OCP sub-sample)

Dan also voiced this anxiety during his interview, substantiating **Shifan's** presumptions about the future of Xiao's principles with the younger generation:

I believe Xiao has changed. And now for the current children they have their own rules, and they have their own thoughts. They will not properly obey the parent's rules or parent's wishes. They have their ideas, their own ideas. (Dan; 62; Male; Parent affected by OCP sub-sample)

As presented so far, most participants placed the responsibility for imparting Xiao's teachings on older people. However, not all parent participants clung to the traditional notion of Xiao. **Yingceng** spoke of the evolution of Xiao and saw this as positive. By stating that "*they talk about everything with each other*" and "*he has really good relationship with my wife*", **Yingceng** suggests that a transparent relationship between parents and their offspring signals a positive and improved relationship, which. Could have an influence on future caregiver's perspectives of the caregiving role:

My generation when we, you know, communicate with our parents and being Xiao means they should obey their rules, their wishes. But we don't have the feelings we are friends. We just obey the rules, the wishes of my parents. But in my son's generation I can feel they are getting to be the friend of me or my wife, you know, my son he has really good relationship with my wife, just like a friend. They talk about everything with each other. (Yingceng; 47; Male; Parent affected by OCP sub-sample)

5.1.4 Subtheme Summary

This cultural context of parents affected by the OCP encapsulates the filial expectation of 'reciprocity, respect and dignity', participants' modelling of the responsibility to 'obey and accompany', and the outlook on 'being a good person'. Whilst the inclination to care for parents who have provided for offspring is a positive sentiment, some participants believed that achieving this required negating their independent will. As a result, findings suggest that the desire to be a good person could mean reciprocating caregiving in a way that requires individuals to be accountable for the holistic well-being of older relatives. Participants expressed their intent to transmit filial values from their past to the future and most participants shared the moral conviction that a contrarian disposition to traditional Xiao carried the consequence of a negative societal perception regarding moral identity, as Xiao is a "cherished" norm.

5.2 Social context: Offspring affected by the OCP

5.2.1 Role modelling and cultural embeddedness

The previous subtheme provided material about the beliefs and enactments of parents affected by the OCP. This subtheme turns to the social context, of offspring affected by the OCP. These offspring also spoke about the intrinsic characteristics of caring for older relatives as taught to them by their parents and demonstrated their devotion, willingness to replicate parents' kind gestures, and dogged determination regarding personal inevitable future care responsibilities. The cultural environment enabled care anticipation, and parents' provision of care for their grandparents served as role modelling to offspring:

Father's mum has been sick for many, many years, so she has to stay in the bed for many years; my mum always took good care of the grandma.

So, this is really good model from my mum to me. I just feel it's a natural thing. You know, family members should help each other, and the younger generation should take care of older generation. (Elaine; 35; Female; offspring affected by OCP sub-sample)

The intergenerational influence on identity and its persuasive enshrined nature was reflected through the narratives of participants. Evidently, the responsibility to care for older relatives was normalised by emulating parents' filial behaviour. Consequently, offspring accepted caregiving as part of their life trajectory, with implications for future decisions relating to the provision of hands-on care:

This is like responsibility in China, so when my parents go to the hospital, sometimes I would go with them and I would see how they care with their parents, so I will do the same in the future. (Jie; 20; Female; offspring affected by OCP sub-sample)

Intertwined with parents being role models, is the cultural expectation of Xiao imbibed by offspring through socialisation. Like their parents' generation, offspring participants also emphasised that the culture of Xiao was a lifestyle that comes with expectations to take responsibility for caring for parents by being good to them and must be adhered to. In turn, this could foster future intergenerational dependence as participants proposed their developing commitment to pass on the attributes of Xiao to the unborn generation:

Maybe I will have a child and I will let my children, my son or my daughter, I will let them know what behaviour and what thinking is true about Xiào. I will let them know that it is in the rule in the society in our country. (Zijian; 24; Male; offspring affected by OCP sub-sample)

Passing down cultural attributes of Xiao would be done effortlessly by some participants, who believed that others assess an individual's morality based on commitment to family responsibility, and the innate values of Xiao:

I think judging a good person in China includes this criterion of how you treat your family and how you are taking care of them. (Geyue; 23; Female; offspring affected by OCP sub-sample)

On further reflection, **Geyue** and **Yun** felt that Xiao I engrained moral values in them. Xiao mandates offspring to care for parents within the social environment; a fact they esteemed highly. **Geyue** believed that Xiao was “*kind of like a necessity to become a person,*” so the belief system was so naturally ingrained that she did not need to consider its principles consciously: “*so in everyday life, I don't really think about it. If you ask me about my moral values, it's definitely one important part.*” Confucianism is a belief system where in part, the concept of harmony involves self-restraint and propriety to minimise conflicts in society. **Yun's** long-standing perception, which he attributed to Confucianism, provided further insight into the extent of societal influence on personal values; that the value of Xiao is “*moral*”, and how that, in turn, influences behaviour until it is the norm; a “*cultural thing, almost in every person's opinion*”:

When I was a boy, I affected with Confucianism in China, so as far as I understand, being Xiào to parents is a part of moral things. It is a cultural thing, almost in every person's opinion, they think that the children should be good to their parents, so I think I just want to be filial to my parents. (Yun; 30; Male; offspring affected by OCP sub-sample)

5.2.2 Perception of social norms

A tangential consequence of how Xiao's principles coalesce with other cultural expectations that significantly impact the provision of care for older relatives is normative ideas about age, gender, or social roles. For instance, the perception of women as the default caregivers:

My mum is a typical mum. That means that usually in the family in traditional China, women usually they take care of the whole family (teach or take care of the children). Women should do a lot of things for the family, even though she has to take care of my grandparents [...]. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

Participants also gave examples of customary expectations that guided social roles in relation to providing care for older relatives, such as that of older relatives who are retired, as exemplified by **Zhirui's** (22; Female; offspring affected by OCP sub-sample) statement that "first I will look for my uncles or maybe my aunts are retired, so I think they have time to take care of my parents". The likelihood of customary expectations for individuals who are female or retired to provide hands-on care for all family members has implications for the capacity of these individuals to make their own choices within society. For instance, **Geyue** (23; Female; offspring affected by OCP sub-sample) shares "My mother is a housewife, so she has a lot of free time. That means she doesn't have to give up her career or anything like that, but her life is definitely disturbed". **Geyue's** declaration that her mother "doesn't have to give up her career" implies that her mother does not desire a career and substantiates the perception that her role as a housewife equates to having "a lot of free time", although it is notable that, **Geyue** comments on the impact of this for her mother's life that "is definitely

disturbed". In line with the common presumption concerning women's responsibility and capacity to care, **Yingyi** states:

[...] but even though he says something like that, even though she complained, she still takes good care of my grandparents. So just like the typical mum in China [...]. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

With **Yingyi's** mother, **Ruiying**, the example she gave in section (5.1.2 Xiao: responsibility to care – to obey and accompany) highlighted the extent she went to accommodate his grandfather's wishes. **Yingyi's** example was concerning the verbal abuse endured by his mother from his grandfather. This excerpt substantiates the default role of women in China.

Male participants from the offspring sub-sample equally felt the societal pressure placed on them as it is unheard of to abandon parents. According to **Zijian**, this ideology is a rule of responsibility that only ends when his father passes away:

That is the understanding of Xiào in my mind nowadays. It is a rule, to take care of my father [...] The only thing that could stop me from this is when he's gone, or I wouldn't abandon him. It is not reasonable. (Zijian; 24; Male; offspring affected by OCP sub-sample)

The overall sentiments that "women should do a lot for the family", "her life is definitely disturbed", "just like the typical women in China" and "the only thing that could stop me from this is when he's gone" implies that offspring will carry on and accept the inherent disturbance this brings, which could leave them with acute, chronic or vicarious stressors that are typically suppressed to 'be a good person'. The result of normalised cultural expectations regarding social roles does not

necessarily acknowledge the stressors that still have to be faced as potentially having free time does not guarantee the ideal circumstances or ability to support older relatives. The responsibility to obey and accompany that was transmitted to this younger generation through role modelling normalises the potential consequence of societal perception when an individual's morality is based on decisions impacting on care for older relatives.

5.2.3 Socio-demographic adaptation

Due to the socio-demographic changes in China, the implications of the OCP and the increased internal migration threatening the traditional family setup, the sociocultural norm for offspring to live closely to parents for the sake of care provision in later life is also threatened:

[..] Especially in my city, [..] it's really a small town, and younger people tend to move out when they have graduated... and most of them really move out to the big cities, so a lot of them don't have the condition to move their parents to the big city as well, so they're kind of in a separating stage and that's kind of like a normality for a lot of young people in China, and that's not really the traditional value of a family, but people get used to that.

(Geyue; 23; Female; offspring affected by OCP sub-sample)

Although tradition requires offspring to live near parents, as **Geyue** states, some are unable to support their parents by relocating them. With the rapid socio-economic development in China imposing geographical separation, some offspring like **Elaine**, reported that people are acclimatising to the inevitable separation resulting from socio-demographic changes by making greater use of technology:

[...] For the older generation, reunion means living together, living in the same city, but in my generation currently, reunion means they can use a different way, even though they are not in the same city, but they can still feel [...] get the feeling of reunion by using the different technology. [...] Many younger, you know, generation they go to bigger city or go to another city, but they still can be with parents in other ways. They can use WeChat to communicate, so it's kind of another reunion. You know, reunion means together, so it's another way to be reunion. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Elaine explains how offspring could “use a different way” to meet filial expectations in line with their own needs and life circumstances at the time. The awareness that the older generation expect to reside with offspring is why some spoke of how they would aim for geographical co-location even if their job had taken them away from their home area:

But from my perspective, from what I've heard a lot is try to be with your parents as often as possible, to accompany your parents. They don't need much of materials, but they need support psychologically. (Feng; 23; Male; offspring affected by OCP sub-sample)

However, for others who do not have that option, reinterpreting the meaning of Xiao so they could find a way of fulfilling it across geographical distance was perhaps not only inevitable but necessary. This could be responsible for the abstract interpretations such as “You know, reunion means together, so it's another way to be reunion” or “they don't need much of materials, but they need

support psychologically” in contrast to the literal expectation of the older generation to live together.

5.2.4 Subtheme Summary

The cultural mandate of offspring to care for parents is entrenched in the social environment, emphasising the cultural belief that underpins the requirement to undertake caregiving. The findings suggest that offspring participants are socialised to expect and accept their roles and the challenges that come with them. Without challenging perceived norms, the family caregiving role could become their sole identity over time, especially with the evolving socio-demographic impact on society. Given the prominence of Xiao as the “rule of society”, the implications of evolving perceptions and societal pressure to accept care responsibility is unknown at this point.

5.3 Cultural context- Offspring affected by OCP

5.3.1 Being Filial and Reciprocity

When exploring the narratives of offspring affected by the OCP, the traditional values of Xiao that were identified in the interviews of parents affected by the OCP are still evident, influencing some participants’ description of meanings associated with their future caregiving roles:

Just because he is my father, I should try myself to help him as there is nobody that can help him or to take care of him. When I was a child, he gave me a lot of love, so I should reward him. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Considering **Elaine's** statement, the values of Xiao stemmed from similar motivations as parents' motivations, which all emerge from a desire and duty to reciprocate past help. As **Jie** (20; Female; offspring affected by OCP sub-sample) expressed "*Just like they spent so much money on me, then I spend more money for them as return*". Although, with more of a focus on parents' financial investment in her, **Jie** corroborated this view with her intention to surpass their level of investment. Participants perceived the significance of Xiao to society as mandatory and as a value that places expectations on offspring. Hence, reciprocating the love and support received from their parents was expressed by some participants as an ideal responsibility:

I should obey their wishes. So, when we were younger, we just learn Xiào, that it's very important to listen to parents, elders, obey our elders. To try our best to accompany parents and when parents are getting older, children should be around to take care of the parents. So, that's kind of what Xiào means. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

The core theme from offspring participants is the significance of prioritising older relatives' needs by obeying them verbatim and maintaining contact, which is consistent with findings from the parent sub-sample:

I will feel that I am a coward or a loser that I even cannot take care of my father. For me, it will be a great shame, you know, when I grow up, if I cannot take care of a single father. It is not tolerable for me. I will try every effort to accomplish this. (Zijian; 24; Male; offspring affected by OCP sub-sample)

Irrespective of life events or circumstances, participants remained determined to honour parents due to their expectations and rules. By calling it “a great shame”, **Zijian**, awaiting care responsibility, perceived the potential stigmatisation of being unable to provide care as a character flaw and personal failure.

5.3.2 Consequences of Xiao

Despite the positive meanings being attributed to fulfilling Xiao, offspring participants reported that Xiao might equally expose them to professional and personal challenges that would require difficult decisions in the future regarding balancing work and care:

[...] Another one is because of Xiào, sometimes different generations have different opinions on different things, for example, if my parents think things in this way and I think these things in that way, you know, Xiào, I should follow my parents' wishes or follow my parents/elder or rules and at this point, maybe the young generation may lose some good opportunities. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

Due to the value placed on fulfilling Xiao, there exists the possibility of losing professional advancements that arguably puts offspring in better positions to provide financial assistance, due to the influence of Xiao's principles concerning obedience and caregiving commitments. Many expressed an intention to quit their jobs to accommodate their responsibilities, however, the question of how participants would align the determination to provide care at all costs with the financial stability required to care for themselves, parents and family remained a concern “because no salary, no income.” **Feng** (23; Male; offspring affected by OCP sub-sample). The objective assumption that all parents and children are

good was a prominent trend among some participants' examples. However, the expectation for offspring to still fulfil Xiao by supporting parents, even when parents had not been reasonable in the past, might not be an equally shared value:

One thing Chinese families don't really understand is that there are really bad parents and there are really bad children. So, for example, if the parents are really bad and they didn't really care for a child from a very early age, but the child is still expected to take care of them when they are old. This is one thing that really confused me. (Geyue; 23; Female; offspring affected by OCP sub-sample)

Therefore, considering the potential loss of professional advancements, some participants spoke about how prioritising parents' wishes, for the sake of demonstrating good Xiao could cause tensions between spouses as shown in the excerpt below, especially where the older person's demands did not appear well founded. This tension could breed conflict:

[...] My friend married a guy who grew up in a single parent family (mum) [...] the guy just listened to his mum a lot, even though the mum's decision is not correct, and the guy still want to follow the mum's decision or suggestion, so that's kind of Xiào [...] That makes conflicts between wife and the husband. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Unconditionally respecting the wishes of older relatives could become a source of stress for offspring. Some of the participants' witnessed experiences that highlighted the challenges the younger generation of family caregivers might

experience when providing care without adequate support or consideration for personal circumstances. For example, **Yingyi** gave an account of his mother's experiences with his grandfather, which highlighted the stress she felt from trying to arrange a nursing assistant that her grandfather would accept:

My grandpa just chased the nursing assistants away and he kind of critiqued nursing assistants without any reason. Actually, my mum thought the nursing assistant had done a very good job [...] They changed to another nursing assistant, but in a very short time my grandpa just let another nursing assistant go. So, my mum just felt a little bit frustrated, and she didn't understand why my grandpa did that because everything seemed fine [...] So, I think at that moment, my mum was really stressed [...]. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

5.3.3 Cultural evolution

The lack of adequate support especially for those affected by the OCP, coupled with the intentional and inherent self-sacrificing attitude expected when providing Xiao, are only some of the factors likely responsible for shifts in cultural interpretation. As evidenced by some participants' comments, some of the changes anticipated by the parent participants interviewed were confirmed. Several offspring participants explicitly stated that they either had or desired autonomy, so they would not always oblige parents and would likely enact Xiao based on their individual circumstances:

It's so different than when it was in the old society in China, Xiào means That we have to agree all that my parents have said, and all decisions that they make, but now I have the freedom and the right to make my decision

and I don't have to agree all the things that they've said. (Jie; 20; Female; offspring affected by OCP sub-sample)

For **Jie**, despite her mother's assumption that she has imparted the principle of "living for others" in section 5.1.3 Xiao: being a good person, her statement in the excerpt above indicated that she interpreted her mother's sacrifices differently than intended. Likewise, **Zhirui** was confident she would prioritise safety and financial stability above strict obedience:

For my dad, he is to follow his mum's wishes. I mean, even though my grandma makes very wrong decisions, my dad still says yes, 'okay, we can do it' but for me, I may say no. If it's harmful or too expensive, I will say no. (Zhirui; 22; Female; offspring affected by OCP sub-sample)

Although participants were observing and describing some evolution regarding the culture of Xiao, adapting its meanings to gain some personal control while juxtaposing the meaning of Xiao between two generations, some participants voiced that the younger generation is not as committed to the ethos because as **Yun** asserts, they do not "insist the Xiao culture":

[...] But I also think they have done better than our generation, they insist the Xiào culture better than our generation because I found in my generation many friends are not that Xiào, not that filial to their parents. [...] the person who is younger than me, they are usually very independent. They are just like the Western children, when they become 15 or to 18 years old, they live outside the house without their parents, they are no longer reliant on their parents as usual. They have to work, they have to make their own opportunities for themselves, so they do not have that

much contact with their parents. (Yun; 30; Male; offspring affected by OCP sub-sample)

Yun's comment suggested not an adaptation in meaning but a more fundamental change away from the orientation of traditional Xiao. Hence, due to the socio-demographic changes addressed earlier, it is perhaps now not unusual, for example, for Chinese parents to allow offspring the sense of independence that **Yun** likened to the attitudes of Western children. Moreover, other participants reiterated differing generational needs as reasons for a different approach. **Elaine** suggested that their parent's generation approached care to meet basic material and physical needs, whereas younger generations consider holistic needs:

Xiào in my generation is broader than the older generation [...] in my generation, we have been thinking about Xiào as a way to provide care or pay more attention to physiological, psychological and sociological aspects. So, think from the holistic way. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Feng's explanation for this evolution of meaning was also down to generational needs being different. This difference was influenced by the socioeconomic status:

[...] So, from my perspective, because we have different social status, social conditions, different economic conditions and the meaning of Xiào might change a little bit because different generations have different needs. (Feng; 23; Male; offspring affected by OCP sub-sample)

Feng previously considered the older generation to have greater psychological needs than material ones. A point to consider is whether offspring participants are redefining Xiao because they view their generation as finding themselves in positions where it would be more achievable to meet certain needs more conveniently.

5.3.4 Subtheme Summary

This subtheme of cultural evolution looks at how future caregivers would assimilate their caregiving roles. The changing views expressed by several offspring participants ranged from the freedom to make decisions that are in their own best interests to intent to refuse parental requests that were deemed unreasonable, harmful, or expensive. Additionally, offspring participants are interpreting Xiao in a broader sense than their parent's generation by opting for abstract interpretations, i.e., prioritising psychological needs and virtual presence ahead of material needs or accompanying parents in person. The independent sense of self could cause tension because although some parents might welcome the positive effects, like relational closeness, some older generation might view them as abandoning Xiao culture in favour of western tradition. The result of this perspective could be that offspring are viewed as being insensitive to the needs of older relatives or they provide the care to meet societal expectations to avoid being regarded as unfilial without adequate readiness for caregiving responsibility, despite having the intrinsic motivation.

5.4 Conclusion

The initial study aim was to explore the meaning of filial piety to participants in China who are affected by the OCP and how their experiences influence their attitudes to current or future responsibility of providing care for their older relatives

living with long-term health conditions. The findings have highlighted several relevant areas for older and younger generations affected by the OCP and provided a detailed insight into their beliefs about caregiving. Findings also reflected the changes in the extent of subjective interpretation of Xiao norms and participants' enactment of Xiao's principles compared to past generations. Xiao the lifestyle has shown that being filial translates to absolute responsibility and accountability concerning all areas of older relatives' lives, which is also what it means to be a good person. Based on these narratives, it was evident that an historic norm for offspring is to consider how all their decisions impact on the current and future care for parents. Nevertheless, in most cases where one child will be solely responsible for caring for parents living longer with long-term health conditions, especially with the socio-demographic transition in China, the reality of achieving filial expectations is creating a cultural evolution. Although many participants have internalised values associated with Xiao, this evolution can be seen through the younger generations' unconventional interpretations of Xiao culture.

Chapter 6: Contextual Factors: Intersections of Xiao, work, and care

In the previous chapter, Xiao the lifestyle focused on how individuals in Chinese society perceive filial responsibility based on cultural expectations. Xiao is a culture of duty with extensive responsibilities, and thus far, findings showed that participants are inherently willing to provide care for their older relatives. However, most parents affected by the OCP expressed their concerns about the evolving attitudes towards traditional adherence to Xiao's principles. The findings from offspring affected by the OCP showed that socio-demographic transitions are largely responsible for the added pressure that is transforming how Xiao is operationalised. Therefore, considering that individuals want to continue to uphold the values of Xiao, it is important to explore resources that the socio-cultural environment affords family caregivers to understand the contributing factors to shifting attitudes. In this chapter, I will address the first objective of this thesis: to understand current and prospective family caregivers' perceptions or experiences of caring for older relatives in China. Also addressing the third objective, to understand the perceived barriers that family caregivers in the Chinese workforce face by exploring the stressors and challenges impacting their circumstances or experiences; specifically, as it relates to determining the influences of social support and Xiao on care provision. Focusing on the theme, 'Contextual Factors: Barriers to balancing Xiao, work and care', I will draw on the analysis and interpretation of the findings from interviews across all three sub-samples **within the phase 2 of this study**. I will delve into the narratives of parents and offspring affected by the OCP who are working and provide hands-on care regarding their witnessed or lived experiences of balancing work and caregiving responsibilities.

6.1 Care anticipation and expectations

6.1.1 Not being “too” much burden

Looking at the sub-sample of parents affected by the OCP, a fact all participants considered was how the reduction in family size potentially impacts an only-child:

Since you know we must take the current situation that we only have one child, one child per family. And they need to care for at least four older persons since we will become old at the same time. (Shifan; 61; Female; parents affected by OCP sub-sample)

Participants understood the need for offspring to manage their personal lives, i.e., supporting their family and attending to work-related responsibilities. Therefore, the absence of siblings to share care responsibilities with, led participants to contemplate the reality of their offspring being inundated with caring for parents and grandparents. This factor created legitimate concerns about how offspring will manage all responsibilities and the resulting impacts on offspring’s ability to provide care adequately:

I just think for myself, for my generation our parents have many children in the family. But for myself I only have one child in my own family. So maybe for my son he has a lot of things and maybe he cannot care for me that carefully. (Ruiying; 60; Female; parents affected by OCP sub-sample)

The potential consequence of these circumstances on the next generation was unsettling and undesirable for parent participants like **Joanna** who worried about her offspring’s finances: “[...] I don’t want my daughter to pay extra money for us, you know, I just don’t want to make the burden for them. They still have their own

family that they need to pay for... it costs them many things for their family.”

Ultimately, the recurring concern from participants' discourses was being a burden and negatively impacting their offspring's ability to care for their nuclear family:

So, they need to pay much effort to educate or to take care of their own child. And we will be a burden. (Shifan; 61; Female; parents affected by OCP sub-sample)

Shifan also expressed that “*I think that when I become old, like my mother's age, they will be busy with their work*”, which showed her consideration for the younger generation's personal and professional obligations. Therefore, concerning the absence of siblings to assist offspring, all parent participants seemed to embrace the notion of not receiving the same level of care they provided for their own parents. The intent to absolve offspring of stressful situations led to suggested solutions such as parents saving for their own future care:

[...] maybe another option for the future is to try to save money for something that really needs a lot of care for us, so I really don't want to burden my son too much. (Xue; 49; Female; parents affected by OCP sub-sample)

Describing several approaches in response to the situation intensified by the OCP, some parent participants suggested they would conceal and manage painful situations and expectations to support their offspring covertly:

The one child policy makes this situation very common. So, for me, I'm thinking maybe I will hide the situation, hide the fact that I need his help, that I need his care. I will not tell him because if I tell him he can do nothing.

He cannot come. He has his work so I may not tell him, not make him sad.

(Yingceng; 47; Male; parents affected by OCP sub-sample)

Regarding this, the concealment from parents might be encouraged by the socialisation process because the idea of shielding others from negative experiences and emotions can be linked to one of the beliefs underpinning Xiao, which is that patience with oneself and others leads to peacefulness. The statement: *“He can do nothing. He cannot come. He has his work”* demonstrated an understanding of one of the obstacles that offspring will face in the future and a lack of hope in the offspring’s capacity to intervene. Given the potentially insurmountable dilemmas, likewise, *“so I may not tell him, not make him sad”* suggested that some parents were aware that their offspring will still have the desire to pay back. Parent participants’ revelations showed that their sacrifice might continue into later life because the *“burden”* might be too great for the younger generation:

So, for me and my husband we want to lessen the burden for my son. So that’s why we want to go to the nursing home. (Wen; 53; Female; parents affected by OCP sub-sample)

With some parent participants beginning to think of practical ways of supporting offspring when the time comes for them to need care, the idea of transitioning into nursing homes seemed like a plausible option for those not living near offspring. Alternatively, others seem to have resolved to delay their expectations around fulfilment of Xiao by affording offspring the freedom to live independently for as long as possible:

[...] So, if I have any requests, now I don't have a request for my own son. Maybe after he has retired when my son gets older, maybe at that time I have some requests for him. (Ruiying; 60; Female; parents affected by OCP sub-sample)

Andrea asserted that no generation of parents would expect complete undertaking of caregiving responsibilities from offspring, which was a unique stance compared to most participants. However, like most participants, the reasons given are to avoid being a burden and possibly to protect herself against a sense that her expectations could remain largely unmet:

And usually, we don't expect the children will take much care for us, we don't want to be the burden of our children, even for our parents, you know, our parents are older, more than 70 years old, even if you ask them, they never expect children will take care, fully take care of the parents. (Andrea; 49; Female; parents affected by OCP sub-sample)

Although **Andrea's** perspective concerning the older generation's intent to avoid burdening offspring could be valid for individuals subjectively, it is significant to bear in mind her comment indicating that caregiving burden has always existed. Nevertheless, a few male parent participants admitted that they had not considered the nature of future expectations for their sons, which could be because they are fortunate to live close to their offspring and they are also currently in good health or because they are not held to the same expectations of providing hands-on care:

So, from the current situation because we are living very close and I can see my son at work often, so that's why I don't have any special

expectations from him. And when I'm getting older, I haven't thought about one day if I cannot take care of myself. I haven't thought about that because I'm healthy, very well right now. (Dan; 62; Male; parents affected by OCP sub-sample)

However, the increasing ageing population in China and the socio-demographic transitions mean that arguably, many are not experiencing the health, stability, and convenience that **Dan** describes, which could relieve offspring of caregiving burden. In the absence of parents having a suitable and sustainable plan for their future care, the desire to unburden offspring might not be realised. Hence, due to the affective commitment between parents and offspring, boundaries that exist between individual and societal expectations are being blurred potentially. The result could be that parents do not want to burden offspring yet due to parents or societal perceptions or pressures (as detailed in Chapter 5: Caregiving Beliefs-Xiao: the lifestyle), offspring remain burdened regardless.

6.1.2 Head versus Heart

Most parent participants highlighted that the concept of Xiao is getting broader, and that people are becoming more receptive to seeing nursing homes as a viable support mechanism for older relatives. **Wen** described an experience that demonstrated a shift in attitudes:

I think the meaning of Xiao is getting broader. For example, in a nursing home, I brought my students to visit the nursing home and that's, kind of you know, a sentence at the front row [meaning in the lobby of the nursing home]. You know, kind of, a sentence and the meaning of the sentence is

“The children around the country take care of the parents around the country. (Wen; 53; Female; parents affected by OCP sub-sample)

Considering that Xiao as a glue to society mandates offspring to look after parents and this was typically done within nuclear or extended families, **Wen** clearly states, *“the children around the country take care of the parents around the country”*. She intended to communicate to her students, that older relatives are now the responsibility of the collective younger generation, and as a result, this could imply that caregiving responsibilities are no longer exclusive to nuclear families or close relatives. Participants expressed concerns regarding the level of support offspring would be able to offer, evidently showing an attempt to adjust to the present circumstances:

That my mother provides the same care with her parents like right now I provide for her but my son won't do that for me. I don't think that I can expect the care I'm giving my mother that he will give me when I become the same age as my mother, well I can't expect that because the time is so different. (Shifan; 61; Female; parents affected by OCP sub-sample)

Bearing in mind that the belief around prioritising older relatives mostly stems from cultural expectations of Xiao, most participants, like **Andrea** spoke of their desire to remain at home. *“So, we do love to stay at home and home is the preferred place for us. So, we mention that someday we cannot be independent”*. While understanding the impact of caregiving, **Andrea** wondered about the implications of losing independence and her ability to take care of practical needs:

We may try to have a nursing assistant to come to my house to cook for us or to buy food for us, to wash clothes or to help us to see a doctor,

accompany us to the doctor or something like that. (Andrea; 49; Female; parents affected by OCP sub-sample)

From parent participants' shared experiences, complex caregiving circumstances brought about the need to be realistic about future care by being pragmatic. One participant, perhaps being an only-child herself, considered nursing homes being the option and hoped to have a sense of safety with nursing homes compared to home care. She shared:

And I think if we find a good authority nursing home, they have a good set up, the management will be okay and the care will be, has some rooms for the care. So, I think the care will be okay for us. So, I will trust this, kind of, good nursing home. (Wen; 53; Female; parents affected by OCP sub-sample)

The openness to alternative types of care like the "good nursing home" resolved concerns around the use of some services, but also highlighted the need for the older generation to reframe past shortcomings of services (which will be addressed later in section 6.3 Quality of formal services) as strengths. Others highlighted concerns around the level of meaningful social engagement they are likely to have if cared for away from home:

I must be older and at that age I'm not sure if I can make new friends, if it is easy for me to make new friends at nursing home, so that's, kind of, a concern for me. (Joanna; 57; Female; parents affected by OCP sub-sample)

A negative perception of nursing homes was a major deterrent for some participants and was revealed to be the predominant reason for **Yingceng (47;**

Male; parents affected by OCP sub-sample) caring for his father at home. Sharing his thought process, he explained *“If my dad went to a nursing home they may, you know, put him in diapers the whole day, 24 hours, whole day. It is not good for him. So, I choose to keep him at home”*. He detested the idea of his parents residing in nursing homes due to lack of personalised care and voiced his concerns about the possibility of becoming dependent on non-family members, saying *“the worst part maybe I must go to a nursing home because I’m not independent. I’m so dependent on others”*. The utilisation of nursing homes negates the ethos of traditional Xiao; hence parent participants were mostly ambivalent. However, despite the dissatisfaction with nursing homes, as expressed by **Yingceng**, due to a lack of better alternatives, some parent participants highlighted the need for their offspring to demonstrate emotional fortitude in using the services. For instance, **Joanna** shared her daughter’s suggestion for resolving the challenges created by sociodemographic changes and its impact on traditional Xiao:

*So, one way is go to the nursing home and another way is to buy a building or maybe several houses together [...] So, my daughter suggests “maybe that one day your friends can live together. The daughter or son can visit you by turns, for example, this week I will visit you and your friends. And next week your friend’s daughter or your friend’s son will visit you and your friends. So that means for the younger generation we just take our turn to visit the parents. We don’t need to visit parents every week. So, it is kind of, saves time and energy. (**Joanna; 57; Female; parents affected by OCP sub-sample**)*

Consequently, unlike participants' perceptions of formal services, the inter and intra generational support network, is parallel to assisted living whereby a non-judgemental environment is created that feels like home. Such a network would serve as a creative way to reconcile individual inner priorities with the demands associated with socio-cultural transitions, thereby reducing demands on only-children. Although, many parent participants initially described their expectations of care in the future as minimal, many further revealed that they would expect offspring to meet the same level of care responsibilities that older generations received should the needs arise:

My generation always takes very good care of the older generation and so my children's generation, the younger generation, they don't need to do much for the elders. So, they may just come back to visit us, that's enough, yeah. [...] I think currently I hope he will come to visit us every weekend, so if my husband and I are getting older and older and if we couldn't take care of ourselves, I hope he can do this same thing we did for his grandparents. (Xue; 49; Female; parents affected by OCP sub-sample)

The hope of receiving the same care that they provided for previous generations highlighted those filial expectations from parents are inevitable as Xiao's principles are essential. **Dan** provided care for his own father by employing a care assistant to come to the home. Considering his previously established concerns regarding the potential neglect in nursing homes, it is significant to note that even though **Dan** declared his determination to alleviate his son of caregiving burdens, nevertheless, he “*will be very disappointed*” if his son cannot fulfil his filial obligations. Ultimately, the desire to unburden offspring could be the determining factor for parents being more open to formal services:

So, I haven't thought about that, thought about the future. I will be very disappointed if he cannot meet what I expect from him. So, when I'm getting older, if someday I will need care, I will not give the burden to my son. And I will have a care assistant at home or maybe I can go to a nursing home. (Dan; 62; Female; parents affected by OCP sub-sample)

All participants in the parent sub-sample had one child and even though moving into a nursing home made logical sense to them, there were emotionally driven hopes that offspring would provide care for them at home:

[...] Maybe I still don't have to go to the nursing home. Even though I have the plan to go to the nursing home, but maybe my son wouldn't take me to the nursing home when I get older. (Ruiying; 60; Female; parents affected by OCP sub-sample)

When considering what most participants shared, although there is some awareness about the difficulties surrounding being cared for at home and participants expressed certain compliance towards nursing homes, like **Andrea** plainly stated, for most, it would be the last resort:

[...] I thought about moving to a nursing home- it is kind of a last choice. We don't want to move to the nursing home actually. (Andrea; 49; Female; parents affected by OCP sub-sample)

6.1.3 Circumstances impacting expectations: offspring affected by the OCP.

Even though differing circumstances impacted how offspring participants interpreted and would demonstrate Xiao, all offspring participants strongly identified with prioritising their older relatives and most showed a determination

to align their actions with their beliefs. In **Zhirui's** interview, she had expressed her intention for her parents to be cared for by retired Aunts or Uncles who she expected would have free time (see section 5.2.2 Perception of social norms), however, if left with no alternatives as an only-child, she would most likely be in the position to attend to her parents' needs:

I am the only-child in my home, my parents would like me to stay in Shenyang because it is near for them and they don't want me to go to other cities because it might be difficult for me to find a job, take care of myself and they may miss me. (Zhirui; 22; Female; offspring affected by OCP sub-sample)

More specifically, despite being aware that the responsibility is theirs alone as they have no siblings to support them, participants like **Zhirui** often showed great concern for their parents' wishes and emotions, because of the closeness they shared due to her being an only-child. The link between an increasing ageing population and declining health of older people raises the likelihood that staying close to home as an only-child would result in becoming a family caregiver. **Geyue** predicted that she would need to be available earlier in life for care responsibilities than her contemporaries and was prepared to change jobs or give up working if it meant being around to care for her parents in their old age:

[...] But my parents had me when they are nearly 40, and I'm the only-child, so I have to consider this problem probably in my 30s. I don't really mind losing my job. I'm probably still very young [...] so I can always look for another job, or I just don't. If keeping my job means that I couldn't be with my parents for very little time I've got, compared to my peers, that

doesn't make any sense to me. (Geyue; 23; Female; offspring affected by OCP sub-sample)

Geyue's account described a common response from most participants regarding what they would do should their parents need their care. Two participants were already in their 30s and gave examples of situations when they had been unexpectedly faced with making decisions about providing care. **Elaine's** father fell ill and was taken to her in Shenyang to be looked after, and due to the distance from her hometown, she had no assistance from anyone. Her mother, who was also living with a cardiac condition, could not travel due to the pandemic, leaving **Elaine** to provide hands-on care alone while maintaining a full-time job:

I'm not a local person. Now I'm working in Shenyang, but my hometown is small, which is about 300 kilometres away. During the pandemic, my mother couldn't come, my relatives are not here, so I had to take care of him by myself. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Elaine's example illustrated how unexpected events could make care provision exceedingly challenging for family caregivers; especially being an only-child living far away from her hometown because of work while also navigating the effects of the pandemic on the socioeconomic front. Participants, especially females, are expected to live near parents due to cultural expectations concerning the provision of hands-on care. However, as employment could keep offspring occupied, this reality is leading some participants to conclude they have little choice but to employ paid carers; just as expressed by the parent generation

participants in the previous sections. **Yun** (30; Male; *offspring affected by OCP sub-sample*) gave an example of this reality, explaining this, “usually, my mother looked after him, but my mother also has to go to work in the daytime so on the daytime, we hire support worker to help my father.” However, most participants were concerned about looking outside traditional family care because their preference for fulfilling traditional Xiao also still resonated with society at large. **Elaine**’s circumstances shed light on how sensitive offspring are to the potential stigma of not fulfilling Xiao the traditional way:

I will not send my parents to the nursing home [...] I believe to put the parents into the nursing home is kind of not Xiào, it’s not good for the child, so the child is not that Xiào. That’s not a Xiào performance. (Elaine; 35; Female; offspring affected by OCP sub-sample)

The interwoven nature of the social and cultural fabrics in China was uncovered under Xiao: the lifestyle, particularly in ‘*Role modelling and cultural embeddedness*’. Role modelling also becomes relevant here. For example, when reflecting on **Andrea**’s (49; Female; *parents affected by OCP sub-sample*) previous quotes in section 5.1.2 Xiao: responsibility to care – to obey and accompany, she provided a detailed description of the holistic needs that must be met by offspring for older relatives and in section 5.1.3 Xiao: being a good person where she stated that she raised her daughter to live for others. However, when contemplating a time when she might face caregiving dilemmas, her daughter **Jie** confidently stated that her parents chose to prioritise her, giving her the inclination to follow the same path:

I must choose one, so I have no hesitations because when they have their parents and me at the same time, they always choose me first. Yes, so I would choose my child first as well. (Jie; 20; Female; offspring affected by OCP sub-sample)

In section 6.1.1 Not being “too” much burden, **Andrea** expressed that older generations had no expectations for children to fully take care of parents and, her daughter, **Jie**, attributed the decision to prioritise her nuclear family to her upbringing. Also, **Andrea** saw nursing homes as the “*last choice*” and showed openness to compromise by being looked after by a paid carer at home. In line with finding alternative means to fulfilling Xiao, a few participants hoped that their circumstances would have improved professionally by the time they needed to support their parents, and that financial support could then alleviate some of the difficulties:

I believe the time that my father gets to a bad condition will be the time I can get my own salary, so I will take the money from my salary. (Zijian; 24; Male; offspring affected by OCP sub-sample)

Generally, however, participants were more conventional in their responses, with many participants pledging to give up work in order to fulfil “*the responsibility of Xiao*” and accommodate parents’ needs. **Yingyi** (35; Male; offspring affected by OCP sub-sample) said “*for the responsibility of Xiào, if the situation really needed me to quit the job, I will quit the job*”. **Feng** (23; Male; offspring affected by OCP sub-sample) also shared his convictions, specifying that “*I think for me the only thing that can stop me from taking care of my parents might be only the job. So, I will quit my job*”. **Feng’s** mother, **Wen** (53; Female; parents affected by OCP

sub-sample), was quoted above stating that “*So for me and my husband we want to lessen the burden for my son. So that’s why we want to go to the nursing home*”, yet Feng spoke of being prepared to take significant measures to guarantee that he would be able to care for them.

6.1.4 Subtheme Summary

Care anticipation and expectations showed how caregiving responsibility posed dilemmas for parent participants despite their understanding of socio-demographic changes and the implications of the OCP. Parent participants did not want to be a burden to offspring, yet perhaps were unable to let go of their desires for maintaining tradition, which could create adverse implications in the professional or personal future lives of family caregivers. The understanding from the older generation about relieving the younger generation of caregiving burden was not consistent with most of the perceptions shared by offspring participants. Therefore, the uncertainty that surrounds the expectations from parents and society at large might be contributing to ambiguous future care arrangements. It can be challenging to predict the nature of help parents might require and when the need would arise, and findings showed that majority of offspring participants are likely to risk their psychological, emotional, and financial wellbeing to continue to fulfil Xiao.

6.2 Career – Care Treadmill

6.2.1 Being a leader

The inclination to remain optimistic in the face of adversity is a show of resilience that is deeply rooted in Xiao’s principles and extends to professional settings. Some parent participants who were leaders in their workplace believed it was a good thing to model good examples to colleagues and employees:

I am a leader for the department, and I feel that it is not really good to take days off because of taking care of my parents because my leaving will influence the whole department. I am the leader, and I need to be there with my other colleagues. (Andrea; 49; Female; parents affected by OCP sub-sample)

As a result, **Andrea** only considered taking time off work as the last resort. Bearing in mind the concern about influencing others in the workplace, in this example, the cultural embeddedness of role modelling resurfaces within professional settings. When **Andrea** especially expressed “*So, I feel that kind of, responsibility for myself to try and stay at work as much as possible*”, she acknowledged the belief that leaders have an intrinsic duty to personally demonstrate good conduct regardless of circumstance. With all working parent participants showing equal commitment to work and care, some only took time off for medical appointments or personal health check-ups. As **Andrea** explained further, “*So usually, I will ask for a few hours, leave and come to the hospital to take care of my mum for some examination.*” She provided insight into her reality of being a leader in the workplace and combining work and care; Sharing that “*I have health problems, and so the last time I took the day off because of myself*”, **Andrea** explained how due to working and caring for her parents, if her time off was not for others it was for personal medical conditions. **Yingceng** gave a strong statement regarding the consequences of fulfilling Xiao by providing care long-term. He stated “[...] *if the employees need to take longer days off, I cannot permit that*”. Additionally, **Yingceng** and other workforce participants could feel justified giving family caregivers an ultimatum that demands prioritisation between working and providing care:

So, they have to make decision if they have to go back home to take care of their parents or they have to quit the job to take care of their parents or they stay at job and ask somebody else to take care of the parents.

(Yingceng; 47; Male; parents affected by OCP sub-sample)

Employers could justify how time off from work negatively impacts their business. Hence, there is likely an expectation for family members to efficiently delegate caregiving responsibilities or quit working and primarily focus on providing care. However, taking time off could lead to potential financial difficulty, like in the case of **Yan**: “So, I think it’s very difficult to make decisions to not work and only take care of my mum, because we need money to take care of my mum”. Following a discharge from the hospital, **Yan**’s mother needed care and she had requested several days off from work. She recounted her employer’s response:

No, you cannot take days off for this time, because we are going to have a big meeting in [name of place], it’s a really big meeting and we need you to be there. It is only for three to four days, so try to think about another way to solve your own problems. Everyone has this kind of difficult situation, everyone has their parents, and they have their children, but you must think about work. (Yan; 49; Female; caregivers in employment sub-sample)

With the demographic transition in China, having older relatives in need of long-term care is a common reality for all participants and there appeared to be a lack of support generally. The comment that “everyone has this kind of situation [...] but you must think about work” also reveals an indifference or absence of empathy considering the significant value placed on Xiao by majority of society.

Though, the lack of professional support is also a manifestation of the pressure the employer feels to make the business work successfully. **Joanna**, a manager working in public service made it clear that her workplace had no clear directives from higher managers regarding the process of seeking support:

“For me because of my position, I couldn’t take days off for taking care of my mum [...] we don’t have clear a system to support us to take days off to take care of parents. Honestly to say I don’t know how to get this support from the upper level. So that’s why I just try to stick to my position and just come to work even though my mum needs the care and my sisters they will come. They will compromise. They will sacrifice themselves and I have to work. (Joanna; 57; Female; parents affected by OCP sub-sample)

Unlike the sub-sample of offspring interviewed, most participants in this group have siblings. Parent participants affected by the OCP, and participants in the Chinese workforce reported that both work and care required their attention and were equally important. Caring for parents was not negotiable, so participants, saw no alternative to continuing to care at the same time as working.

6.2.2 Employers’ support

Considering the limited numbers of days employers typically allowed participants to take off from work, there were mixed findings concerning the perception of support offered to participants. For instance, **Niu** (47; Female; caregivers in employment sub-sample) stated that she received tangible support from her employer. *“So, I think my school supports me, for example when they arrange the courses, they will try to make mine a little bit less, you know, not give me much work to do.”* In addition to this, she appeared confident in her employer’s

willingness to accommodate her caregiving responsibilities. She continued, “*and when I take days off, they are willing to allow me to do that, to take days off.*”

Xiang also felt fortunate to have a supportive employer as she was offered a flexible schedule. With her salary paid in full despite taking two weeks off to care for her father in hospital, she had an appreciation for the good nature of her employer. Still, the expressed support she received appeared to be at the discretion of her line manager:

My boss just told me, “That’s okay, you should take good care of your dad and if the company needs you then we will call you and you can make some calls to deal with something”. So, it’s really good to me and they didn’t cut down my salary or anything else, so that’s really good. (Xiang; 37; Female; caregivers in employment sub-sample)

Most workforce participants had employers who would let them take time off to care, contingent on losing some of their salary. **Sutong** felt compelled to continue showing up for work because although she appeared convinced that she would be granted time off for caregiving, the reduced hours resulting from caregiving, and the pay would cause financial problems:

I cannot get the full attendance salary, so that means I have to get less money because I need to go back home to take care of my dad or my mother-in-law, so that’s why I try to stick at work and try to be full attendance. (Sutong; 50; Female; caregivers in employment sub-sample)

In situations where individuals must work and provide care simultaneously, good support from employers was very significant to participants’ ability to manage challenging periods. **Tong** shared how three older relatives needed hands-on

care within a six-month period and due to the complexity of commuting between the hospital, work, and home, he requested several days off. When the company insisted on his presence, he took a risk based on his perception of his workplace contribution:

If you want me to come to work I will quit the job. So, they think about me, because I am a good employee, so they really want to keep me, so they told me okay. (Tong; 43; Male; caregivers in employment sub-sample)

Although **Tong** saw the need to threaten to quit his job to be granted compassionate leave, this approach is unlikely to be fruitful for most employed family caregivers. Statutory annual leave for participants varied, with the highest being fifteen days per year and the lowest being 5 days per year. In a seemingly extreme case, **Yan** reported how being involved in an occupational accident provided an opportunity to be with her mother and simultaneously work from home:

So, I should say the company gives me one week, five days off the whole year, for the whole year. Last year I changed to another job and around September I had an accident, I had a fracture of my ankle where I worked, so I stayed at home to do the online work and it also provided me with a little bit more time to be with my mum. So, that's how I can take the days off from the work. (Yan; 49; Female; caregivers in employment sub-sample)

6.2.3 Caregiving time

A parent participant's recent experience of supporting an older relative in the hospital aptly described the time-consuming nature of managing work and

caregiving. Aside from cultural expectations, the professional expectations contributed to an already challenging circumstance as **Andrea** summarised her experience to be “*hospital, work, and hospital. No home*”:

[...] two weeks I am staying in the hospital in the evening to take care of my parents. And then in the morning I go to work directly from the hospital. And then after work I go to the hospital directly from work and stay in the hospital. So it is, kind of, hospital, work and hospital. No home. No time to take care of my family, my own family. (Andrea; 49; Female; parents affected by OCP sub-sample)

Andrea’s statement continued “*So, at the moment the only thing I can do is work and taking care of my parents. So, it is just two things. So, I cannot take care of others because I have no time, no energy*”. **Andrea** cited work and caregiving duties as reasons for the lack of time or energy to attend to her family’s welfare. As a high earner, **Andrea** had more days of leave than other participants, yet, as shown in the excerpt below and consistent with most participants’ experiences, time off work was for others, i.e., offspring and parents. Reflecting on the level of support available, **Andrea** described how her spare time was divided:

Yes, I will usually take the 15 days off per year. But usually I will split the 15 days into several parts, for example maybe five days for my daughter and then later, you know, if my parents are fit I can spend other days, you know, the holidays, not holidays but days off with my parents. Andrea

Several parent participants who were working parents had some assistance with caring responsibilities. For instance, in this excerpt, **Wen** (53; Female; parents affected by OCP sub-sample) shared how having her husband’s support allowed

her to focus on her professional work and caring responsibilities. She stated, “during daytime I can work in my workplace, in the morning or in the evening, I do some housework or other caring for them. My husband supports me very much. So, in my own home I do little things”. The end of that excerpt indicated that **Wen** credited her husband’s contribution for the opportunity to reduce her domestic tasks, allowing more time to continue supporting her parents. With caregiving being long-term work for some, participants who had good support did not underestimate its positive impact on their ability to combine work and caregiving duties. Like **Wen**, **Shifan** was appreciative and considered it a privilege to have a paid carer to support her. She acknowledged how support with meal preparation allowed her to connect with her mother beyond providing hands-on care:

*But I just say that I’m very lucky that I have a home maid to help me to prepare supper. So sometimes I just have supper and again my mother will talk with me for a while, and I need to talk with her about the whole day and usually help her in the evening with her personal hygiene before she goes to bed. (**Shifan**; 61; Female; parents affected by OCP sub-sample)*

Adapting caregiving or work responsibilities was necessary for any semblance of a work-life balance and to keep up with professional obligations. As a result, the nature of participants’ jobs had great influence on how well caregiving roles could be adapted. There were several participants in the group of offspring who were yet to provide hands-on care but were already anticipating the effect the responsibilities would have on their livelihoods. For instance, **Jie** is an international student with hopes of continuing her further education abroad. In anticipation of caregiving responsibilities, she expressed “[...] when I grow up I

will have my career and sometimes it will be very difficult to manage taking care of parents and my career.” However, she had a pragmatic perception concerning the challenges of providing care and working simultaneously. **Jie** understood the dilemma she would be facing and that it was normal for everyone in the country:

It seems normal for everyone and it’s difficult for everyone to make the balance between their own family and their parents’ family or taking care of their parents. (Jie; 20; Female; offspring affected by OCP sub-sample)

Zhirui equally shared the normalised attitude, referring to it as “*the reality*” and indicated his acceptance, “*I will be very exhausted but that’s the reality because for the elders, they usually will get sick when they’re getting older and older.*” Impending caregiving responsibilities were seen as inevitable, and although he realised the physical exhaustion he could experience, **Zhirui** believed that he must be prepared to accept those responsibilities. “*So, I think at that moment, what I need to do is try my best to try to keep the balance between my work and taking care of my parents,*” which he admitted might create anxiety for him and impact his functioning at work:

I know I will worry about my parents in the daytime, and I will think about how they are, but I have to work, so I think I have to accept the reality and try my best to make the balance. (Zhirui; 22; Female; offspring affected by OCP sub-sample)

6.2.4 Subtheme Summary

In this Career-Care Treadmill theme, participants faced competing cultural expectations because Xiao placed workforce participants in the primary caregiving role, yet there was no guaranteed support from employers regarding

taking time off for caregiving duties let alone respite. Individuals who had support from their spouse, other relatives or somewhat flexible employers acknowledged the positive impacts on making caregiving circumstances more manageable. Nevertheless, working participants who provided care and were equally committed to both, risked being overwhelmed by attempts to fulfil all expectations in addition to having low or no job security when prioritising caregiving duties. The compounding pressures would be detrimental to the health of current and future family caregivers.

6.3 Quality of formal services

6.3.1 Nursing Homes

The likelihood of going into a nursing home facility in the future was widely considered among participants. Parent participants held their older relatives in high esteem, and the expectations, for some, were for nursing homes to be a supportive place that would ensure the safety of their older relatives. In relation to this, **Shifan** believed that the expectation of being cared for at home was no longer reasonable. *“Most people like me of my age think the same way. That we can’t expect our children to look after us as parents, we can’t expect that”*. She considered this outlook to be a rather common opinion, however disappointing:

The only way for us is to go to the nursing home. Most people of my age think in this way. And of course, we feel sad, but we must prepare ourselves beforehand to be in that kind of a life. (Shifan; 61; Female; parents affected by OCP sub-sample)

In line with this view, **Xue** (49; Female; *parents affected by OCP sub-sample*) expressed how she wished for the environment of nursing homes to be more

homely and be a place where a community can be cultivated, *“For me, I think it’s a place where they can provide the place to live and provide food to eat and provide some activities to make fun and, you know, make some friends.”* Aside from catering for nutritional needs or creating a physically and cognitively stimulating environment, she hoped for compassionate care, emphasising that *“good attitudes for elders and the care should be considerate, you know careful care,”* finalising that *“that’s what I want to have in nursing homes.”* Even though all participants revealed that they considered nursing homes as one of their future options, the majority were disappointed when exploring this option. **Andrea** felt dissatisfied with the quality of the nursing home she viewed and the lack of options regarding catering for a common health condition like diabetes. In her words, *“the condition of the room is not as comfortable as home.”* Therefore, the value that she placed on being in an environment that provided similar qualities to the care one would receive at home, made her consider nursing homes as a last resort:

[...] they may need some specific food. But there is not much choice for the food in the nursing home. So that’s why I still think about currently nursing homes are the last choice. (Andrea; 49; Female; parents affected by OCP sub-sample)

She felt a lot of resistance towards the idea of utilising nursing homes. Continuing to reflect on her experience, she found that the structure was rigid, *“there is not many times for the food so especially for some special condition, like diabetes you know.* Limited mealtimes and restricted food options indicated lack of person-centred care, resulting in her ambivalent attitude towards nursing homes. In

addition to the issue raised by **Andrea**, **Wen's** narrative highlighted issues related to the nursing home environment when taking her parents there to visit:

[...] when they arrived and they see many older people and small rooms they don't like. I also take them to a much better nursing home, but they don't like anymore. (Wen; 53; Female; parents affected by OCP sub-sample)

Having too many people in a small space did not elicit confidence in the quality of care her parents were going to receive. In addition, Wen was concerned about a high attrition rate of staff. "So, I think in the nursing homes currently, there is a high turnover of staff." Consequently, the high turnover led her to questioning the potential effect of "new staff to take care of the elders, who may not be familiar with the elders such as the personal preferences and personal history", and the risk associated with a constantly changing care provider. In relation to this, workforce participants like **Sutong** (50; Female; caregivers in employment sub-sample) described a time when she used a nursing home temporarily for two days. According to **Sutong**, "when I came back, I found my dad got [...] some bad thing happened on his skin, so I was not very happy, so I don't trust nursing home anymore". Subjecting older relatives to uncaring treatments in nursing homes would be considered unfilial for parents who were regarded as the source of life as shown in section 5.1.1 Xiao: Culture of reciprocity, respect, and dignity, which is something all participants would want to avoid. Therefore, despite being open to the idea of using nursing homes to alleviate caregiving pressures, the perceived lack of training and poor management of older relatives' health conditions by nursing home staff resulted in a lack of trust for these participants. **Sutong** ascribed the guilt she felt to that singular experience. "From that thing, I

mean the bad thing happened on my dad, so that's why I decide not to send my dad to the nursing home anymore". Ultimately, her conclusion, "that's why I say a nursing home is the last choice, it's a conflict decision", corroborated the view that most participants only consider nursing homes in desperation. Like **Sutong, Niu** is a workforce participant in similar circumstances and had visited a lot of nursing homes in hopes of finding a suitable support service for her father, only to come to the same conclusion that they were not homely, "the nursing home was not family like- it is a little bit cold". Her perception of the nursing staff's attitudes was enough to overturn her consideration for nursing homes:

[...] the nursing assistant they look not that good, not well trained especially the attitude to the elders. So, I felt sorry if I send my father to the nursing home. So, I made the decision I will not send my father to the nursing home I will take care of my father at home by myself or with my mum together. (Niu; 47; Female; caregivers in employment sub-sample)

Some of the offspring sub-sample of participants already had personal direct experiences that influenced their impression of nursing home services. Nursing homes were considered unsafe and **Zijian (24; Male; offspring affected by OCP sub-sample)** specifically likened them to prisons. He stated, "I would not go to a nursing home or a long-term care facility because it's like a prison in there". He associated the service with a prison environment, and explained, "I am not satisfied with the food safety and infection control management in the centres". **Jie (20; Female; offspring affected by OCP sub-sample)** saw nursing home staff as unprofessional generally and shared that "in China the environment in the nursing home is not that good and people there provide help that's not fair to every people." She articulated her expectations for staff to be even tempered with

older relatives, bemoaning that “[...] *they are easy to be angry with old people because, you know, sometimes the old people couldn’t understand what they said,*” suggesting that the staff could be impatient with older relatives when helping. Bearing in mind that Xiao held a moral significance for individuals in Chinese society, due to the reputation of nursing home quality, **Elaine** believed it would be a cultural violation and she deemed the decision to “*put the parents into the nursing home is kind of not Xiào*”. Conclusively, most participants were not keen to use nursing homes as their experiences negated the values associated with being filial, as demonstrated by Elaine:

[...] in the future if I cannot provide care for my parents by myself I will ask help from other relatives. I will not send my parents to the nursing home.

(Elaine; 35; Female; offspring affected by OCP sub-sample)

Negative experiences and concerns around safety influenced most participants’ appraisal of nursing homes as a support mechanism. This section not only continues to highlight the concerns that encouraged participants to care for their parents at home or consider the use of paid carers as another alternative to families providing care, but it reveals reasons beyond quality of care. The typical explanation for providing care at home was inadequate care provision in nursing homes. For example, what **Yingceng** witnessed was the concerning ratio of staff to residents in a nursing home, which made it unsuitable for his father’s needs. In his interview, this experience specifically led him to refrain from leaving his father in a nursing home to providing home care:

So, because in that nursing home, usually one carer will provide care to four or maybe eight elders, but for my dad's situation he needs one to one care. (Yingceng; 47; Male; parents affected by OCP sub-sample)

The reputation of nursing homes was also **Ruiying**'s stated reason for caring for her parents at home. Again, the theme of desiring a homely environment for loved ones resurfaced with **Ruiying** saying “[...] *If I take my parents to the nursing home, I think in that setting there is no kinship or family affection or family's love in that environment*”. She continued to share that “*some bad things or bad news will stop me having the option to take my father to the nursing home*”. When she referred to “*option*”, the context of what she said connoted willingness, illustrating that the potential of her father being poorly looked after would mean disrespect and she was not willing to take that risk. Continuing in similar vein, she attributed her lack of personal psychological safety to the perception that her father's health might decline faster in such an environment. Consequently, such environment was deemed unworthy of parents and constituted the general bad reputation for nursing homes to a large extent:

And even sometimes my father says, “Okay I can go to the nursing home”. But for my parents if they are taken to the nursing home, maybe he just feels worse and didn't have any hope. So, I think I don't have any option to take my father to the nursing home. (Ruiying; 60; Female; parents affected by OCP sub-sample)

Parent participants suggested financial constraints as another explanation for providing care at home. For instance, the reason **Ruiying** gave was that her family could not afford a nursing home that would provide a higher quality of care

services. *“Maybe that’s a good nursing home and has good reputation and may provide better care for my parents, but I think we just can’t afford it”*. She continued this sentiment, referring to her family as *“an ordinary family”* and that *“the best nursing home it is just for the rich people.”* Belonging to an *“ordinary family”* meant she believed that nursing homes that can ensure respect and dignity of parents are too expensive and are luxuries designed for the wealthy. **Niu** (47; Female; *caregivers in employment sub-sample*), validated this perspective by adding, *“I don’t have much money to hire a nursing assistant, it is kind of a little bit expensive for my family.”* However, though most participants across generations, including the participants in employment, agreed that financial constraint was a significant stressor, notably, those who managed to afford a more expensive nursing home were still restricted from alleviating caregiving pressures:

Preferred nursing home was too far from home and too rural. I had to take them to a nursing home near their home, but they don’t like also. The price is much higher, but they don’t like. (Wen; 53; Female; parents affected by OCP sub-sample)

This excerpt from **Wen**’s narrative indicated that resolving the financial constraint for some participants did not resolve their mind. Taking her parents to a nursing home that was considered *“too far from home”* or one *“near their home”*, made no difference to her parents’ satisfaction, suggesting that it was not location, quality or price that was the source of disappointment for the older relatives in this instance, it was more likely the existing attachment to residing at home being cared for by their loved ones as tradition stipulates.

6.3.2 Domiciliary services

Aside from older relatives potentially harbouring anxiety about nursing homes, several participants had explored alternative care to build a compromise that enabled their parents to receive care at home. **Sutong**, a workforce participant had been open to employing someone to look after her father at home but had yet another bad experience. *“So, for us, even though we paid, we still had to keep our eye on him, to watch him take care of the elders, so we stopped to have somebody to take care of my dad”*. Despite affording home care, there was no trust and with that experience she lost hope of getting a well-qualified and trained home carer:

The only services I know is about hiring somebody, but we don't trust them.

They're usually not that good, so that's why we don't want to have anyone.

(Sutong; 50; Female; caregivers in employment sub-sample)

Showing how the significance of Xiao upbringing influences caregiving decisions, **Sutong** disclosed that her caregiving responsibilities began at a very young age, *“[...] when I was a student in the primary school, I just started to take care of my grandma,”* and credited her experience; *“so that's why I am so experienced in taking care of elders,”* and confidence in her ability, to that early responsibility. Therefore, it is possible that being taught the principles of filial piety (Xiao) from a very young age was responsible for her strong preference for being the sole carer as opposed to nursing home or domiciliary care. *“So now I don't trust anyone. I believe what I do is the best for my dad”*. The lack of a clear pathway for recruiting proficient and trustworthy carers remained a pertinent issue for parent participants. In relation to this, parent participant **Wen** (53; Female; *parents affected by OCP sub-sample*), considered aloud the likelihood of a

system that could provide assurance with domiciliary services regarding safety concerns and service allocation, *“and they can train, allocate them and make sure they are trustful or something, like that.”* **Wen’s** vision suggested that with adequate training and vetting, participants could *“feel safer, you know, and they will provide safe care for the elders”*. The trust issues with nursing home services coupled with the influence of appraising care provision through the lens of Xiao left workforce participants like **Jerry** (42; Male; caregivers in employment sub-sample), without alternatives beyond shouldering the burden alone or employing paid carers to live with their parents. He explained *“My father, he has his brother and my mother, she had a sister [...], but they have their own things that they need to deal with. They don’t have time to help me”*.

Although the practicalities of providing care at home would be inconvenient for majority of participants from the offspring sub-sample, they also remained generally motivated to provide care at home. For instance, **Zhirui** wondered about scheduling a paid carer to come and sit with her parents in the evening but decided she would continue to do so herself:

So, I am thinking about, you know, if I had someone only coming to my house in the evening and taking care of my parents, that seems not realistic, not very common I mean. Currently it seems not common, so that’s why I think it’s impossible. I also think about the one I hired for the day care, she or he will work in the daytime and in the evening, I also believe she wants to take a rest, so I will take care of my parents. (Zhirui; 22; Female; offspring affected by OCP sub-sample)

Zhirui contemplated various options. While revealing that family was the first port of call; *“So first I will look for the person from the cousins and relatives, for example, my uncles or maybe my aunts because they are already retired”*. She also stated, *“maybe I can hire somebody around 40 or 50 because for that age, they may be better at understanding my parents’ needs”*. The idea of hiring an older carer that would *“be better at understanding”* the needs of her parents indicated that they might provide better quality care. **Yun** (30; Male; offspring affected by OCP sub-sample) would look towards his social circle for much needed support, *“I have some friends that can provide actual support for me, [...] I think they are very loyal friends that can help me in a very practical way”*. The offspring participants thought up various potential solutions to future caregiving challenges and the findings revealed similar distrust of formal care services as the older generation. He explained, *“I just don’t trust these kinds of people; I heard some news about how nursing assistants abuse the elderly or maybe poison in the water to the elders”*. **Feng** supported his mother to care for his grandparent and has witnessed and had first-hand experience of meeting various caregiving needs. Regarding providing domiciliary care, he expressed that *“I also thought my dad will give a hand”*. His responses revealed that the familial support could be the reassurance as an only-child:

So, we can be together to take care of my mum [...] I know I can learn, for example, just like newborn baby, at first, parent did not know how to help the baby to feel comfortable, but they learnt. (Feng; 23; Male; offspring affected by OCP sub-sample)

However, due to factors such as migration for educational or employment purposes, offspring participants can be resigned to use formal care services

regardless of their doubts about the quality of care that their loved ones could receive. **Jie**'s view corroborated the sentiment shared by the older generation that were interviewed, that majority who use the services do so because they feel they have "no choice":

If in that time, I would go abroad and I would ask someone in the hospital to help to care about my parents. Maybe they can't take care as good as myself, but if I have no choice, I have to do that. I have to ask someone for help. (Jie; 20; Female; offspring affected by OCP sub-sample)

6.3.3 Hospital experiences

All participants had experiences of relatives in hospital due to worsening health conditions, which they built their perception around and some participants had positive experiences whilst others had negative experiences. For **Geyue** (23; Female; offspring affected by OCP sub-sample), personalised care was very important, and she did not feel this could be provided through medical care as "any medical care for the entire nation, it's not going to be good. It's not going to be really personalised or customised for each patient". The majority had experienced or witnessed relatives providing hands-on care in a hospital setting. The experiences encountered by the offspring sub-sample on these occasions greatly influenced their view of formal care services. **Elaine**'s experience confirmed **Geyue**'s assumptions when she spoke about receiving minimal support from healthcare practitioners:

[...] after the surgery, I am expected to take care of my father in hospital but in fact, I really wanted to go home to make some food for him, but I

could not leave the hospital, so I can't do some sandwiches as food for him. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Elaine was despondent when explaining how the expectation for offspring to provide care continued within the hospital environment, culminated in a sense of feeling stuck in the hospital. Having to provide care in the hospital meant she could not go home to prepare food for her father. **Elaine** and **Yun's** experiences highlighted the lack of support received in hospital. In this excerpt, **Yun** expressed a need “*for deeper information, for more knowledge*”, showing his desire to learn skills:

I got some basic training from the nurses or the doctors from the hospital. They told me how to accompany with my dad when he walks or goes to the toilet but for deeper information, for more knowledge about the company or support, I just have my own way to help my dad, I think when I feel comfortable and my dad feels comfortable, it works. (Yun; 30; Male; offspring affected by OCP sub-sample)

The sub-sample of parents affected by the OCP generally found hospital experiences strenuous for family caregivers of older relatives on admission. **Dan's** perception echoed that of the younger generation, explaining how family members must take on a lot of responsibility in the event of a hospitalisation. “*So, I think if one family member got sick and admitted to the hospital it will be a very hard job for the other family members*”. **Dan** highlighted a significant instance when he was unsure if his mother-in-law had dementia as they were unable to get a formal diagnosis. Yet, irrespective of this, in his view there was no adequate

post diagnostic support available, implying that individuals under these circumstances had to fend for themselves:

So honestly to say I don't know if she got the diagnosis. But from my experience, you know when I see her behave, and see her memory getting worse so I can tell she has got dementia. But I know in the hospital I don't believe there are any formal resources for patients after they've got diagnosed with dementia. We don't think there are any formal resources to educate caregivers no. (Dan; 62; Male; parents affected by OCP sub-sample)

For **Yingceng**, the experience of seeking care at a main hospital was very challenging. He shared “So for the bigger hospital I brought my dad to the bigger hospital and it's so difficult,” the reasons being that “it is too crowded too many people. And it is really difficult to get appointment with the doctors”. The experience was made more arduous by learning that his father's surgery would not be followed by any rehabilitation in local hospitals but that it would be provided in the big hospital which was a distance away. This would have meant his father traveling in a frail condition to receive rehabilitation. Given this, **Yingceng** reported that his family felt they had to choose oral medication in a situation where surgery would have been the ideal treatment:

That means the doctor can give surgery, but nobody will provide the rehabilitation service to my dad in the hospital. So, I should say even though in the bigger hospital and some technology, you know, it's not that good. But in Shanghai where my sister is working, in Shanghai the technology is good, and they can connect the rehabilitation with the

surgery. So it is, kind of you know, the whole process they can provide the care. So, we make a decision we won't take that surgery because my dad cannot fly to Shanghai. He's too old to fly. So, we made the decision we will not take the surgery, we choose the medication, it is not that expensive. (Yingceng; 47; Male; parents affected by OCP sub-sample)

Other parent participants also revealed that families were heavily relied upon to provide care within a hospital setting due to lack of rehabilitation. Referring to her hospital experiences, **Andrea** described sharing caregiving responsibilities between family members, nurses, and other patients in a shared unit with her mother, following a minor stroke:

So, she still can move around and sometimes my dad will go to the hospital to take care of her for a while. And the nurses working on that ward will take care of her, part of her care and the roommates, my mum stays on the unit, stayed in the room. Usually in China we have two or three patients share one room, so they are called units. So, the roommates will take care of my mum a little bit. (Andrea; 49; Male; parents affected by OCP sub-sample)

Yan (49; Female; caregivers in employment sub-sample) had also experienced relatives of patients within the hospital relying on each other for support. For example, “one nursing assistant for another patient, he teaches us how to suck [...] do the suction, how to make my mum comfortable, so we learned from each other. I think that's one way to learn the skills”. Perhaps older relatives and family caregivers benefitted from building a sense of community under these circumstances, nevertheless, the absence of support from hospital staff, as

described by participants, was overwhelming for some offspring. A critical example was **Wen**'s situation, where she was significantly responsible for her father's care whilst in hospital. She reported that the nurses' visits were irregular, and there were many demands placed on her by staff:

In the hospital room, so no provision to leave that unit. So, I was taking care of my father taking my dad to have some tests during that time. I was anxious about that, having to take many tests. I'm not sure that his diseases as I was not sure how his disease will progress. And also, you know, for the medication they will come to my dad's room to give him the medication. So, it's not bad. I will stay with my dad and they won't come to the room much often. The nurse also taught me how to make injections, insulin injections. (Wen; 53; Female; parents affected by OCP sub-sample)

Even though **Xue**'s mother received a diagnosis for dementia, in line with **Dan**'s previous assertions, participants reported a lack of substantial support from doctors. In this instance, **Xue** received some symptom-related information that described the illness, "she would be easy to be lost, so we needed to watch her otherwise it's not safe":

But I cannot remember anything else he taught us, he didn't say anything else and later on, I think after half a year, after the first diagnosis and we went to hospital again [...] so we brought her to the hospital and the doctor said it was the symptoms. That means the disease was getting worse and worse, so that's all. (Xue; 49; Female; parents affected by OCP sub-sample)

Aside from lack of post diagnostic support, parent participants also experienced a deficit in accurate communication from healthcare professionals. In **Xue's** case, her entire family had to support her mother following a stroke. During this experience, she described the doctor's input as tangible and supportive as the doctor assuaged their anxiety and depression at the initial stages, stating that the doctor said: *"For every patient, we have to say the same time, your mum is fine"*, meaning they must reassure family despite knowing the severity of a patients' condition. The doctor encouraged them to keep her mum engaged by communicating with her frequently. According to **Xue's** retelling of events, the doctor believed that his encouragement was sufficient. In line with the doctor's recommendations, **Xue** continued, *"we called my mum every twenty minutes or even less than twenty minutes and my mum kind of responded to us and for this whole night, nobody slept."* However, the approach employed by the doctors could be said to not be transparent, despite the intention of supporting the entire family who were present, as he did not disclose the true extent of her mother's condition:

My brother and my sister-in-law and my sisters and other family members, they were all in that room and in the next morning, the chief physician, he came in very early and he checked my mum, and he told us that she is so lucky to have you all because she was so dangerous. He said "we didn't say much about the risk of the severity of the illness last night. We say something about that, but we didn't exactly mention how dangerous she was but this morning, I check her and I see that she will come back, so she is getting recovery, so she is really lucky. (Xue; 49; Female; parents affected by OCP sub-sample)

Some participants described their experiences with health care professionals as insensitive. **Joanna's** mother had three hospital admissions, during which, Joanna felt that the nurses lacked understanding concerning the needs of older people living with such conditions. She made a distinction between 'knowing' and 'doing' what is best for older relatives:

So, my mum, she was admitted to the hospital three times. So, during that period I got the feeling nurses, you know, all staff they do not understand the needs of elders very well. Even from my own experience, even though I have some knowledge about elderly care, but when I really do the care for elders, for my mum, I don't think I'm capable. So that means the staff need to be trained, not only on the knowledge but also training on skills. And so, taking care of elders, take good care of elders first you must have the willingness to take good care of elders as the physiological part and psychological part is more important. (Joanna; 57; Female; parents affected by OCP sub-sample)

About half of the family caregivers in the workforce who were interviewed, described the existing health care system positively with room for improvement. The areas where they envisioned improvements were especially associated with doctors' availability. For instance, **Xiang** (37; Female; caregivers in employment sub-sample) confidently asserted, "I think the medical system is very strong in China but patients just like my dad, cannot see the doctor immediately". This group's experiences also confirmed that family members were practically relied on to employ nursing assistants to provide care within hospitals. Finding a paid carer (nursing assistant), to provide care for her father whilst he was in the hospital, was not a straightforward process as **Niu** (47; Female; caregivers in

employment sub-sample) described her efforts to respond to an advert in search of the right person:

So, I found this nursing assistant from the advertisement, actually there is another hospital who does rehabilitation. And in that hospital, they have a small organisation, and they will introduce some nursing assistants who are good at taking care of the patients just like my dad. So, I went there, and I got the information, and I made a phone call, so I found a nursing assistant [...] And for the technique, the caring technique I think she learned as she takes care of my father. Sometimes she didn't know how to do it but we teach her and she understands and she will try to do it. So, I think we are satisfied with her. (Niu; 47; Female; caregivers in employment sub-sample)

Finding a carer who was in her mid-age really pleased **Niu** as she enthused, “So we were very satisfied with the nursing assistant we had in the hospital. We think we were lucky. It is a lady around 50 years old,” and her description of their exchange suggested that she attributed the carer’s flexibility and ability to prioritise both her and her father to her expectations. In this excerpt, she continued to share the satisfying characteristics of the carer, stating that “she was really kind to my father. I should say the attitude of her is really good [...] She is really patient and very caring”. About half of the workforce participants also spoke more specifically about areas of development for healthcare practitioners in hospitals. A consensus between these participants was that the level of commitment, care and compassion amongst nurses varied from one person to another. **Tong** acknowledged that some nurses possessed the necessary skills and temperament to make a positive impact with the quality of care that was

provided. However, based on what he witnessed, he expressed that “*some of them may not have that kind of good attitude and the skills*” and by suggesting the “*same level of liable*”, he posited that accountability was lacking:

[...] and I hope everyone for nurses, each nurse they should have the equal or same level of liable for the performance and that will be very good for the patient. (Tong; 43; Male; caregivers in employment sub-sample)

Consequently, some practitioners could be perceived as emotionally distant, as exemplified by **Yan’s** example, leaving family members to depend on one another regarding clinical interventions that typically needed medical expertise:

My mum got a problem with her breathing, and she was finding it so difficult to breathe, so I asked the doctor to try and think of something, some way to solve the problem, and the doctor said, ‘Okay so how about giving some injection, one kind of medication.’ So, the nurse... I can tell, the nurse didn’t do it very quickly and she is not in a hurry. So, I was so angry and shouted to the nurse, ‘Try to be fast, please help my mum.’ So, from that moment I just felt that they have no empathy, they are a little bit cold. (Yan; 49; Female; caregivers in employment sub-sample)

However, **Jerry** had very positive experiences using hospital services and unlike several participants, he felt welcomed and taken seriously and had an extensive relationship with hospital staff:

So, since 2015, I have been going back and forward to the hospital many, many times, so I think I’m more familiar with the unit, dialysis unit. And I should say that the doctors and nurses in that unit they are very nice. They

treat patients as if they are their own family members. It is not easy for them to do that but I understand because we go there, we see the doctors and nurses and they see us many times per week or many times per year. And some patients have been there for more than 10 years. So, that's why, the nurses and doctors, they treat the patients like their family members, and they feel very warm, and very touched and they talk to us about something, how to take good care of the patients. (Jerry; 42; Male; caregivers in employment sub-sample)

Extrapolating from his example, with patients repeatedly using the same services and interacting with the same staff members through the course of a decade, it is strongly suggested that continuity of care played a big part in quality of care that older relatives received. Similarly, **Shifan** (61; Female; parents affected by OCP sub-sample) had positive experiences that were closely credited to the connections her husband, **Dan**, had at the hospital:

So, yes, the doctor gave my mother-in-law some treatment plan at the moment, and now, since my husband, he is working at the hospital, he is not a physician, he is staff in the lab. But he can ask questions to his friends in the hospital. To his doctor's friend. So, we do get advice, and we do have the treatment plan for my mother-in-law. We just didn't bring her to the hospital often. (Dan; 62; Male; parents affected by OCP sub-sample)

Dan's last statement, that "we do get advice, and we do have the treatment plan for my mother-in-law. We just didn't bring her to the hospital often," highlighted participants who had access to information from clinicians in the hospital, and how they felt competent enough to provide domiciliary care as a result.

6.3.4 Subtheme Summary

From these narratives, participants who had relatives in nursing homes felt that the care provided was not person centred and lacked good quality. Considering how their experiences were described, their older relatives had unfilial experiences, so they opted to provide care at home. Also, participants questioned the experience and trustworthiness of paid carers at home while some found it culturally unusual. Due to a lack of options for those affected by the OCP, utilising nursing homes or paid carers seemed inevitable. Even in hospital settings, participants had to provide hands-on care or employ a nursing assistant. Participants experienced systemic shortcomings in the form of a lack of post diagnostic support and a lack of education about the health conditions of care recipients for family caregivers. There were no formal procedures to help source a verified carer and some participants could not afford the cost of what they considered to be good quality formal services. Those who could afford good quality care discovered that older relatives were not always persuaded. Some participants had good experiences in hospitals they had attended for many years where the staff treated them like family. This was another indication that traditional principles associated with relationship with others were important aspects of what was appraised as good quality care. As such, some participants were beginning to envision innovative solutions like co-housing with other older people so that offspring could share caregiving responsibilities, therefore, bridging the gap between cultural expectations and the need to adapt to contemporary life.

6.4 Conclusion

In this chapter, participants from the sub-sample of parents displayed an understanding of socioeconomic and sociodemographic challenges to the traditional enactment of Xiao's principles. However, throughout their discourse, there was a noticeable pervasive longing for the way things used to be. Anxieties regarding their own safety and well-being created uncertainty about how open they truly were to embrace the use of formal care services. Assuming that older participants were open to alternative forms of care, the reality of the younger generation affording good quality care for their parents and maintaining a balance between caring and working, was challenging. This challenge was further complicated for those who did not use formal service support, limiting the time and options for several participants and their families. The findings revealed that fulfilling the traditional social roles and financial constraints were present or were anticipated to be stressors, but participants were willing to endure difficult circumstances to fulfil their filial obligations. However, being open to using formal services or having external support or an understanding employer could not mitigate the issue of perceived poor quality of care. Most participants across all sub-samples had reservations about the quality of formal care services. Furthermore, the negative reputation of formal care services hindered its utilisation, yet participants felt at a loss and without options. Ultimately, family caregivers demonstrated innovative means of adapting to circumstances they viewed as inevitable, yet it is unclear how feasible it would be to realise a solution that also upholds their cultural standards.

Chapter 7: Caregiving Conditions – Caregiving responsibility

The content of this chapter relates to the first and fourth objective of this thesis: to understand the experiences and explore the attitudes and preparedness of current and prospective caregivers to manage caring responsibilities for older relatives with needs for on-going daily care and support. Prior to undertaking this research, I was aware of the growing demand for family caregivers, and some of the societal factors influencing their circumstances in China as shown in

Chapter 3: **Phase 1**: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents. While analysing the findings, it was evident that regardless of socioeconomic status or how participants interpreted Xiao's principles, the sheer amount and nature of participants' responsibility presented a complex dilemma and major stressor for individuals. This chapter addresses the intricacies of providing care under the theme 'Caregiving condition'. In this chapter, I turn my focus to discovering the daily and complete requirements involved in providing care. Within each subtheme, I will present findings from the perspectives of parents affected by the OCP, some of whom are balancing work and care, participants in the Chinese workforce, and the offspring affected by the OCP who have witnessed or directly provided care to an older relative living with a long-term health condition.

7.1. Demands

7.1.1 Physical (hands-on) demands

All participants in the parent sub-sample were directly involved in supporting older relatives, and the nature and degree of support depended on individual caregiving contexts:

My mum is a stroke patient, and she cannot walk very well, so she needs some walking assistant and aids to walk and when I go to her house, I will help her to do laundry and clean the clothes and wash her hair and do some cooking for her; make some food, maybe lunch or dinner when I was there. (Andrea; 49; Female; parents affected by OCP sub-sample)

Andrea described her experience after her mother was discharged home from hospital following a stroke. She had to provide hands-on care, which included clinical skills such as maintaining clinical equipment and supervising medication:

I had to work at the daytime and in the evening after work I go to the hospital to prepare the dinner, buy some food for my mum and wash out fluid injection, you know, the fluid injection and also make sure my mum takes her medicines, to take all of her medication on time. (Andrea; 49; Female; parents affected by OCP sub-sample)

In addition to these tasks, **Andrea** was supporting her mother with all household chores and assisting with mobility. **Xue**'s circumstances differed a little because, unlike **Andrea**, she had support from her father-in-law who had a long-term health condition while providing care at home:

My father-in-law would take care of my mother-in-law, even though he had some disease but he still could walk a little bit, so it was okay for him to do

some simple things and I prepared lunch but sometimes I also prepared some milk or bread, so they would have very simple lunch and then later in the evening, when I went back home, I prepared the dinner and we will have a form of dinner. [...] most of the time I went to bed after ten o'clock in the evening. (Xue; 49; Female; parents affected by OCP sub-sample)

Despite this support, she still had to provide hands-on care for her mother-in-law which regularly kept her occupied until going to bed every night. **Wen** had also disclosed in section 6.2.3 Caregiving time how her husband supported her by taking care of immediate family needs, which allowed her to focus most of her efforts on her parents to balance this with personal commitments:

And in the evening after my work, about 5pm I go to their home again and do some housework and prepare supper, dinner. And do some medicine round just like in the morning. My father only takes medicine twice in the morning and in the evening. And during the daytime there is no medicine. (Wen; 53; Female; parents affected by OCP sub-sample)

Just like **Andrea**, **Wen** had work commitments and like **Xue**, she had support, yet she had to prioritise her parents' needs as the onus was on her to visit daily, support with medication, provide meals, and pay very close attention to their health needs. All parent participants' descriptions of their caregiving duties seemed laborious, although they all appeared to minimise the amount of caregiving responsibility they had when discussing the effort that went into providing care. In relation to this, **Shifan (61; Female; parents affected by OCP sub-sample)** described "a typical day" in her life, explaining "I usually get up at 6 o'clock and then I do my routine hygiene and I'm in a hurry a little bit to take some

time to care for my mother". After completing tasks that ranged from injecting insulin to dealing with incontinence, she had little time for much else. Similarly, **Joanna** divulged how difficult she found providing hands-on care when their hired carer had days off, despite having the help of her sisters:

I felt that it is really difficult, you know, to hold her and to get her up from the bed. It really needs strength we don't have that much strength. So it is, kind of, difficult part for us as well, also you know food, feeding her always takes much time. (Joanna; 57; Female; parents affected by OCP sub-sample)

As seen, when describing their caregiving tasks, parent participants had to "*hurry a little bit*" and found some caregiving tasks "*kind of*" difficult, yet some simultaneously recognised juggling care and work with other responsibilities as physically demanding. Although others did not explicitly state it, their duties started when they woke up and finished when they went to sleep.

The offspring participants also provided insight into witnessed and experienced intricacies of providing care for their older relatives. Their interviews reflected adjustment in caregiving behaviour associated with fluctuation in caregiving demands:

[..] sometimes if my grandparents, they got fever or got cold or some condition is not stable, then in that moment, my mum will be a lot of stress. She just thinks about them a lot and in the early morning she goes there and comes back to work and it's kind of a little bit exhausting for her. (Feng; 23; Male; offspring affected by OCP sub-sample)

Considering the inability to predict changes in older relatives' health conditions, these participants emphasised the obstacles faced while attempting to support parents. For instance, similar to parent participants' experiences, **Feng** described the physical difficulty and exhaustion that resulted from his mum providing care early in the morning and heading straight to work. Some spoke of the investment of time and energy involved, for example, **Geyue** (23; Female; offspring affected by OCP sub-sample) said, *"A lot of energy and time into taking care of him or her is definitely essential"*. Given that the process of supporting an older relative was not always straightforward, she also expressed how limiting the caregiving role can be for individuals who routinely put their lives on hold. Based on her perception, she shared that *"You couldn't really have a life when you have another person's life just relying on you"*, most participants from this sub-sample were indirectly involved in supporting their parents to provide hands-on care. For instance, **Jie** (20; Female; offspring affected by OCP sub-sample) found herself in a position to support her mother with caring for her grandparents, sharing that *"there is some limitations for my grandparents, like they go to the toilet and so we have to give some help like that"*. Families who had help from nurses while their relative was in hospital but found themselves without formal support following discharge also found it exceedingly challenging:

Sometimes I can't do everything well. I really hoped there was a person to give me a hand. So, during the hospital life [...] in the hospital, we had a male nurse assistant to help me. In fact, he helped me, and he also gave my father more professional caring. (Elaine; 35; Female; offspring affected by OCP sub-sample)

For those already caring for parents directly, having to balance work and care was strenuous. Below, **Yun** described the adverse consequences on his productivity at work:

[...] when I go to work, I just feel lack of energy. I feel less energetic. Usually, my work time is 8am from 5pm, no later than 6pm. So, the usual work is like that. (Yun; 30; Male; offspring affected by OCP sub-sample)

Despite the impact of caregiving on his functionality at work, **Yun** had to adjust his and his father's living arrangements. They previously lived together, however, preempting having to physically carry his father up the stairs, he saw no option but for them to separate from one another in favour of a living situation that would accommodate his father's limitations:

[...] the house I lived in is a house without elevator so if he lives with me, I must carry him from the first floor to the floor which I lived. So, this is not very convenient, so my father lived in a building with an elevator. (Yun; 30; Male; offspring affected by OCP sub-sample)

7.1.2 Cognitive and emotional demands

Most parent participants were unsupported regarding the intensifying needs of their older relatives and this situation could cause increasing emotional and cognitive demands. The stress of having to fulfil increasing care responsibilities pushed **Shifan** into an insidious process of overthinking without a resolution in response to her mother's worsening condition. This situation could create existential issues due to the pressure to attain an ideal where the practicalities might not always be plausible:

I struggle very hard to try to solve these kinds of problems. So, this makes me feel, thinking, thinking, and thinking what I should do [...] So, I try in another way and think, "What's the proper way to show my respect or to try to respect her dignity and this is the real problem that I'm facing. (Shifan; 61; Female; parents affected by OCP sub-sample)

The culture of Xiao, however, made it imperative for **Shifan** to relentlessly fixate on finding solutions because one that would make them both happy was often not achievable, yet making her mother happy would be perceived as non-negotiable societally. The continuous thought processes involved striking a balance that would reconcile her caregiving capability with the meanings underpinning beliefs as it was of the utmost importance to her that her mother was treated with dignity and respect. In other situations, the expectation was on offspring to be readily available to support parents by showing up daily:

I went to my parent's home twice a day ordinarily. In the morning I go to their home about 6:30 to prepare some breakfast and give my father some medicine. My father was diagnosed with diabetes in July this year. And he's over 80 years old. Not very good memory now, so he forgets his medicine. So, I will watch him take medicine and tell him to take the medicine [...] Sometimes I feel bored. I feel bored. But I also think it's normal. They are old and they say something many, many times. (Wen; 53; Female; parents affected by OCP sub-sample)

For **Wen**, this meant ensuring that parents complied with their medication regime and were eating appropriate meals, which naturally requires cognitive resources to process the practical tasks and make decisions, not just for herself but for her

parent's daily routine. The lack of mental stimulation was a challenge many family caregivers faced. In her narrative during interview, **Wen** was very explicit about how she sometimes made excuses to go home because she sometimes found her role mundane. Despite the perspective that *"it's normal"*, she would make excuses to leave, stating *"I just tell them, I need to go home early because the day is very dark, it's not very safe. So, I need to go early"*.

Although it was wholly unusual for any participant to openly admit to not delivering an ideal level of Xiao, the emotional reaction this lived experience elicited in **Wen** suggests she had reached the limits of her mental and emotional bandwidth in those instances. Although participants identified the need to support parents holistically in Chapter 6: Contextual Factors: Intersections of Xiao, work, and care, it appeared that family caregivers tended to focus on the practical aspects of caregiving and not the mental and emotional resources needed to provide such support. Majority did not believe they possessed the range of skills to support older relatives due to lack of training and had to learn in real time. **Xue** spoke to this effect, saying *"nobody taught me, I haven't learnt anything from others. From nurse? No no. I learnt from the experience, from the way I worked for them"*. By *"worked for them"*, she meant looking after her parents:

For example, I treat my parents-in-law just like children, I mean, I will do anything, make them happy, so if they wanted some kind of food, I will try to make that kind of food or maybe buy that kind of food but even though I treated them as children but I cannot critique, I mean, when the child grows up, sometimes I will critique, I will use the serious tone but for the elders, we cannot do that. Cannot use that harder way to say some bad

words or anything. (Xue; 49; Female; parents affected by OCP sub-sample)

As offspring are not expected to disagree with parents, this could lead to concealment of thoughts and feelings out of respect for older relatives. Describing how she coped while recounting an incident where her mother-in-law stood up and went out in the middle of having her hair washed, Xue shared:

So, I had to run after her to pull her back, kind of persuade her to come back, use some soft words. For example, I may say, 'Okay, come back, I will give you some food that you like, and I cook something you like, so come back and let's continue to wash your hair' and even though at that moment I was so angry that I have to control my feelings. I couldn't be angry to them, I cannot shout out to my mum-in-law and I just take the emotion inside of myself and sometimes I got angry with myself. I was thinking, 'Why I got this kind of mum-in-law, why?' (Xue; 49; Female; parents affected by OCP sub-sample)

The example given by Xue, demonstrated the impact of increased pressure as a result of repressing her emotions. Her statements, *"I couldn't be angry to them, I cannot shout out to my mum-in-law"* and *"I just take the emotion inside of myself and sometimes I got angry with myself"* showed how repressing of her emotions led to her blaming both her mother-in-law and herself. Even though Xue cared for her in-laws and prioritised their happiness, and her understanding of the interaction described between them was intended to give respect to her mother-in-law, the dilemma of learning a skill on the job meant treating them like children but unable to reprimand. Consequently, finding solutions in this context could be

experienced as counterintuitive, highlighting a discord between perceived ideal parent-child relationships and the reality of reversed roles, resulting in emotions running high. **Ruiying** had experienced similar emotionally challenging circumstances and wondered if her father's bad tempers were intentional rather than a result of illness:

Sometimes I thought he just does it because he is a sick man. So he will lose his temper. But sometimes I still think maybe he's not that sick because he didn't lose his temper at other family members. It is just only bullying my mother and I who treated him carefully and we think we had already taken care of him very carefully, but he still loses his temper although we didn't understand my father. Sometimes I become angry and misunderstand him. (Ruiying; 60; Female; parents affected by OCP subsample)

Ruiying, perceived that her father did not bully everyone, and his behaviour was targeted. She suppressed her emotions to be respectful, despite thinking his behaviour might be intentional. **Yingyi** (35; Male; offspring affected by OCP subsample), **Ruiying's** son had noticed the relationship between his mother and his grandfather, but recognised his behaviour was not rational, saying, "my grandpa can have some bad words, so he gets angry without any reason and maybe sometimes he is not reasonable". In the absence of adequate support, participants could end up focussing solely on daily caregiving activities with a manner of indifference due to limited resources to help family caregivers in supporting older relatives:

I felt that she didn't, you know, feel anything. She, kind of, lacks emotions. I feel so sorry for her. She was a primary school teacher, and she was very smart and considerate person. But now when dementia attacked her and dementia happened, she just lost her life. So, I'm afraid I will have this disease when I get old. I hope I won't have this disease otherwise I will make a big burden to my child. So, I hope I will not get this disease.

(Joanna; 57; Female; parents affected by OCP sub-sample)

Joanna's experience with seeing the overall decline in her mother's well-being caused her a lot of anxiety. She wondered what would happen if she also got dementia. As for the offspring participants, Feng worked to create a sense of purpose and harmony between generations, **Feng** engaged his grandparents in various activities such as cooking, which he found rewarding:

I think taking care of elders is a great work, also a demanding process. [...] even though I have work and I have my job and I try to balance my job and part of the caring work, for example, when I rest and have the days off from my work, I will cook for the elders. So, they love the food I make and so I try to do what I can do, and I cook for them and sometimes I just go outside with them to have a walk or have something fun together.

(Feng; 23; Male; offspring affected by OCP sub-sample)

Irrespective of the “demanding process”, he was able to cultivate a beneficial relationship while maintaining unconditional positive regard and an empathetic attitude towards his older relatives. In contrast, **Zijian** spoke about feelings of regret and loss in relation to having prioritised his academic studies ahead of caring for his mother, when she had cancer during his school years:

The first time my mother got cancer was 2011. At the time I was at middle school. You know, in China the middle school students must study for quite a long time, instead of doing any family job. So, I sometimes do some family job for my mother, but most of the time I am busy on study [...] I didn't know much about people, about life that time. I thought it is reasonable that time, but I feel regret now. (Zijian; 24; Male; offspring affected by OCP sub-sample)

In **Zijian's** case, he was younger and did not understand the implications of prioritising his studies above family responsibilities. Most participants were not able to anticipate threats to older relatives' health and well-being when making certain life choices. The stressful and complex process of providing care could also be responsible for participants feeling lost in anticipation of the next change in their caregiving context. For instance, when **Yun** had to provide care unexpectedly, he highlighted the paradox of being alone, which made him feel disoriented, yet he remained determined to shoulder the responsibility of caring for his father. Concerning this, he expressed *"I feel no direction to do with the situation but after a time, I decided that I want to take care of him very carefully. I want to help him"*.

Changes in the relationship between the younger generation and the parent they care for could evoke emotional responses of grief for the caregivers:

And I think there's not much time because when my dad is not sick, we usually chat with each other, talk about anything about the life and my dad also cooks for me, he will make me some delicious food but now he cannot chat with me, and he cannot cook the dinner for me any longer. So, I feel

the family affection is becoming less and I just feel very tired and just feel very down. (Yun; 30; Male; offspring affected by OCP sub-sample)

Yun grieved the loss of the close relationship he had previously had with his father, and the absence of social interactions between them caused emotional difficulties for him.

7.1.3 Organisational demand

Participants in the parents' sub-sample articulated the need to coordinate their older relatives' care needs whether they were providing it themselves or relying on external support. **Andrea** provided a summary of some tasks that she had to prepare in advance because she also had to work, which involved liaising with healthcare professionals. She explained:

And also, I communicate with doctors, communication with the physician to prepare, to arrange things for the next day. So, for the next day I have to go to work in the morning and my mum stays in the unit. (Andrea; 49; Female; parents affected by OCP sub-sample)

In some situations, some participants had to attend to competing care needs of other family members. Like in the case of **Shifan**, she had to simultaneously support her mother and younger brother:

Also, my younger brother receives dialysis and sometimes, some bad things happen. For example, he suddenly feels sick from the anaemia (low haemoglobin level) and needs to receive blood transfusion and then my mother is waiting for me to return home to take care of her [...]. She needs me to take care of her. And then in another way my brother needs my help.

So, I need to coordinate. (**Shifan**; 61; Female; parents affected by OCP sub-sample)

In her interview, **Shifan** disclosed the pressing demands she was responsible for coordinating. Despite arranging with professionals involved in her family's care, being able to cope with various family member's needs left her with a sense of achievement:

*Yeah, arrange or coordinate to see the doctor to get the right blood in the emergency department he is usually seriously ill [...]. Sometimes I'm really proud of myself since I can cope with so many things, so many things, yeah, the work task, the family, brother, mother, younger brother. (**Shifan**; 61; Female; parents affected by OCP sub-sample)*

On the other hand, even though **Joanna** had a paid carer, having other commitments made caring for her mother difficult:

*We have to, you know, have at least two persons to take care of my mum, so that's, kind of you know, a difficult time for me and my sister [...] I haven't taken care of my mum by myself. So, I always be with my sisters to take care of my mum together when the carer, you know, she took days off. So, the difficult part for us, even though we have the carer at home to take care of my mum, but the carer she needs to have several days off especially in holidays. (**Joanna**; 57; Female; parents affected by OCP sub-sample)*

Joanna had the support of her sisters in addition to the paid carer, yet the cover during periods when the carer took leave fell on Joanna and her sisters to

organise. In cases where older relatives were not fully reliant on offspring, participants felt responsible for their parents' safety:

I took over a half day for them and they buy little things. I buy these things for them, but they don't want them. They just want to go there by themselves, and they enjoy. The purpose is not, I think the purpose is not to buy the little things they just want to go out. Go outside and go far from the home and they go outside and I'm afraid they're going to fall and for their safety I want them to go out just near our home. I don't want them to go far away and take subway and I'm afraid they fall again. They like doing that. (Wen; 53; Female; parents affected by OCP sub-sample)

Wen's parents could act on their intentions and wanted to be autonomous, but **Wen** thought they did not always consider the possibility of accidents. The implication of this was that as an only-child, **Wen** felt it necessary to run errands on their behalf. However, her attempts were futile because, as **Wen** acknowledged, their true needs were not being met by her intervention. The central focus of caregivers' narratives concerning the management of older relatives' care was the struggle to balance needs:

[...] at first my father didn't go to the hospital but since that day his lungs became worse, very aggressively and we took him to the Chinese hospital to start the treatment. And we found we'd almost delayed his illness [...]. (Ruiying; 60; Female; parents affected by OCP sub-sample)

Ruiying's father chose not to attend the hospital after breaking his femur due to a fall, which delayed his treatment. Responsible for maintaining their relationship, **Ruiying** felt at blame. Offspring participants also shared witnessed experiences

of organisational needs within their family. By contrast to situations where an older relative might be at some sort of risk due to ageing or age-related decline in health, in situations where an older relative was independent without any care needs, relationships were balanced though still reciprocal. For **Zhirui's** family, being an intergenerational household and with her mother being in relatively good health, family members found a way to be considerate of one another:

I'm the one child of the family and we are living with my grandma, but she is really healthy, and she can do anything for herself but because living together, we try to adjust to kind of use for each other's self. For example, my grandma will get up early and go to bed early, so usually in the evening, we will turn down the volume of the TV in case this distracts her from going to bed and in the morning when she gets up, she usually goes out to the supermarket or does some exercise, and she doesn't make any noise because she knows we are all sleeping at that time. (Zhirui; 22; Female; offspring affected by OCP sub-sample)

The families of those with complex needs or who were not in good health found themselves needing to organise many aspects of care. **Geyue** detailed some of the things her mother had to do in order to be prepared for her role as a family caregiver supporting the grandparents in hospital:

A lot of things, small things. She has to go to hospital every day, basically, and she has to find nannies, she has to find food because my grandparents don't really get use to the hospital food. It's really awful. So, she basically cooks every day to bring them food. (Geyue; 23; Female; offspring affected by OCP sub-sample)

When considering the demands of organising care, most of the offspring participants spoke about finances being a potential stressor for their families.

Yingyi who was playing a supporting role to his mother, expressed how it was rather difficult to provide appropriate remuneration for a paid carer:

Usually, we pay a lot higher salary, I think it will be a little bit stressful for the family and if they pay a little lower salary, then the nursing assistant might not be satisfied with the salary so it's kind of difficult to get this right salary for both sides. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

Elaine (35; Female; offspring affected by OCP sub-sample) who had been providing hands-on care for her parents also envisaged the cost of treatment and wondered how she would manage in the event of a relapse in their health condition. She said “[...] if the disease comes back, you know, the whole family will spend a lot of money”. However, despite financial pressure, **Zhirui** (22; Female; offspring affected by OCP sub-sample) remained ever committed to contributing towards the improvement in his father’s health, stating “so I think there is no going back after I made the decision that I wanted to help my father to recover from the sickness”.

7.1.4 Subtheme Summary

Overall, participants’ narratives in this section revealed the level of demands they had to meet to adequately provide care for their older relatives, reflecting the level of health needs of older relatives. Combined with work responsibilities, most participants providing hands-on care reported having no time for personal activities. The need to physically assist older relatives was a source of stress for

parent participants, some of whom had health conditions of their own whilst also working and caring. Furthermore, the cognitive load of accounting for all areas of older relatives' needs were a source of stress for the parent sub-sample. The offspring sub-sample felt some of these pressures when supporting their parents in their caregiving role. Irrespective of whether their efforts were appreciated or acknowledged, participants remained motivated to continue with the provision of care. The energy and time needed to manage health crises or changes in care needs of older relatives could be further depleted, resulting in the demands becoming emotional stressors. Ultimately, driven by beliefs about their role and within the broad construct of caregiving responsibility, participants often internalised feelings as a default response to demands and often minimised or normalised their difficulties. This normalisation of the impact of caregiving demands could mask the realities of the support needs of family caregivers.

7.2 Proliferation of Stressors for parents and offspring

7.2.1 Internalised social roles

The culture of Xiao left participants with a sense of responsibility for others and this responsibility manifested differently for all participants. Some parent participants were vocal about the increased pressure they felt to provide care due to their age or gender. For instance, *"I'm the oldest one in the family so I always think, and I always believe I should be the one to take the responsibility to take care of my parents. Joanna (57; Female; parents affected by OCP sub-sample)* Joanna is a woman who is also the first born, and she felt a responsibility to relieve her younger sisters of caregiving duties. She explicitly highlighted that her intention to take on more was due to being the eldest. Her conclusion was a confident, determined, and optimistic *"I can do it'*. Furthermore, **Shifan (61;**

Female; parents affected by OCP sub-sample) echoed **Joanna**, corroborating that being the eldest made her feel obligated to undertake more caregiving responsibilities. *“I always think that I’m the oldest and I should take as much as possible”*. **Shifan** said of her youngest sister, *“She usually gets up very early in the morning and her work is quite demanding [...] And after her retirement she has to look after her granddaughter”*. She spoke of how despite being the youngest, her sister’s responsibilities are increasing to the same level as hers. She added empathetically, *“So, I don’t want to disturb her [...] And it is not an easy job either”*.

Her position as eldest meant that **Shifan** felt the strongest obligation to care for her parents and look after her siblings, yet by her statement, *“especially when I become older and older and I’m not so strong and so full of energy, like, as when I was young”*, she acknowledged that as she got older she may not be in the best position to provide care or would find caregiving even more tiring than she already does. With **Shifan** and **Joanna**, as eldest siblings, both women understood the weight of their undertakings and were open to enduring these challenges if it meant relief for their siblings and adequate care for their parents.

On the other hand, reflecting on their caregiving duties, **Yingceng** (47; *Male; parents affected by OCP sub-sample*) and **Dan** (62; *Female; parents affected by OCP sub-sample*), both men, expressed a relative ease associated with the roles they played. *“So, I always follow my wife’s orders, you know. If she wants me to do something, I will do it. So, I’m the helper of my wife”* **Dan**. When his wife took her mother for an outing on her days off, he would provide practical support. *“I will drive, and I will set up the wheelchairs and I will pull the wheelchair for her. So that’s, kind of, the things I will do. So, I think it is not very difficult for me.”* **Dan**

attributed his ease to the traditional but indirect role he filled to support his wife when it came to providing care, mainly because he saw himself as “*the helper*” and not the primary caregiver. In **Yingceng**’s case, he believed that his siblings have an equally shared responsibility to provide care to his father:

We have a sentence in China “If you have money, you can provide money for parents and if you have your own strengths, I mean time or energy or be around, you can provide the care to your parents directly”. So, it depends on different situations. (Yingceng; 47; Male; parents affected by OCP sub-sample)

Yingceng was content about collaborating with his siblings in a way that would not impact his own work. “[...] so, we can arrange the time. So, I believe I don’t need to use the work time. I can work as usual”. With the good fortune of being able to share caregiving responsibilities with several siblings, he expected his younger siblings to cater to the hands-on aspects of their parents’ needs. “*But my sister or brother they can come to take care of my dad. So, I don’t think it’s a problem because I have so many siblings*”. His understanding of the roles, going by his statement “*if you have your own strengths*”, suggested that he believed the strength of his mostly female siblings rested in their ability to provide hands-on care.

The intersection of family position and gender can be seen when juxtaposing **Yingceng**’s perception of what is expected of him as the eldest, with **Xue** (49; Female; parents affected by OCP sub-sample), who is also the eldest and also has male and female younger siblings but is a woman. Neither **Xue**’s professional status nor multiple offspring household could relieve her of providing hands-on

care. She explains, *“I remember it was 2015 and my mum got a stroke, and she was in the hospital, and she got many treatments, they needed someone to watch her [...] So, my sister and my brother, they were watching her in the hospital”*. **Xue** also regularly went to the hospital to provide respite to her siblings. Despite having siblings to share responsibilities with, the sheer difficulty of simultaneously caring for both parents and her mother-in-law who had advanced stage dementia, left her with no other choice but to leave her job. She continued, *“it seems like I don’t have time to work and also my grandson was just born so many things were together, so I quit my job as it so it was difficult for me”*. Women in this study raised more contextualised discussions around caregiving intricacies, indicating the expectation placed on them, compared to the privilege afforded to their male counterparts. Within the context of issues that proliferate stressors, finance was a major factor that compounded stress for family caregivers. According to **Andrea** (49; Female; *parents affected by OCP sub-sample*), living in China meant children must pay 15% of the total expense of each treatment *“even though parents have the health insurance, children still have to pay part of the money for their health and hospitalisation”*. Nevertheless, unlike **Yingceng**’s circumstances, having siblings with whom to share caregiving responsibilities did not relieve **Andrea** of providing care physically and providing hands-on care did not alleviate her from contributing financially because she earned more. Regarding sharing caregiving responsibilities, she stated, *“[...] there is no rule, you know, it depends about myself and my brothers and usually I pay more than my brothers because my brothers earn less than me”*.

The expectations concerning social roles could also be seen in the offspring participants who did not see themselves as capable or being obliged to provide

hands-on care. Despite assisting his mother to care for his grandmother, **Feng's** appraisal was that his minimal experience would be insufficient for him to provide good personal care:

I don't think I have this ability to do a very good job, I don't have this kind of skills, I don't have matching skills about how to take care of my mum, go to the toilet or how to help my grandma go to the toilet or to help them to walk. I don't have this much experience. (Feng; 23; Male; offspring affected by OCP sub-sample)

Feng, Wen's son, also questioned his capacity to navigate providing financial support as typically expected of sons. **Yingyi's** mother, **Ruiying**, provided care for her father. When considering a time when he might need to undertake caregiving responsibilities, due to being an only-child, **Yingyi** had doubts about providing care due to the need to financially support his family:

I think if I need to stay at home and take care of my mum 24 hours 7 days a week, I think it should be short-term, otherwise I cannot get income, I cannot support the family, I cannot live. (Yingyi; 35; Male; offspring affected by OCP sub-sample)

Being the only offspring with a decision to either prioritise hands-on care or financial support could be a really challenging decision, hence, “*I cannot live*” represented the struggle that he could face if he gave up work to care.

7.2.2 Stifling duty of care

All participants expressed their willingness to care as Xiao's values motivated them but the practicalities of taking up caregiving responsibility left some participants with little freedom and eroded their role identity. Some parent

participants felt discontent, when efforts to meet filial expectations meant making sacrifices such as giving up their work:

I felt a little bit uncomfortable, strange feeling. I knew I didn't feel very well because my husband can work and earn money back but I cannot work, and I have to stay to take care of the parents-in-law and to take care of everything for the family but my husband has to work because he needs to earn money and I'm the person in charge of the money and I will use the money to take care of everything for the family. (Xue; 49; Female; parents affected by OCP sub-sample)

Despite overseeing her husband's money and understanding the necessity of her husband earning to provide for the family, **Xue** still felt uneasy about giving up work to become a family caregiver. Aside from giving up work, she and her husband had built their house in his parent's yard and were fully responsible for their care. she found herself obligated to accept caregiving responsibilities that she perceived ought to be shared with her husband's older s brothers. *"Also, my parents-in-law they have four sons and I feel a little bit like they only live with us but not live with other sons [...]"* **Xue's** in-laws felt at ease living with them and the time devoted to providing care for them was because of this attachment her and her husband. *"Other sons of my parents-in-law, they didn't provide any care for them, only me and my husband"*. Nevertheless, the circumstances were bittersweet for her because of the personal sacrifices she made and the lack of support or contribution from her brothers-in-law.

Shifan (61; *Female; parents affected by OCP sub-sample*), revealed how she struggled with understanding the best way to look after her mother who has

dementia among other long-term health conditions. *“I try to use my thinking ways to force her to have the same way of life, or same way of thinking or behaviour, but my mother is not happy”*. Doing what she thought was best affected their relationship and made them both unhappy. **Shifan** was determined to preserve her mother’s autonomy for the sake of her well-being to avoid having *“a very bad time”*, but her attempts to *“let her behave or to think in her own way,”* made her worry about her mother’s physical well-being, which she explained, *“but she’s old and she really can’t take care of herself, take good care of herself. So, if we don’t care for her, I think the situation will become worse and worse”*.

Generally, participants felt they had limited options for providing care adequately and **Wen** (53; Female; *parents affected by OCP sub-sample*) corroborated the anxiety **Shifan** had about her mother, saying *“and they’ll get hurt or burnt when they cook”*. In **Wen**’s situation, her mother has mild cognitive impairment and Wen thought her mother was not conscious of the level of support that she required. She continued in the excerpt *“And I smell the odour outside the door, but they are inside, and they can’t smell that. They tell me, “No need to come. No need”*. Therefore, it was deemed necessary by most parent participants to support older relatives through constant supervision to keep them safe. Reflecting on parents’ need for constant supervision, **Dan** was optimistic when speaking of the potential freedom they would have if able to have paid care for his mother in-law. *“So, I would say there will be a big difference. It will be a relief, you know, we will get more freedom”*. Despite living together, when the carer takes a couple of days off, their caregiving continued. This meant they had to always take mother in-law with them to circumvent accidents:

We will bring her with us wherever we go. We cannot leave my mother-in-law at home by herself because she cannot walk stable. And she forgets to turn off the gas and turn off the water, you know, sometimes she will pee in the room not in the toilet room. So, she needs somebody around every minute. (Dan; 62; Male; parents affected by OCP sub-sample)

Workforce participants who remained in work after taking on caregiving duties had to adapt their approach to work. In the case of **Sutong**, a teacher who had been consistently caring for three older relatives since the year 2000. In supporting her father, **Sutong** found it difficult to complete schoolwork.

[...] I'm a primary school teacher. My dad usually [...] elimination for him is really long-time job. It usually takes two to three hours and I need to massage a little bit and wait and let the stuff out. So, I give him enough time to do the stuff, and I also score some homework at the bedside. (Sutong; 50; Female; caregivers in employment sub-sample)

Cohabiting could be seen as an avenue to ease the daily difficulties for participants combining work with caregiving but had challenges for the quality of the relationships within the family unit. The need to combine work, caregiving and family life drastically reduced or erased the time left for participants to connect with spouses and children. In the case of **Xiang**, her father's condition was seen as the cause of her anxiety and short temper:

I am concerned about my dad's condition. So, it is totally different. "I mean if dad he didn't get sick, I will have a good temper. I will enjoy my life. But now I need to worry about my dad, so it is really different. (Xiang; 37; Female; caregivers in employment OCP sub-sample)

Similarly, **Lisheng** (56; Female; caregivers in employment OCP sub-sample) shared how the health implications of caregiving had significant consequences for her professional duties, “*So, I should say, when I’m at work, I cannot concentrate, myself, on my work*”, which she associated with the anxiety she developed in response to her caregiving role. “*So, I should say, my stress, psychological stress, a little bit high. And my husband got a high stress as well*”. For **Lisheng**, while it was clear that she was aware of her deteriorating health and connected it to the stresses of being a family caregiver, she concluded by saying “*So, we need to adjust to this kind of situation.*” This implied that she was resigned or reconciled to continuing to work and care as she felt she had no other choice.

7.2.3 Financial and environmental constraints

As shown in section 7.1.1 Physical (hands-on) demands, providing care for older relatives often required substantial financial contribution from offspring. Participants who had the role of contributing money were under immense pressure to keep earning. However, those not earning due to taking on long-term or full-time caregiving responsibilities also needed financial support for example, to make the home environment more conducive to caring. **Yingceng** thought it would be beneficial for home environments to be “*reconstructed a little bit*” with good ventilation or nursing facilities to ease caregiving demands, “[...] *for example, for the toilet room it is too small, and it is not convenient for family members to take showers*”. Also, during the winter periods, older relatives could be engaged in meaningful indoors activities in the community and he hoped the government would make the necessary investment:

So maybe, you know, the government will provide some space or room for elders to take their hobbies. And, you know, provide some inside exercise machines for the elders to do some simple exercises. (Yingceng; 47; Male; parents affected by OCP sub-sample)

While the employed status of older participants like **Yingceng** and individuals like **Xue**'s husband allowed them to work, care, and have some time off, those with hands-on duties routinely expressed a lack of opportunity to take a break. *"I watched my husband go outside to have a walk or have something fun with his friends, but I couldn't do that."* **Xue** desired to have some respite from her duties, but she recognised that it was important to earn money as earners were seen as more important because of their ability to provide financial support:

I couldn't ask my husband to stay because I didn't earn money, you know, in the rural areas the people who earn money are the people who are more important for the family because if he couldn't earn money, nobody can support the family. (Xue; 49; Female; parents affected by OCP sub-sample)

However, the lack of parity of esteem between those who earn and those with domestic roles left her with feelings of not being in control of her life. She expressed feelings of sadness and some hopelessness regarding change because she *"knew that the reality"* was for her to *"take care of everything"* for her mother-in-law. A few offspring participants were already providing support financially. **Elaine** and **Yun** in particular, illustrated how the cost of care added to their stress. For example, **Elaine**, who is an only-child living and working a long distance from her family home, explained:

For example, after my father was discharged, he received injection twice a week and each injection are about 700 RMB, which will be over a long time, so I think it's too much for a common family. (Elaine; 35; Female; offspring by OCP sub-sample)

“A common family” that is, those with lower social economic status, would have an expensive challenge to overcome. Nevertheless, having no option but to attend to care responsibilities as the sole offspring required participants like Yun to coordinate care and spend beyond their means. “The cost of medical treatment is very expensive, and my salary is not that high. So, I feel a lot of pressure”. Yun assisting his mother to care for his father who was diagnosed with stroke highlighted that “[...] if we want to have a better carer, they usually ask for 6000-7000 RMB per month.” As the cost of adequate care would be nearly double his entire monthly salary, and his mother’s income is only marginally higher than his salary, they must continue working full-time and providing long-term care to sustain their current situation:

After paying all kinds of insurance, my actual income is 4000 RNB per month. I spend about 2000-3000 RNB for my dad’s treatment. The other is paid from my mother and her monthly salary is about 5000 RMB (Yun; 30; Male; offspring by OCP sub-sample)

7.2.4 Trust issues with formal services

Aside from increased pressure due to financial constraints, many offspring participants emphasised the risks associated with employing paid carers to assist with their caregiving responsibilities. In this section, trust issues regarding the poor quality of formal care services are not viewed as a contextual systemic

barrier to meeting support needs, but as the lasting result of said barrier on the future caregiving landscape. **Geyue** did not identify as a caregiver but has family members providing care for older relatives. She emphasised the importance of a high standard of care from paid carers, *“personalised care is really like an essentiality for me, because I wouldn’t trust anyone else to care for my parents”*, and described the need for carers that would provide excellent care for her parents:

So, I need it to be very trustworthy and making me realise that they can take good care of my parents, knowing their condition, knowing their needs, really loving environment. (Geyue; 23; Female; offspring by OCP sub-sample)

Issues around safety were a source of anxiety for most participants, for instance, **Feng** (23; Male; offspring by OCP sub-sample) expressed his concerns about the reputation of formal carers, *“I just don’t trust these kinds of people, I heard some news about how nursing assistants abuse the elderly”*. **Jie** (20; Female; offspring by OCP sub-sample) who wished to study abroad and prioritise her career and family, revealed that she viewed caregiving as her responsibility and would prefer to take care of her parents herself. She posited that employing carers could result in abusive situations, saying *“but when I spend money to ask another body for help, it just feels like a career they must do and if they do bad or take good care of them or bad, nobody knows”*. Although, she may not take on the hands-on aspects of providing care, she perceived carers who have no familial association with their older relatives as being without obligation to treat them well. To this she said *“[...] and so, I think they don’t monitor themselves to do very well, like a daughter”*. **Yun** Corroborating **Jie’s** views, he shared an

experience that grounded his perception, *“I think when my mum and I are with the support worker and my dad, the support worker will behave very carefully to take care of my dad”*. Most participants who have assessed that they would need support with their parents believed that paid carers do not have the same sense of responsibility as family members:

[...] the time we don't spend time with them, actually I don't know the situation, but I have a feeling that they will not take care of my dad that carefully. I think she will not show the responsibilities just like the family members give my dad [...] She was not in the same room with my dad, she was just watching some TikTok videos in another room. So, she cannot take care of my dad very, very nicely. (Yun; 30; Male; offspring by OCP sub-sample)

Wen, a parent participant, stated that *“good nursing assistance is very helpful, but it is difficult to find someone that can be trusted”* and shared how she would resort to mounting cameras to monitor carers, indicating that when it comes to matters of trust, family caregivers may struggle to ask for external help:

I don't know. I'll just, like, have a camera around the room. I'll have a camera because I don't trust them that well [...] If I'm confident to find a carer now, I will do so. I will have to do this by myself as much as possible. (Wen; 53; Female; parents affected by OCP sub-sample)

Interestingly, **Feng, Wen's** son, also spoke about the possibility of quitting his job to care. Therefore, his decision to go to the extent of surveillance was not something he desired but he felt a lack of options as he would have to work:

[...] so, I think if I cannot provide care to my mum, I will hire somebody to come to my house. Maybe I will set up some camera in the room and to monitor the nursing assistant to check how they work. I don't want to do that. (Feng; 23; Male; offspring affected by OCP sub-sample)

7.2.5 Subtheme Summary

Overall, in this subtheme, I have described how the pressures of providing care and potentially having to work were compounded by social roles. Traditionally it was expected that the responsibility for the hands-on aspects of caregiving fell to women or the older offspring. This was still the case for several participants and was seen to undermine their self-agency. It appeared to leave male participants feeling unskilled and overloaded female participants. However, due to anxiety regarding the health and safety of their loved ones, participants were motivated to continue providing care. For some participants, this meant round-the-clock supervision as many had a deep distrust in formal care services, with some opting to live together with their parents, which affected their health and functionality at work.

7.3 Coping

7.3.1. Problem focused

This section looks at various crucial factors that were instrumental in participants' ability to solve problems pragmatically. These factors included but were not limited to having useful connections in different professions, a flexible schedule or supportive family members. Looking at parent participants, **Shifan** received some assistance from her professional network to relieve some of the duties relating to the care of her parents:

[...] Sometimes I am really proud of myself since I can cope with so many things, yeah, the working task, the family, brother, mother, younger brother. And sometimes I feel exhausted, so exhausted and so nervous. But at that time since I'm working inside the hospital... So, a lot of my colleagues, for example in the emergency department, they will help me to manage some things or help me to arrange or plan some things for me.

(Shifan; 61; Female; parents affected by OCP sub-sample)

All participants regarded care responsibilities to be the duty of family members and an expectation that must be met. In the absence of a paid carer for instance, **Joanna** and her sisters rallied around one another to provide care for their mother:

So, for my sisters, two sisters they are living in my hometown. If they come to Shenyang, it will take four hours by car. And my second sister, actually both of them are teachers in some school. My second sister she is working in some continued education school and my little sister she is working as a teacher in the school for deaf mutes. So their work load is not as heavy as mine. So that's why they can take days off to take care of my mum. And they support each other, especially my second sister she will come to Shenyang by car. [. . .] but we try to be together to support each other.

(Joanna 57; Female; parents affected by OCP sub-sample)

As described by **Joanna**, her siblings took on care responsibilities, and being teachers with a lesser workload than herself, they were the ones to take time off work. **Xue** detailed how her family scheduled their caregiving responsibilities

based on employment status. Those in employment took on the responsibilities over the weekend while those unemployed provided care on weekdays:

My oldest sister, she didn't have a job at that time, and I didn't have a job at that time, so we took care of our mum, I mean, taking more care of my mum. My second sister had a job at that time and my younger brother had his job at that time, so they came to take care of my mum at the weekend. They had two days off from the work, so they would spend those two days to stay with my mum to take care of my mum. (Xue; 49; Female; parents affected by OCP sub-sample)

Time pressures meant **Xue** found herself drawing on support from her father-in-law who also had a health condition. She explained, “Sometimes, my father-in-law would take care of my mother-in-law, even though he had some disease, but he still could walk a little bit”. The tradition whereby women are expected to care for their daughter-in-law at a time of birth added to the extensive demands on **Xue**, so that she sometimes relied on neighbours to care for her parents-in-law in her stead:

For my grandson, at the first time, in China, the lady who gave birth will have one-month total rest, that's the Chinese tradition. Actually, as mother-in-law, I should take care of my daughter-in-law very well, but I didn't have enough time, so I only took care of her, I remember two or maybe three days and so it wasn't continually, it was intermittently and at that moment, I asked my neighbour to watch out for my parent-in-law in the daytime. I prepared food ready for them and then my neighbour can watch my parents-in-law a little bit, then I could go to my son's house and

take care of my daughter-in-law. (**Xue**; 49; Female; parents affected by OCP sub-sample)

Even with all the effort and focus on resolving the challenges of competing needs, **Xue** was unable to fulfil all the responsibilities for her mother, concluding that “*if the caring needs from my mum-in-law were so huge, if that situation was bad, I will cut down the times I visited my mum*”. Caregiving context for individual families dictated the nature of support needs for siblings. Evidently, participants who had siblings felt it was of great importance for them to show up physically to support parents. However, for **Ruiying**, the responsibility of hands-on care was placed in the hands of a few family members, especially daughters, and yet these efforts were perceived to be inadequate regarding filial competencies:

*[...] my sister and I usually do more work, including some cooking, cleaning and other caring things etc. And my two brothers will take care of our parents every two to three days. It is our common sense that we have a big family get together per week no matter where you are, you must come back for this meeting to take the responsibilities for our parents [...] my siblings think they behave more filial piety to my father than me or become more obedient to him I think. (**Ruiying**; 60; Female; parents affected by OCP sub-sample)*

Despite the tentative relationship with formal carers, the majority who employed this path found having paid carers useful as they provided family members much needed respite. Among other participants was **Dan** (62; Male; parents affected by OCP sub-sample), who had a live-in carer: “*So, the home maid is a 24-hour home maid. So, she is living with us in the house*”. However, as **Joanna** explains,

the formal carers may have to leave their role to provide care within their own family:

[...] since we are very busy, so when my mum got dementia we hired a carer, a 24-hour carer to take care of my mum. And now we have hired three carers, home maid. They are very good actually. The first one she had to stop working for us because her child has, she was going to have grandchildren. So, she had to go back home to take care. And the second home care she left because she had to take care of her own father-in-law. And the third one, I mean she has been working with us, for us for almost four years. And she is a really good home carer. (Joanna; 57; Female; parents affected by OCP sub-sample)

Some participants coped with demands of care responsibilities by actively planning for different possible events that could occur within the context of their circumstances and role as a family caregiver. **Shifan** described having to plan everything she must do in each day:

I need to make a good plan. In the morning before I get up, I must think about what should I do? How should I do? You know, which way. So, I need to have a very good plan so that I can do the right thing at the right time. [...] When it is difficult to do this, I find another appropriate time, so I don't have to pay so much physical energy to help her. I think I'm a good nurse. (Shifan; 61; Female; parents affected by OCP sub-sample)

Also considering future care needs, **Andrea** explained how she formed the habit of saving money ahead of her parents' annual hospital appointments and possible emergencies:

I am saving the money at present for when something happens. Usually, my parents will go to the hospital once a year. So that means I have to pay and have to be ready for that time. (Andrea; 49; Female; parents affected by OCP sub-sample)

Wen revealed in section 7.1.2 Cognitive and emotional demands, how she would make excuses to leave after visiting her parents due to boredom. On these occasions, she made time for other interests that her duties as a family caregiver would not have allowed her to have time for:

[...] so they will agree with me, to go early and if you get home make a call and tell me you are safe at home", but I will go swimming, go shopping and see a movie. (Wen; 53; Female; parents affected by OCP sub-sample)

Another way participants intend to cope with practical support was offspring participants' innovative solutions to facilitate caregiving. The purpose was to educate relatives to address the expectations to accommodate parents' needs and simultaneously earn a living. A few participants suggested the use of technology to help maintain life and work responsibilities. For instance, the use of social media platforms such as WeChat was considered by **Elaine**, to coordinate care activities and get support from relatives who might not otherwise have the knowledge and expertise needed to provide care, especially if she must be at work:

[...] I can teach relatives to provide the good care for parents. So, I may teach relatives through the video chatting, such as WeChat, and teach the relatives how to take good care for my parents. (Elaine; 35; Female; offspring affected by OCP sub-sample)

Likewise, **Feng** reflected broadly on how the development of artificial intelligence could contribute to relieving family caregivers of certain pressures. His hope was for “*machines*” to transform tasks that would be physically carried out by family caregivers or paid carers:

I can have this kind of machine in my home, so if my mum needs a cup of water or my mum needs to go to the toilet room and needs help, maybe the robot can help her [...] That's kind of one way for me I think about, maybe it can help me balance my work and my caring responsibilities. (Feng; 23; Male; offspring affected by OCP sub-sample)

7.3.2 Emotion focused

Some parent participants coped through identifying positives in providing care. Although caring for her father created anger and feelings of rejection, **Ruiying** shared her learning of empathy and approval through providing care for her father:

[...] sometimes I become angry and misunderstand him. But then in these years, year after year when my parents got older and older, I started to appreciate their differences each year. They became more elderly, and their eyesight has got worse. And he couldn't hear you worse and worse. (Ruiying; 60; Female; parents affected by OCP sub-sample)

In the excerpt above, **Ruiying** detailed how her “*appreciation*” came as a result of understanding her parent’s worsening health. She later revealed that the change in circumstances was responsible for the pity she felt towards her father, which seemed like her basis for continuing to provide care. She explicitly stated, “*And I started to feel sorry for my dad. I have more love for my father and my mother*”. **Ruiying** explained that “*when they behaved badly I started to understand them and we became more obedient to my parents’ requests*”. The way she responded to the emotional challenges was in line with the traditional ethos of Xiao. Despite having to accommodate her father’s anger, **Ruiying** considered herself to be in a privileged position to provide care to her father. Her statement that “*I thought it is a good thing, a good thing overall*”, suggested that she had repressed her anger and was able to temper her response during repeated incidents:

[...] And now I became more careful for my father and when he loses his temper I didn’t talk back to my father or my mother. I just stay silent. I didn’t talk to him at that time. So, I became more and more, I feel more and more easy when he loses his temper. (Ruiying; 60; Female; parents affected by OCP sub-sample)

Another parent participant who could be seen positively reframing was **Andrea** (49; Female; parents affected by OCP sub-sample), who was trying to meet the expectations of her roles as a wife, a mother and a daughter, which was not always feasible for her, as stated “*[...] I don’t see any time for my husband, and he is OK with it all*”. **Joanna** feared that her friend would not understand her mother’s condition and perhaps felt unsafe asking for help, which led to questioning her friends’ ability to assist her with providing care:

So, I think my mum, because of my mum's, you know illness I'm afraid my friend's wife couldn't understand what happened to my mum. And she may not, be good at taking care of this kind of patient and also for me this is my mum. I should take care of my mum. I cannot put the responsibility to my friend's wife. It is my own job. I just thought it's not a good way to solve the problem. So, I never asked for help from my friend's wife. (Joanna; 57; Female; parents affected by OCP sub-sample)

Perhaps due to obligation, lack of safety or altruism, participants had to overcome adversities associated with the multiplicities of their roles. Being proud of their capability and believing they coped well enabled them to not sink in despair. Considering the difficulties associated with caregiving responsibilities, **Joanna** revealed that she deliberately avoided thinking about needing care in the future because she found it stressful:

I am not brave to think about that day, you know. When that day comes and I will have a way to sort it out, but now I don't want to think about it, do you know what I mean? So I have seen some other friends and they've had to, you know, face those challenges. It is really hard. So, for me I don't want to think about it right now because this has not happened yet. [...] the thought is a bit stressful. (Joanna; 57; Female; parents affected by OCP sub-sample)

By not planning for the future, participants like **Joanna** may struggle to address caregiving needs, especially if they suddenly increased. To fulfil the responsibility of caring for their parents, some participants coped by making sacrifices to fulfil Xiao:

Sometimes my friends they told me, “Why are you not sending your parents to your other sisters, maybe your parents can stay with other sisters for half the year or maybe for one year they can relocate, kind of you know, they relocate to take care of the parents?” I said, “No, why do I need to do that?” “I want to do more. I should do more. (Shifan; 61; Female; parents affected by OCP sub-sample)

For instance, in response to pressure to urge siblings to take on more responsibilities, **Shifan** believed the contrary, that she had to increase her own responsibilities as she associated the need to persevere with hardship as inevitable. As such, **Shifan** praised the importance of having a healthy community of colleagues and friends who could offer her emotional support when she needed it. She felt that it was beneficial to be able to talk through difficult caregiving situations and considered herself lucky to have a considerate social network to rely on:

[...] whenever I feel bad or need emotional help I will talk with this friend, who understands me in every aspect [...]. I feel that I’m very lucky, really very, very lucky that my colleagues and my friends give me a lot of support. They help me in many aspects. (Shifan; 61; Female; parents affected by OCP sub-sample)

Similarly, to the parent participants, many offspring participants placed a high value on overcoming adversity and spoke about it with pride. A few offspring participants spoke about how caregiving responsibility was beneficial for building character:

[...] I grew up, you know, I can do so many things for my father that I never thought I could do. At this moment, I must do these things, and I found that I am capable and have a lot of potential to do all the things myself, so I feel mature and grown. (Elaine; 35; Female; offspring affected by OCP sub-sample)

In the above excerpt, **Elaine** credited her maturity to her ability to handle all the caring responsibilities alone. However, whilst resilience building is crucial to adjust to their caregiving role, as seen in **Yun's** example below, caregiving demands could manifest as stressors for participants who would otherwise benefit from having a network that could provide emotional support. Being an only-child, **Yun** spoke about his father's expectations of him having a family and grandchildren:

[...] I am the only child for my dad, actually for him I am his motive and hope. I think he wants to, because now I haven't had a family, I haven't got married, so I think his inner hope is that I, he thinks I should have a whole family. He wants to see my children, he wants to see his grandson or granddaughter, so that hope will also help him to recover. So, I think I want to get more support from the spiritual support or mental support. (Yun; 30; Male; offspring affected by OCP sub-sample)

In this context, there was an increased pressure to start a family as **Yun** perceived that his father considered his improvement of health to be contingent on the idea that *"he wants to see his grandson or granddaughter, so that hope will also help him to recover"*. Disclosing that he would like psychological and spiritual input to help him manage these expectations showed the emotional co-

dependency that could exist between parents and offspring. It also shows the psychological consequences that can result from proliferation of stressors on offspring without adequate coping resources.

7.3.3 Subtheme Summary

Overall, this theme of coping demonstrates a range of coping mechanisms employed by participants to manage their caregiving duties. Some were pragmatic in their approach to solving problems by enlisting the help of others or using technology to ease caregiving demands. Caregiving also developed ways of coping with internally challenging aspects of being a family caregiver. Some of the means adopted were self-sacrifice and positively reframing challenges. Other participants described ways of coping that could potentially be maladaptive such as self-blame and avoidance of the inevitable reality of needing to be cared for in the future.

7.4 Caregiving consequences

7.4.1 Physiological and psychological impact

All workforce participants expected themselves to deprive self in one way or another to accommodate older relatives' needs. When referencing the expectations placed on family caregivers. **Sutong** eloquently articulated that:

You love this person and then you can do this job better. So, the first heart is the heart with love. The second heart is the patience. You need to be patient. The third heart is you need to be careful, heart is careful, care for those, you know, very careful. Do everything very carefully. The final heart is doing it. Resilience, I should say, meaning keep doing it, cannot stop.
(Sutong; 50; Female; caregivers in employment sub-sample)

According to these experiences, love, patience, diligence, and resilience make a better family caregiver. All participants spoke about acute, chronic, and vicarious consequences of caregiving for their physiological and psychological well-being. Parent participants like **Andrea**, expressed their struggle with feelings of guilt for not having the time to personally devote to the care of parents:

[...] sometimes it is hard. We don't have enough energy to take care of our parents. So, you know, usually we have to work in the daytime and so we have to spend our other time to take care of our parents after work. So, from that part we feel a little bit guilty for taking less care for our parents. So especially when they get sick, and they really need the family members around, but we cannot provide enough care because we have to work. So, we have to hire somebody else to take care of our parents. So, at that moment I usually feel guilty. (Andrea; 49; Female; parents affected by OCP sub-sample)

Furthermore, in section 5.1.3 Xiao: being a good person, **Andrea**, reflecting on what it means to be a good person, shared how she taught her daughter “*to live for others, meaning no time for herself*”. The most important expectation was that parents are well supported. From the statements shared by participants, Xiao at its core demands resilience from offspring. In relation to this, **Ruiying** also tried to adhere to the “*four hearts*” expectations as she endured abuse while caring for her father, however this only resorted to blaming her father for his condition. In her words, “*I think if he became more tough and has more courage he can stand up and walk by himself*”. In addition to this, she also likened her father to a baby, lacking courage and behaving somewhat cowardly, suggesting that negative

interactions could lead to mundane caregiving activities and a potential consequence of long-term suppression of thoughts and feelings:

When my dad gets up every day he is becoming more and more like a baby. We must do many things to take care of his clothes. He always wants to change his clothes when he gets up in the morning. After the surgery he began to use wheelchair and he became more careful with himself. And he doesn't have enough courage to stand up and walk all by himself [...] he has behaved somewhat cowardly and does not have enough courage to recover from the illness. (Ruiying; 60; Female; parents affected by OCP sub-sample)

In relation to having to work and provide care simultaneously, **Xiang** blamed herself for being unable to give her undivided attention to her father resulting in a late diagnosis:

And for the children even though we cannot provide back the best things for the parents, but we still want to provide a better thing for them. So I feel a little bit guilty because if I can notice that my dad has got something wrong he can be diagnosed earlier, I felt a little bit bad about that. (Xiang; 37; Female; caregivers in employment sub-sample)

The series of examples given by participants connect through varying levels of prioritising others to achieve the ideal to love with four hearts. The additional responsibilities of caregiving took their toll on **Yan** and led to resentment aimed towards her circumstances. Pondering her circumstance, **Yan** described:

In my mind, sometimes I complain a little bit. I will ask myself why mum got this disease. Why I have to take care of my parents like this? Why

other parents live so well? Why this happened to me? (Yan; 49; Female; caregivers in employment sub-sample)

It is notable how participants journey through guilt and despair often end on a positive note. In the continued excerpt, **Yan** concluded

[...] but even though I have these complaints sometimes, but I still do the things to help my dad and to take care of my mum, because I also learned from my parents when I was young, I saw my parents taking good care of my mum's parents. (Yan; 49; Female; caregivers in employment sub-sample)

There is an expectation to be conscientious and courteous always whilst supporting parents, which indicated the need for offspring to be adaptable externally and internally. For many participants, it was the tenacity witnessed as offspring that was responsible for inspiring their fortitude. Consequently, the effort to give their parents a deserving and good experience in their later life could have emotional and psychological repercussions as those affected by OCP will be underprivileged to care for their parents as was done for their grandparents. **Jerry** is an only-child from the first generation affected by the OCP. **Jerry** committed his life to supporting his parents and, when his parents needed care, having “four hearts” meant he gave up his education and later gave up his job:

I remember when I graduated from the junior high school I stopped going to school; I stayed at home and took care of my mum. So, my mum passed away around 2002 and after my mum passed away later my dad got sick himself and he suffered. (Jerry; 42; Male; caregivers in employment sub-sample)

He explained further, *“but I mean it is unfair to him, so that’s why I decided I will not let him feel sad in his later life. So, I try to do what I can do for him. I quit my job. I stay with him every day and I watch him, and I make him safe at home.”*

The love and concern he had for his parents led to prioritising their needs and eventually ceasing work to provide care full-time. Reflecting on his personal loss, as a result of the impact of the sacrifices he made, **Jerry** shared his concerns about whether his own future child would be able to live up to this high standard:

The quality of the child maybe not that good, and maybe I cannot earn more money to support him, to give him or her a good quality of life. So, I’m thinking maybe if I got married, I may not have a child. (Jerry; 42; Male; caregivers in employment sub-sample)

Providing adequate care for his parents had serious impacts on **Jerry**, with his age and financial status impacting on his prospects of marriage. In his own words, he described *“And I should say taking care of my dad and taking care of my mum, yes, all these things impact my life a lot and influences my own personal life, such as the marriage. Now, I couldn’t get any girlfriend, because of this special situation”*. Referring to his circumstances as *“this special situation”* likely meant that he perceived his circumstances to be unique. However, lack of higher education and financial stability would greatly impact many participants’ ability to have the life they desired at present, or in the future.

Within the context of family caregivers and the time spent fulfilling caregiving commitments, losing important opportunities was found to be common for most workforce participants. For example, **Niu** said:

So for me I think if my father didn't get sick I will have more time to do the favourite, my favourite things. And one of my favourite things is travelling... But now for me I've no time to travel. (Niu; 42; Female; caregivers in employment sub-sample)

The shared reality of needing to prioritise work despite the high value placed on supporting loved ones meant that participants had little or no time for personal endeavours. **Sutong** (50; Female; caregivers in employment sub-sample), who already combined work with caregiving duties during the week expressed how her weekends did not equate to available personal time. “*So usually at weekends, Saturday and Sunday, I will take over all the jobs, you know, to take care of my dad.*” Similarly, **Shifan** (61; Male; parents affected by OCP sub-sample) could only rely on her spare time to complete some paperwork and provide training remotely. With time being divided between working and caring, she stated “*I need to do some paperwork. Sometimes I need to provide training for nurses in my spare time, like, evening time after supper through the web.*”

There is a concurrent theme of loss that runs through workforce participants' narratives. Particularly, **Jerry's** experience showed the price of the sacrifice he paid when he said, “*I have many, many things I want to do if my dad was not sick.*” Therefore, we can assume that as long as he is expected to provide care, he would be unable to start his family:

So, if my dad, he was not sick I would like to find a girlfriend to marry that girl and have my own family. [...] I think I have many, many things I want to do if my dad was not sick. (Jerry; 42; Male; caregivers in employment sub-sample)

Despite her decision to provide care at home, **Sutong's** self-sacrifice led to self-neglect and her health condition posed a threat to her life and risked the future of her caregiving responsibilities. On one occasion, an artery in her nose broke and caused a severe nosebleed. According to **Sutong**, this serious incident was the turning point where she began to take better care of herself. *“So, from that time, I decided I need to pay more attention about myself,”* hence, the fear of experiencing a severe injury caused her to delegate responsibilities for tasks that could worsen her condition:

So, for example my dad usually threw out some stuff on the ground, so actually I should pick up the stuff for him, but sometimes I'm afraid if I change my position, my blood pressure is not that stable, maybe some bad thing happens, maybe in my brain, some vessel broken. [...] So, I try to avoid that action, so I ask my husband to do that [...] That's one way I try to adjust myself to this situation. (Sutong; 50; Female; caregivers in employment sub-sample)

Only one participant was able to reflect on the difference of not having to shoulder care responsibility for older relatives anymore, once they have passed away. **Xue** was very explicit about the benefit of having regained control over her life and being able to finally do what mattered to her. The emergence of a new identity reflected a renewed sense of pride in what she did with her time:

So, I feel relaxed and freedom right now. I'm so happy to work and I have my way to earn money and I got my salary and I feel happy because there's not much care demands there and so just really relaxed and

freedom, feel free. (Xue; 49; Female; parents affected by OCP sub-sample)

The intricacies of caregiving responsibility were challenging for **Shifan**. She made a clear connection between the physical demand of her role, her depleting energy and “*physical state*”. **Shifan** was already resigned to believe that “*life is not easy*”, so she likely had no other expectation for her situation to improve:

So, I don't care too much just do what you should do. So, you see life is not easy. Especially with my physical state, my physical state is not quite so strong to cope with it and I need energy and I feel tired, and I feel weak [...] It is hard sometimes. Yes so, many responsibilities I need to take on.

(**Shifan**; 61; Female; parents affected by OCP sub-sample)

Her focus on responsibility, however, suggested that the physical demands resulted in emotional dissonance for **Shifan**. Particularly, her statement that “*I don't care too much, just do what you should do*” substantiated this assertion as it implied that she responded automatically to the needs around her. Again, it is significant to note that neither **Shifan** nor **Sutong** were motivated to cease their caregiving duties to prioritise their health. Therefore, the predominant solution was to “*adjust*”. Many workforce and parent participants found their caregiving role restrictive. As previously established, **Andrea** (49; Female; parents affected by OCP sub-sample) had no spare time, but she later revealed “*all the days are to take care for parents except I really need to take days off because I can't speak. It is that bad situation, otherwise no days for me*”. The severity of the impact of caring for her parents while maintaining her leadership role at work resulted in days that she would be so exhausted she could not speak and at these

times she relinquished her responsibility as a mother to her husband. *“The only thing I can do is take care of my parents and my daughter can be taken care of by my husband”*. **Dan** (62; Male; *parents affected by OCP sub-sample*) described the implications of this reality on the health of other family members as *“exhausting, not only physically but also mentally exhausting”*.

The physical demand of providing care could be so excruciating that it caused conflict in households. **Yingceng** described how tensions between his mother and father, over her commitment to personally caring for her parents, escalated. This was a cause of unhappiness for **Yingceng**:

So, I think before the problem for us is the conflicts between my dad and my mum. They often argued with each other. They were not happy living together. So, it made us unhappy. My mum didn't want the carer to provide care because she thought they don't need that care. So, she thought she could provide care to her husband but she can't. So earlier this year when my mum lived with my dad they were living together, one day they argued again, and my dad was so angry, and he hit my mum. And my mum told me he hit her so badly and she has to go and call help from the neighbours and so at that moment after that I brought my dad out of the house.
(**Yingceng**; 47; Male; *parents affected by OCP sub-sample*)

Although Offspring participants were aware of the deleterious impact of providing care for older relatives, this did not deter the majority from desiring to follow in their parent's footsteps, but it could be why their generation responded with more openness to alternative forms of care. **Yun** witnessed his mother's exhaustion, from repetitive adjustments to juggle work and caregiving whilst enduring sleep

deprivation. He provided insight into what instigated his suggestion for a more permanent solution:

We have a carer, a support worker, but my mother also has to do a lot of work for my dad, for example, at night my father woke up six to seven times per night, so every time my father woke up, my mother has to be interrupted for that, so actually I really love my mother, so I came up with the idea [...] send my father to a nursing home. Yun; 30; Male; offspring affected by OCP sub-sample)

7.4.2 Financial impact

Caregiving had a financial impact and given that OCP was implemented differently in the rural parts of China, the policy could contribute to inequalities:

So, the policy is: if you have only one son, no other children, you will get this 1000RMB/year [as a contribution to care costs], if you are older than 60. If you have two daughters, no other children, no son, you can have this money as well and others you cannot have. So, I understand, that's the policy because in the one-child policy, for the rural area, the first child is daughter, you can have another chance to try if it's daughter or son. If you get another daughter, two daughters still be considered as one child because it's the rural area, they need labour [...] But if you have one daughter as the first child and the second child is the son, you cannot have another children, so that means in the rural area for the one child policy, they can have two children but the first child should be a daughter. Then they can have two children. (Xue; 49; Female; parents affected by OCP sub-sample)

In situations where family members had a son as the first child or two daughters or a daughter and a son, they received an allowance of 1000RMB/year towards care, though this was insignificant in the potential overall costs. Whilst some families might be able to afford the cost of healthcare because they were high earners, others, especially those without job stability, might be unable to support parents as expected:

[...] because I have a regular job with a better income, a better salary so it seems okay for me to support my parents. But I have been thinking about other family if they don't have stable work, a stable income and how they can provide care for their parents, you know, especially for the money.
(Andrea; 49; Female; parents affected by OCP sub-sample)

All participants that considered the use of nursing homes, indicated that the nursing homes that would provide high standards of care for parents were typically unaffordable:

I've visited that nursing home once. I saw some nurses, so it feels, you know, not only care they also provide medical care. So, it makes me feel good. Also, the food there looks fine, for example, they have vegetables, they have the meat. So, it seems very nice food. Also, the living conditions are good too, so that's why I think that that nursing home is good one for me. But the price of this nursing home is expensive, so I'm a little bit concerned about the price. *(Wen; 53; Female; parents affected by OCP sub-sample)*

Yingceng also commented about the cost of good quality nursing homes but with a hope for improvement:

[...] So I think the cost for the nursing home is kind of expensive. I hope the cost will decrease a little bit in the future. (Yingceng; 47; Male; parents affected by OCP sub-sample)

However, most participants, including those in the offspring group, spoke about finances as a potential stressor as was covered in section 7.2.3 Financial and environmental constraints.

7.4.3 Subtheme Summary

Overall, caregiving consequences saw the various impacts that could result from caregiving. Parent participants engaged in self-blame and experienced guilt resulting from outcomes that were often outside their control. The expectation to love, be patient, diligent and relentlessly resilient set high goals for most participants and sometimes led to them neglecting their own health needs and deprioritising individual agency or freedom. Despite this negative impact, this did not lead family caregivers to give up their responsibility to care. Many workforce and parent participants had resigned themselves to having an uneasy life balancing work with caregiving commitments. Parents had to choose between prioritising offspring or older relatives and individuals had to choose between their parents or potentially having a family of their own. The reality of the consequences of caregiving was dire, before considering the financial impact. This financial allowance from the government for those affected by the OCP insignificant compared to the cost of providing care. For an only-child offspring, having job security becomes the most important goal for themselves, their nuclear family, and their ageing parents.

7.5 Conclusion

In this chapter, the findings showed that participants are willing to be present for their parents in their later years and all participants believed that providing care was not only the right thing to do, but also a very rewarding way to support a loved one. They focussed on ensuring the happiness of their older relatives. However, there were several personal barriers to providing care in a meaningful or effective way on a more regular basis. These barriers related to internalising emotions about the challenges of caregiving and being unprepared or trained for in providing care. Whilst participants maintained positive relationships on the surface, the daily demands of caregiving took their toll on their health and psyche, and for some, negatively impacted their life. The risk of providing poor quality care due to exhaustion or health complications did not deter participants from continuing care provision.

In the following chapter, I will discuss the findings from the previous three chapters in relation to the study objectives and critically engage existing literature with a focus on cultural influences on caregiving process.

Chapter 8: Discussion, conclusions, and key recommendations

8.1 Introduction

This thesis comprises three interrelated studies, starting with the scoping review as presented in *Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China*. Chapter 3: *phase 1: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents*. and the *phase 2* presented across *Chapter 5: Caregiving Beliefs- Xiao: the lifestyle*, *Chapter 6: Contextual Factors: Intersections of Xiao, work, and care* and *Chapter 7: Caregiving Conditions – Caregiving responsibility*. This final chapter will present a key summary of my findings, indicating their original contributions to existing knowledge and highlighting the implications for selected caregiving conceptual frameworks. I will briefly revisit the study's objectives before discussing the findings. Strengths and limitations of the study will then be discussed, followed by practical recommendations for research, policy and clinical practice, and the chapter will end with a conclusion.

The scoping review presented in Chapter 2 clarified that whilst extensive literature is available on caregiving process and the implications for family caregivers of older relatives in developed countries, there is a dearth of equivalent research in China. This could be due to the limited time the nation has had before transitioning into an ageing society, compared to developed countries like Australia, United Kingdom and the United States (United Nations 2015b). Furthermore, studies captured in the scoping review were predominantly

quantitative studies and focused on the influence of shared values and traditions on caregiving, i.e., they adopted an essentialist view of culture, and most papers retrieved reported cross-sectional studies and did not gather data across generations. Therefore, it was unclear how much caregivers subscribed to the fundamental value of *Xiao* (孝), or whether family care continued only from a sense of duty not from a sense of affection (Quinn et al. 2010). Whilst the intention for **phase 1** in Chapter 3 was partly to accustom myself to Chinese people and culture, the findings presented revealed that the normative values of *Xiao* permeated participants' cultural beliefs.

8.2 Contribution to Knowledge

As presented in previous chapters, several assumptions influenced this research study. Firstly, that the socio-cultural environment has a more direct influence on individual coping responses in a collectivist society. Secondly, individual experience or perception of caring for older relatives is subjective and lastly, the perception of experiences dictates the processes involved in making care decisions. Bearing this in mind, I anticipated that through understanding the socio-cultural environment's influence on attitudes, experiences, and perceptions of family caregivers, I would be able to make recommendations that would be underpinned by rigorous research. This thesis makes a novel contribution to knowledge and is the first study I know of that adopted a social constructivist approach, making it possible to comprehensively explore rich information about caregiving processes in China from multiple generational perspectives. To capture these insights in discussion, it is important that I return to the research aim's four core objectives, which were:

1. To understand current and prospective family caregivers' perceptions or experiences, or the experiences of their relatives or friends with caring responsibilities for older relatives in China.
2. To explore the meanings of filial piety (Xiao) to current and prospective family caregivers, i.e., to what extent do participants subscribe to these cultural values.
3. To understand current and prospective family caregivers' attitudes about balancing work and other areas of life when caring for an older relative, particularly the influences of social support, Xiao, and perceived barriers to providing care.
4. To explore the attitudes of current or prospective caregivers, and the preparedness of family caregivers to manage caring responsibilities for older relatives with needs for on-going daily care and support

Prior to addressing the objectives listed above, it is noteworthy to state that the themes presented within **phase 2 of this study in** Chapters 5, 6 and 7 were inextricably linked. As such, I will address the research questions and present the study's contribution to existing research accordingly. Initially, I will present an overview of findings under the overarching theme and following this, I will situate my findings within the context of wider literature.

8.3 Summary of Findings

The themes of the findings within **phase 2 in** *Chapter 5: Caregiving Beliefs- Xiao: the lifestyle*, *Chapter 6: Contextual Factors: Intersections of Xiao, work, and care* and *Chapter 7: Caregiving Conditions – Caregiving responsibility* were captured under the overarching theme of 'Competing pressures- motivation, meanings, and preparedness', interacted dynamically. This interaction reflected participants'

experiences and expectations, showing the intricacies associated with their caregiving responsibility. The themes highlighted that the cultural beliefs embedded within the social environment drove the motivation, which served as an anchor for family caregiving. Notably, the anchor provided participants with a strong determination to provide care in the future regardless of numerous anticipated challenges. Further, despite Xiao being a culturally shared value, findings revealed a lack of structural support for working family caregivers, which will be the reality of prospective caregivers as only-children. Hence, despite parents' efforts to unburden offspring, poor quality of formal services, inconsistent training, education, or support with older relatives' long-term health conditions means that proliferation of stress is inevitable. The final theme concludes that the extent of caregiving demands will ultimately lead to significant physiological, psychological, and financial impact, especially for women and older caregivers, because of stressors and ineffective coping, encouraged by the cultural mandate of endurance and resilience, often interpreted as self-repression. This is the basis of shifting cultural attitudes, as although offspring participants regard Xiao highly and want to care for their parents in old age, their efforts are frustrated because of socio-economic needs, sociodemographic demands, and the governments' lack of nuanced understanding of the needs of family caregivers, which manifests as generic interventions. Consequently, individuals within society are taking unconventional approaches to align their beliefs with proactive, pragmatic, and necessary adaptations to ease caregiving burden.

8.4 Competing pressures: motivation, meanings, and preparedness

8.4.1 Caregiving paradox: implications of filial discrepancy between ideal and actual self

As established from the start of this thesis, China is a nation associated with a collectivist culture, which tends to promote interdependence, meaning that in their socio-cultural environment, self-construal incorporates prioritising others' needs. Therefore, the attention people are socialised to give to others' needs influences their outlook. A main gap in extant research that this doctoral study sought to address relates to understanding how caregivers exercise their individual agency in relation to their attitudes and capacity for caregiving. This understanding required an exploration of how participants interpret Xiao, experiences, and attitudes towards providing ongoing daily care and support, and preparedness regarding balancing current or future caregiving responsibilities with work.

Findings from this doctoral study highlighted associations between expectations placed on family caregivers by their socio-cultural environment, stressors, and coping responses. Each participant indicated the significance of supporting their parents as society expects of "a good person" (filial expectations (based on belief)) and they would most likely aim to enact this (filial performance). Nevertheless, if unsupported, caregivers may not cope with caregiving demands and filial discrepancy may manifest due to incongruences between belief (ideal) and performance (actual). As a result, participants must make difficult decisions about how to balance future caregiving responsibilities with other responsibilities to address filial discrepancy.

Most participants expressed that their caregiving responsibility carried a risk of being "burdened", captured as physical, cognitive, emotional, financial, and

organisational demands. The inclination to deny personal interest in favour of providing care to older relatives is standard practice in China. This inclination is exemplified in a participant's decision to give up travelling abroad to stay with her parents, for instance. Furthermore, the wider impact of this expectation can be seen when another participant describes that caring for ageing parents has now become the collective responsibility of the younger generation. Essentially, the obligation to meet parents' needs sets societal expectations for who will provide care for future generations of older people. Findings from this doctoral study show that the traditional view of caring for older relatives was an obligatory duty or a way of repaying parental debt but could create caregiver burden. By contrast, the contemporary experience of caregiving is based on the notion of compassion, which can fuel participants' innate calling to care for their parents with love and devotion. Such egalitarian transformation in filial attitudes highlights the importance of open communication of needs and concerns between older relatives and caregivers. However, despite these changes in attitudes, the act of caregiving is still heavily focused on the physical and the pragmatic. Hence, participants relying on institutional care experienced great shame and regrets because they could not offer more physical and practical care to their ageing parents. Further emotional bonding is hampered by the inability to express appreciation and forgiveness, denying families the opportunity to achieve catharsis and reconciliation in life's most vulnerable moments. Although findings from this doctoral study suggest that reciprocal relationships require mutual support, compassionate duty, and emotional investment for adequate care, such emphasis on task fulfilment inevitably makes forging emotional connections difficult. Findings revealed a caregiving paradox whereby all participants had

strong positive meanings attached to the fulfilment of Xiao, serving as motivation to care for parents. However, willingly reciprocating caregiving against all odds, according to the traditional understanding of Xiao had the potential to put caregivers under pressure.

8.4.2 Repaying parents for past sacrifices

Caregivers tend to operate in a 'balanced mode', i.e., balancing various personal choices to fulfil cultural expectations. The responsibility to care for older relatives was normalised by emulating parents' societal beliefs, intertwined with the cultural expectation of Xiao, which was imbibed by participants through socialisation. Nonetheless, the intention to nurture parent-child relationships and accommodate caregiving activities extensively, out of a strong desire to repay parents' past sacrifices, links participants of this study with a 'reciprocal mode' whilst attempting to maintain a 'balanced mode'. All study participants positively highlighted parents' earlier sacrifices, positing caregiving as 'the right thing to do', and this altruistic world view has bred the value of reciprocity for generations. Considering this, aligning with findings from research with caregivers of people with dementia in the UK (Quinn et al. 2010), reciprocity based on altruism serves as a crucial motivator for family caregivers. Concerning their desire to repay parents by fulfilling their cultural expectations, societal values led caregivers to have high expectations of themselves, and caregiving stress occurred when there was perceived incongruity between role performance and ideal role identity or role aspirations (Montgomery and Karl 2009). Hence, the collectivist values of Chinese society promoted a sense of incongruence.

Factors such as self-efficacy beliefs (Crellin et al. 2014), meanings and the motivations attributed to caregiving (Quinn et al. 2010), have implications for

caregivers' idiosyncratic views, role adjustment and their social behaviour over time. Regarding the process of caregiving within a social context, McAllum et al. (2021) found that taking on a caregiving role involved three aspects, all of which would be affected by culture; viz role acculturation i.e., getting used to the new role; role negotiation and identification i.e., caregivers adapting to care demands within the scope of their own life; and role learning i.e., caregivers acquiring expertise from health and social care professionals as well as co-caregivers. Findings within this doctoral study showed that the wish to fulfil Xiao, practical ability to do so, and the intersubjectivity of Xiao differed between participants, exposing an apparent three-way tension. This tension was illuminated in the participants' contextual cultural discourses, as they pertained to the authority and influence of Xiao.

As older relatives' long-term health conditions progress, their support needs intensify and become harder to meet, especially as needs around social life, personal care, and psychological health are not as straightforward as it may seem (Abdi et al. 2019). Hence, incongruence between a caregiver's performance and aspirations, levels of caregiving required, and the nature of support can all have adverse implications for role identity (Montgomery et al. 2007). Drawing from this doctoral study findings, when caregivers feel weary from having no break from caregiving responsibilities or feel guilt for parents' negative experiences, for example, there will be stress from the discrepancy between their experience and their perceived ideal role identity as a good and dutiful caregiver. There is considerable research around obligation and willingness to care. For instance, in the UK, recent findings suggested that caregivers for older people living with long-term health conditions can feel obligated to fulfil the role, irrespective of their

personal preference (Parveen et al. 2019). Becoming a caregiver may imply willingness to do so. However, the person may be providing care due to a sense of obligation or lack of alternatives (Quinn et al. 2010). Individuals may feel under pressure to demonstrate willingness to care for their parents and may suppress feelings of stress or struggle (Au 2017). However, even in situations where there was also obligation, having a sense of choice about taking on caregiving has been found to be protective and strongly associated with caregivers' well-being (Al-Janabi et al., 2018). In the Chinese caregiving context, family caregivers of older relatives may perceive themselves to be in a liminal position, i.e., performing caregiving duties that relate to cultural functions, which can cause them to struggle with their personal identities or ability to provide care as competently as expected. The obligation to continue to care in a context of exhaustion or lack of willingness could result in a sense of detachment. The accelerated internal migration from rural to urban areas, which puts geographical distance between generations of the same family, and the cost of care provision, which is unaffordable to many (Lin 2019), may intensify this sense of detachment and negatively impact caregivers' wellbeing, as there would be no way out of their stressful situation.

8.4.3 Changing nature of Xiao: influences of the One-Child Policy and globalisation

The one-child policy (OCP) that was implemented in China in the late 1970s and rescinded in 2015 had a great influence on reducing the number of children available to support ageing parents. Given China's long history of patrilineality, one of the unintended consequences of the OCP is that women who were home-based by virtue of tradition are now able to achieve greater social equality due to

their improved status within the workforce. In support, Warmenhoven et al. (2018) found that women born after 1978 (Gen X) did not subscribe as strongly to norms of patrilineality compared to other groups, including men born after 1978 (Tu and Xie 2020). Despite these changes, women tend to be limited from gaining career advancement (Wang and Klugman 2020). Mitigating this limitation might be the motive behind parents' heavy investment in daughter's education to ensure that they stand a chance in a fiercely competitive labour market. As such, China is one of the highest suppliers of international students across the globe (Liu 2016a) with some of the female participants in this current study aiming to travel to the West to further their education.

The number of Chinese students coming to the United Kingdom (UK) continues to grow significantly (Tu and Nehring 2020), with a high proportion being female (Zhang and Xu 2020). Zhang and Xu (2020) showed that exposure to western countries could be a powerful advantage to being competitive in the labour market in China. Due to stringent UK visa requirements (Tu and Nehring 2020), the majority of Chinese immigrants studying in the UK return to China. This return would most likely come with expectations to support parents or extended family who heavily invested in their education, as suggested from this study's findings, particularly under the subtheme of 'reciprocity'. However, investment in a child gaining overseas education may not bring the anticipated advantages. The oversupply of transnational students and improved domestic higher education can make it difficult for overseas returnees, referred to as "hǎi guī" - 海归, to land desirable or high-paying jobs and they are sometimes referred to condescendingly as "seaweed" (hǎi dài - 海带) or "work-waiting returnees" (Liu

2016a: 48). Paradoxically, exposure to alternate ideologies gained from time spent outside China, could alter individual thresholds of filial obligation and moderate the impact of Chinese cultural values on role appraisal (Kuo 2011). Exposure to Western societies may lead individuals to internalise values around individual autonomy. Even for younger generations who are yet to leave China, findings from this doctoral study showed that some may prioritise their offspring ahead of parents and some explicitly stated their intention to reject parents' directives to provide care. Ultimately, with a critical gap in social care (Zhu and Walker 2018) and long-term care support (Du et al. 2021), current and future caregivers will be left to provide the necessary care for older relatives alone, which would be detrimental for their well-being (Zhou 2019).

Although caregivers within an individualist society also struggle to balance needs and are reluctant to stop providing care due to feelings of obligation, they appeared able to prioritise self and their own identity (Quinn et al. 2015). However, a longitudinal study in the United States of America (USA) among Chinese older people who reside in the community found a high mortality risk when filial expectation is more than receipt and lower mortality risk when offspring are fulfilling Xiao more than expected (Li and Dong 2019). Also, older Chinese immigrants in Canada suggested that valuing "emotionally oriented" filial piety (*Xiao*) and "behaviourally oriented" filial piety (*Xiao*) as equals could be weakening the traditional message and complicating filial perceptions (Zhang 2020). Likewise, another study of Chinese immigrants in the USA stated that the younger generation reported distant relationship with parents compared to older generations (Guo et al. 2020). The studies conducted in Canada and USA (Guo et al. 2020; Zhang 2020) found that while the weakening of the traditional

message of Xiao in the West does deter offspring from supporting parents, they still worried about disappointing their parents if unable to meet filial obligations (Guo et al. 2020).

The situation for younger generations in China could be quite precarious compared to those in Canada or UK, since state governments in Canada and the UK support family caregivers, whereas there is not yet such support in China. This doctoral study's findings suggest that offspring affected by the OCP are more likely to be emotionally close to their parents compared to their parents' generation, and there is also a subtle expectation from parents to be cared for at home. Therefore, while caregiving beliefs stemming from the socio-cultural environment gave a sense of belongingness to participants, they also served as structural and cultural barriers to caregivers addressing personal unmet needs or seeking formal support with caregiving responsibilities. Ultimately, a novel finding from this doctoral study is that future caregivers' decisions could be detrimental for parents if they decide to co-opt the input of formal services but could be detrimental for themselves if they prioritise parents' needs and do not access formal services.

8.4.4 Self-neglect: Coping with stressors of fulfilling Xiao

Confucian beliefs of Xiao established the propensity for de-prioritisation of self, which resulted in social pressure being a part and parcel of the cultural environment, and led to the tendency of parents to place demands on their offspring as revealed in *chapter 2: scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China* and *chapter 3: phase 1: preliminary study-intersections between the culture of Xiao (孝) and caring for older relatives in*

China: perspectives of UK-based Chinese students on future care for their parents. Caring for parents in families affected by the OCP has compelled participants to reduce their work hours and take salary cuts. Alongside financial repercussions, participants' experiences included being a leader at work with no clear directives on how best to support caregiving colleagues, severely limited respite from work to provide necessary care and travelling long distance to provide care or receive treatment despite ill-health. In one participants' case, having to be absent from work due to an injury created an opportunity she would not normally have to stay off work and spend time with her mother. Despite these conditions, maintaining good communication with parents was considered a necessity by most participants, regardless of the quality of their relationship (Bedford & Yeh, 2019). As an outcome of role modelling, offspring affected by the OCP envision choosing to live frugally and sacrificing professional or personal ambition to the extent of permanently leaving jobs to meet the needs of older relatives in the future. Findings showed that participants' attempts to combine various personal responsibilities often led to them neglecting their personal needs or those of their offspring, as they prioritised their parents and their employment.

Alongside the consequences of the OCP, when we consider that patrilineal values still persist within mainland China as suggested by Warmenhoven et al. (2018), the expectation that women should oblige the traditional model of care would cause many women, retirees and those unemployed to be overwhelmed with caregiving activities. This doctoral study revealed that due to the socio-cultural environment and participants' internalised sense of duty to fulfil Xiao, attempting to divide time between providing care and other aspects of life typically left participants with impossible dilemmas. Such dilemmas often resulted in

participants persevering whilst enduring difficult or dangerous situations. An example of this came from participants who neglected their own health and continued a role as a family caregiver due to lack of suitable alternatives. Although caring for older relatives was still mostly seen as an obligation, findings showed that the socio-demographic transition in China is causing a shift in attitudes. For instance, traditional Xiao expects offspring to care for parents at home as parents affected by OCP in this study are doing for their own parents, but the only-children in this study agreed they might reluctantly co-opt the use of nursing homes whilst hoping that long-term care services would improve in terms of quality and cost.

Also, with rapid socio-demographic transitions, findings from this doctoral study show that there is an excessive demand placed on caregivers who are employees, perhaps due to the highly competitive job market in China. Notably, the move from rural areas to cities has not downplayed men's interpretation of familial responsibility, suggesting that traditional familial gender norms play a key role in caregivers' identities, enabling rural men to move to urban areas as migrants, leaving women behind in the rural areas, to care and work (Lin 2014). This internal migration was shown to lead to strains caused by caring from a distance as being at a geographical distance precluded fulfilling Xiao according to tradition. The societal transitions in China are aggravating the demands of Xiao, making it more difficult to fulfill filial expectations. Notably, the interplay between the perception of demands associated with caregiving and strong motivations to reciprocate care provided by their parents in early life, especially as only-children, appeared to indicate anticipatory and distinct stressors that could further develop into chronic stressors over time.

Amongst papers reviewed in *Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China.*, it is interesting to note that researchers are recently beginning to explore coping responses of caregivers in China explicitly. The two papers that explored coping, Xiuxiang et al. (2020) and Tang (2020), found that being filial is a coping strategy. However, this doctoral study's findings show that Xiao could also be a stressor. With changes to cultural expectations and attitudes against the backdrop of the socio-economic changes in China, findings from this doctoral study revealed that participants used both problem and emotion focused coping responses to deal with stressors, including societal pressure. For instance, caregivers described some active steps they would take in a difficult position, such as leaving their jobs, employing paid carers with cameras in-situ to monitor paid carers. They also described emotion-focused strategies, such as drawing on family and social support, positive reframing of negative experiences or adopting avoidant coping strategies.

Nevertheless, despite the tangible support some family caregivers in this doctoral study received from paid carers, it still did not offer them respite. Therefore, with evolving cultural interpretations and adaptations, the mere anticipation of providing care could also become a source of stress for offspring in position to take on future caregiving responsibility. The acute issue is that only-children will need to work and would have to find paid support because their responsibility to undertake caregiving could come with demands so great that other responsibilities are significantly hindered. In support of this doctoral study's findings, Tang (2020) suggested that intensive demands leave individuals overwhelmed, causing them to fall behind with other responsibilities and possibly

threatening their sense of self, despite the meaning they associated with their caregiving role. Evidently, despite the overlap between meaning and motivation, poignant tensions could result in inter-generational conflict as some participants might decline caregiving responsibilities to make life manageable. Considering the increasing ageing population in China and the evolution of Xiao culture, offspring could accept or reject caregiving as part of their life trajectory if society becomes more individualistic. Most participants intended to follow tradition by prioritising older relatives' needs, however, a few spoke of prioritising their nuclear family, with this seemingly influenced by witnessing others doing so. As such, Morais et al. (2019: 468) suggested that “mental representation of caregiving and attachment are important dimensions to consider when adult children feel unprepared and worried about needing to care for their ageing parents”.

8.4.5 Cultural or structural barriers - sustaining family caregiving

Findings from this doctoral study suggest that a cultural barrier to sustaining family caregiving, contributing to the underdevelopment of formal services for older people in China, is the cultural underpinning of 'Ren(忍)' (endurance of hardship). Ren steers family caregivers away from being open about their experiences as they share the belief that it is good to persevere during hard times (Lam et al. 2015). Hence, caregivers remain modest or lack clarity about their needs as evidenced in Chapter 2. The approach of “*Ziran- being natural or spontaneous as opposed to being constraint*” is a contemporary notion about ageing in China where older people embrace the idea of ageing well and being independent by refusing to be financially dependent on offspring (Qi 2021: 591). Therefore, despite noble intention, another cultural barrier emerging from findings

in this doctoral study, is that current caregivers do not want to be “too much” of a burden offspring. Considering this, findings show that some caregivers concealed their emotions and caregiving challenges from offspring. Hence, it has been suggested that younger generations are not put under caregiving pressure and are less resilient than Chinese society expects presently (Shea 2020). With changes to communities and cultural values in China as suggested by this doctoral study, caregivers’ unmet needs could potentially result in or exacerbate existing existential crises, resulting in isolation and loneliness of both caregivers and older relatives.

Although Lu et al. (2021) asserted that rapid evolution of Xiao is leading to an increasing number of older people desisting from burdening their children, findings from this doctoral study show that the cultural environment still dictates that offspring should prioritise older relatives’ needs. With family at the heart of care provision, traditional values of Xiao are expected to drive caregiving processes (Laidlaw et al. 2010). Thus, study participants emphasised the importance of family harmony and belongingness within a collectivist society. Social support received from family members, and not friends, serves as a protective characteristic against depression (Yang and Wen 2021), so older people in receipt of Xiao are not going to be depressed (Wu et al. 2018). Considering this, informal care will likely continue to take precedence over formal care (Wang et al. 2021).

In a cross-sectional study with Chinese adult immigrants in Chicago who were primary caregivers of older relatives, a stronger sense of filial obligation was significantly linked with reduced levels of developmental, emotional, social and physical burden (Guo et al. 2019). However, regardless of filial obligation, when

expected levels of filial piety were not enacted, this was found to be a significant risk factor for suicidal ideation in older people (Simon et al. 2014) and depressive symptoms in offspring caregivers (Guo et al. 2015). Therefore, in the context of a collectivist society, the societal expectation that the younger generation will address the needs of the older generation can be a 'double edged sword for their mental health' (Guo et al. 2018: 1448). This obligation can make it very hard for offspring to turn to formal services for support. Similarly, the traditional system of family caregiving heavily relying on women and retired or unemployed relatives (social roles), makes it exceptionally noteworthy that understanding cultural and structural barriers to accessing support is critical to understanding the nature and degree of unmet needs.

Considering formal support as a stressor rather than solely a relieving factor is also important to ascertain the sustainability of caregiving process. One major structural barrier for the study participants in seeking external support was concerns about poor quality formal care (Wang et al. 2018; Shen et al. 2019b). The exploration of factors challenging the traditional ethos of Xiao revealed deep seated distrust of formal services. Findings from this doctoral study showed that inadequate formal support was a significant stressor for family caregivers. The lack of adequate long-term services was stressful for family caregivers and even more complicated when cultural influences posit the importance of family care over formal care, as echoed by Miranda-Castillo et al. (2010). Therefore, factors such as low levels of service support, poor service organisation, caregivers' lack of awareness around their own needs and having to deal with guilt at times when they are unable to manage care demands (Oliveira et al. 2019), result in the personal health needs of caregivers remaining largely unmet (Queluz et al. 2020).

Older people may not be keen to go into nursing homes (Ma et al. 2019) and this doctoral study findings equally showed that parents affected by OCP are equally ambivalent about the option of nursing homes when they get older themselves.

Although Luo et al. (2018) suggested that nursing homes are a reasonable option, many participants in this doctoral study expressed reluctance to use them. In the absence of adequate formal services in China, despite the series of governmental policies (Fang et al. 2020; Ye et al. 2021), caregivers are often left to provide financial, social, emotional and physical support for care recipients and themselves with limited support received for themselves (Lambert et al. 2017). Formal service providers need to respond to increasing pressures on younger generations due to the difficult challenges that those who would strive to balance work and care will face, and the high level of expectations that younger generations put on themselves, based on their perception of parents' commitments to supporting their own grandparents.

Another structural barrier to use of formal services is connected to relatives' limited awareness of the need to seek formal help (Zhang et al. 2021), hence unmet needs of caregivers of older people in the Chinese community setting continue to increase. Family caregivers' self-awareness or opportunity to reflect enough to seek for service improvement is impeded when they have little personal time. Therefore, it is inevitable that they would be hindered by structural barriers characterised by disjointed inequitable services and deficits in old-age care training (Yang et al. 2021a). Most participants expressed preference for domiciliary care during interviews, however, acceptable community services were not available and negative first impressions turned some participants and families

away from seeking formal support again. The findings from this doctoral study highlight the need for high quality culturally attuned services.

8.4.6 Need for culturally attuned formal services

In this doctoral study, when attempting to access necessary information or support to look after their loved ones, participants experienced significant difficulties that ultimately led to quitting employment, for instance. For one participant, lack of options and resources meant completely sacrificing educational needs and the possibility of one day having a family. Conversely, those who had some support in the form of a maid or paid carer attributed this resource to luck, expressing feelings of privilege and gratitude. In the end, most family caregivers delivered care as they deemed fit. It is evident that health inequalities regarding aged care can be the result of approaches that fail at accounting for significant aspects of the beliefs, identity and values of family caregivers and their older relatives, which directly influences their preference for domiciliary care. Furthermore, findings in this doctoral study showed that stressors in the Chinese context are changing because of societal changes. Hence there is emerging evidence about stressors associated with domiciliary care (Lin 2019), caregivers being isolated from social networks (Zhang et al. 2019b), nursing homes' long waiting lists (Tang 2020) and lack of support from primary healthcare workers (Wang et al. 2018).

The far-reaching impact of being filial, combined with the lack of culturally attuned services that addresses parents as an extremely important aspect of caregivers' lives, could result in iatrogenic harm caused by formal services (Beale 2021). The notion of being filial could continue to limit family caregivers from accessing the right treatment. In support, it appears that the Chinese government's response to

the evidence presented by researchers about “caregiving burden” of family caregivers is to build nursing homes in the hope that it relieves them of stress. However, despite the governmental effort to increase nursing home places, about 45% of existing beds are unused (Fang et al. 2020). Findings from this doctoral study show that nursing homes are considered unethical. Therefore, placing an older relative in a nursing home can be seen as unfilial (Tang 2020) and is understandable given the concerns raised by participants in this doctoral study about standards of care. Considering that community-based services are still scarce compared to the number of nursing homes (Knapp et al. 2021), the impression given is that family care may become less of an option in future (Lin 2019). However, this is contrary to findings from this doctoral study, which suggest that formal services need to give caregivers opportunities to do what is best by their parents, making community services such as day-care centres more viable options (Tang 2020).

Concerns about the use of formal services expressed by participants in this doctoral study resonate with research around minority ethnic communities in the UK. Findings from Shafiq and colleague’s study could explain why African Caribbean and Irish ethnic populations in the UK are hesitant to seek help from formal services for their health conditions (Shafiq et al. 2021). Similarly, a systematic review examining the perceptions and experiences of people living with dementia and family caregivers from Black African, and Caribbean populations in USA, UK, and Netherlands, indicated inadequate formal care provision. In the study, staff members were perceived to be defensive and unprofessional, leaving relatives with no other option but to cater to the needs of older relatives themselves (Roche et al. 2020). The absence of robust integrated

health and social care systems means that these caregivers must fend for themselves out of necessity (Mayston et al. 2017). In the multi-cultural society of the UK, there are some expectations that people who have a good understanding regarding the complexities of cultural needs within various communities should lead services; typically an individual(s) belonging to the community in view (Parveen et al. 2017). However, in the Chinese context, where formal services need to be improved for the whole population, emphasis should be placed on appointing individuals with leadership attributes needed to manage complexities associated with understanding the subjective and relative nature of caregivers' beliefs to provide interventions that can benefit the majority. This would create an avenue for genuine psychological safety, where there is interpersonal trust and mutual respect between health and social care stakeholders (West 2021).

Younger generations of Chinese caregivers might have a hybrid of self-construal that needs urgent attention as the clashes between the values of independent and interdependent self-construal could compound matters for them. This notion is also evident in minority ethnic research in the UK where there has been some attention to changing values across generations due to assimilation of ideas from the majority individualistic culture (Miyawaki 2015; Giebel et al. 2019). Additionally, a systematic review that explored barriers to access and satisfaction amongst minority ethnic caregivers (Greenwood et al. 2015) showed that minority ethnic caregivers often refused external input or undervalued formal services. Such an attitude was also found in this doctoral study. However, considering the commitment to dignifying parents at all costs (Greenwood et al. 2015) and knowing that domiciliary care workers in the UK (external support) are not necessarily afforded time to reflect on their practices (Kelleher et al. 2022), care

staff still have limited knowledge around provision of culturally attuned care (Manthorpe et al. 2012). This may reinforce minority ethnic communities' beliefs that the system cannot care for their loved ones (McKenzie et al. 2017). Health inequalities in multi-cultural societies can manifest as minority ethnic communities being offered primary care services, whilst majority communities are offered specialist health or social care services for the same condition (Dodd et al. 2022).

The consequences of inadequate understanding of the complexities surrounding intricacies of caregiving were well articulated by a study participant. Their quote truly reflected what participants understood as fulfilling Xiao traditionally, for those with caregiving responsibility to have “four hearts” each: to love, exercise patience, love diligently with care, and the resilience to never stop providing care. However, it can be argued that the significant deficits in the numbers of global healthcare workforce needed to support people with long-term health conditions (Liu et al. 2017a) puts family caregivers at great risk, especially in China, despite (or because of) their commitment to the “four hearts”. Therefore, understanding and accepting individual interpretation of Xiao begins to address issues relating to efficiency and equity of long-term care provision in China (Yang et al. 2021a).

8.4.7 Preparedness: Barriers and Facilitators

A cross-sectional study relating to the unmet needs of older people living with long-term health conditions in the Eastern part of China, showed that meeting activities of daily living is a challenge, especially with older people living in high-rise buildings and family caregivers having little to no care training (Chen et al. 2018). Additionally, Zhang et al. (2019a) suggested that family caregivers feel isolated and disconnected from their communities as a result of younger

generations moving to other cities for schooling or employment and becoming estranged from the sense of 'home'. This suggests that current caregivers are providing care in solitary situations, and as such, findings from this doctoral study show that current and potential caregivers minimise rather than acknowledge their needs.

This is a barrier to preparedness for the role as personal and role strains could limit family caregivers from deriving meaning from their role, yet these issues are not openly discussed. Some study participants' examples demonstrated how family caregivers could perceive themselves as being patronising towards older relatives to whom they wanted to show respect and dignity, to make them compliant with care. Possibly this is due to lack of training about other strategies that could be used. Participants' lack of training in understanding and managing health conditions often led to them questioning the purpose of their difficult circumstances, their sense of self and the loss of the person they used to know. Given the context of Xiao and having to be in such an uncomfortable position, findings show that preparedness could be an afterthought and not given necessary attention, as it is seen as 'natural' to provide care.

In addition, there is growing evidence to show that personality traits such as extroversion, agreeableness, conscientiousness, and neuroticism have implications for caregiving processes, especially with regard to how carers adjust to and manage care burden (Kim et al. 2017; Baharudin et al. 2019). Personal variables, such as personality traits and coping styles, play a critical role in mediating psychological distress (Zhang et al. 2022). For instance, caregivers of people living with dementia with conscientious personality traits are in a better position to navigate extensive demands associated with care responsibilities

(Baharudin et al. 2019). In support, Zhang et al. (2022: 238) asserted that those who are “less extraverted, agreeable, or conscientious were more neurotic, employed dysfunctional coping strategies, and experienced guilt emotions, reported more psychological distress and reduced sleep quality”.

Given the narratives of participants in the current study, societal expectations and principles of Xiao, and existing evidence around personality traits and coping, available evidence strongly suggests that cultural values play a crucial role in caregivers’ appraisal of role. More specifically, the complexity of the nature of cultural values and their inter-relationship with the multiple factors highlighted above, make it pertinent that individual appraisal of role is deeply explored. For instance, within the context of this current study, meeting ideal expectations of society could lead to the assumption that this individual is being highly conscientious. However, their reality might be a completely different experience. As such, education, and training, addressing knowledge gaps for family caregivers of older relatives regarding cultural values (role expectations) and education concerning the provision of good quality care (covering adaptive coping, self-care strategies and long-term health conditions of older relatives) must be addressed with clear key aims and objectives.

Participants in this doctoral study emphasised the relevance of interconnectedness of family to support one another. Juxtaposing this finding with caring for people living with dementia in Singapore (Koo et al. 2021), the impact of OCP in China, as it pertains to this doctoral study, may subject caregivers to various stressors, given only children will have much smaller family networks to call upon. With limited coping mechanisms including less social support, this predisposes caregivers to feeling culturally obligated to provide care, despite

being unable and unprepared (Parveen et al. 2019). Such context for caregivers, could therefore create a disabling environment for older relatives in the community as growing evidence shows the benefits of ageing in place and benefits associated with evolving space and relationships (Clark et al. 2020; Ward et al. 2021; Keady et al. 2022). This could serve as a deterrent to deriving meaning from caregiving activities or limiting what stakeholders need to know with regards to serving older people, especially those living with dementia better (Harding et al. 2019; Reilly et al. 2020).

Current caregivers have been found to experience more psychological stress, as opposed to physiological or financial stressors (Shen et al. 2019b). Confucian beliefs in China encourage future caregivers to be stoical by containing their emotions and reframing inner thoughts and desires (Cheng, Lo and Chio 2010, as cited in Au et al. 2013). Further, the financial circumstance of families, time expended on providing care, and incongruence between care demands and individual capabilities are sources of stress for family caregivers (Bífarin et al. 2021). Yet, caregivers have limited access to professional support in the community, for reasons ranging from safety concerns around home visits to services limited by time pressures on care professionals (Xu et al. 2021). Findings from this doctoral study corroborate these points but find that physiological and financial stressors would equally be of great concern. This doctoral study's findings showed that caregivers would go to the extent of leaving their jobs to repay parents for past help but demonstrate no knowledge of interventions to lessen the impact of providing care without a source of income. In response to societal changes, parents of an only-child would more likely need financial support compared to parents with more than one child (Zhang et al. 2019). Thus,

future caregivers would be exposed to significant psychological, physiological, and financial stress, and attention needs to be given to all three aspects to aid caregivers' preparedness.

Caregivers have to engage with a series of changes and care transitions over time (Moral-Fernández et al. 2018), yet, as found in this doctoral study, in China, Xiao may prevent caregivers from using formal services as support needs for older relatives increase (Qiu et al. 2017), as a result of the services not matching expectations they have for their parents. Hence, as findings show, the demands that constitute "care responsibility" and the resultant stressors proliferate within the socio-cultural environment, impacting individuals in the wider family or societal networks who are not primary caregivers (Pearlin et al. 1997). To prevent this, it is of utmost importance that intricacies relating to the initial phase of being family caregivers, such as: shock, linked with care recipients' long-term health conditions; the need to adapt to caregiving demands; dealing with confusion, anxiety, acceptance and resistance of caregiving context, are taken seriously (Moral-Fernández et al. 2018). Even though Lu et al. (2021) suggested that a combination of mixed care and state-based care (home and long-term settings) is reasonable for the future, participants in this doctoral study are very likely to provide hands-on care irrespective of parents' encouragement of independence. Therefore, they may need to take steps to prepare in advance in order to make community care more feasible. Hence, a key message from findings in this thesis is that offspring cannot reciprocate the level of support that parents of only-children are able to give their grandparents, suggesting that caregiving preparedness must shift from endurance into building resilience. It is equally important to stress the need for adequate resources from the state for community-

based support in order to circumvent mortality risk (Li and Dong 2019) or depression (Wu et al. 2018; Yang and Wen 2021). As such, paid carers, nurses and doctors having adequate bio-psychosocial knowledge about practical preferences of older relatives might help in preparing caregivers for the future long haul of caring.

Zhou (2019) suggested that the Chinese government has a significant role to play in the development of interventions aimed at promoting contemporary ageing services, which would be a facilitator for caregivers' preparedness. In the context of service design, it is crucial to reflect physical and mental health needs in training content for healthcare professionals to drive forward relationship-centred care, ultimately enhancing discourse around value-based resource allocation (Fang et al. 2020). Sensitive interventions that are informed directly by caregivers would have a positive impact as most participants wanted to see 'homely' nursing home environments providing flexible visiting times, nurses coordinating care, encouraging home or community visits for older relatives away from nursing homes, special statutory holidays for only-children to care for parents and psychological support.

In a number of collectivist societies, religion has been found to influence care and to provide a coping strategy for caregivers of older relatives living with long-term health conditions. For instance, in Singapore an aspect of filial piety (Xiao) is the expectation placed on those who are still alive to reference ancestors, using prayer to create moments that aid social support (Koo et al. 2021). Similarly, in Indonesia, prayer intensified amongst family caregivers to manage caregiving demands with positive approaches to prayer found to enhance caregivers' satisfaction (Kristanti et al. 2018; Kristanti et al. 2019). Within the UK context, a

recent systematic review also found that religion played a prominent role for the African-Caribbean population to manage stigma linked with long-term mental health conditions (Shafiq et al. 2021). In this current study, however, participants did not explicitly mention religion during interviews, although it was possible that the principles of Buddhism-Taoism which are embedded in Chinese culture, influenced the values and actions of participants, especially as there was so much emphasis placed on “being a good person” and how “natural” it should be for offspring to take good care of parents. The overt discussion around religion and spiritual connection as a coping mechanism in the Singaporean context (Koo et al. 2021), could partly be a result of the diversity of the nation when compared to China as this may make religious presence more obvious. In China, Buddhism is considered to be the most influential religion and its philosophy deeply aligns with that of the political party over time (Xu and Campbell 2018). This may make religion itself a less overt topic of discourse and might perhaps explain why participants in this current study did not overtly refer to any religion.

Commonality between Koo’s findings (Koo et al. 2021) and those of the current study lie in the strongly held beliefs and practices regarding societal expectations around intergenerational support, focusing on offspring spending regular and meaningful time with older relatives and role modelling the principles of Xiao. The difference however is that providing care for older relatives in China was not negotiable, mainly because available formal services could not be trusted to provide adequate care. As such, most participants in the current study who had to care for older relatives, gained fortitude from it. However, given the implications of OCP in China on the numbers of offspring who are available to care, the acute issue is how offspring will be able to sustain these attributes. In this respect,

increasing the numbers of general practitioners (GPs) and improving training content would provide the necessary resources and instil confidence needed to address caregivers' unmet needs (Shao et al. 2018; Wang et al. 2020a).

Economic cost of dementia in low middle income countries like China has been attributed to indirect cost, with the biggest challenge being the resources that are consumed by the huge number of caregivers (Mattap et al. 2022). However, recognition by policymakers of the sheer number of demands placed on caregivers with limited coping mechanisms found in this doctoral study would be the right step in the right direction. Existing literature has found inverse relationships between the level of preparedness and burden and mental health problems (Scherbring 2002; Onu et al. 2021; da Rocha et al. 2022). Findings from this doctoral study suggest that the prominence of Xiao overshadows the attention given to preparedness, indicating that role normalisation may restrict caregivers' confidence to articulate what they do. Despite having policy such as the UK Care Act (2014) for instance, caregivers' needs continue to be underrepresented in health and social care policies (Jose-Luis Fernandez et al. 2020), suggesting that the social and interactive environment through which caregivers' identity may emerge is still limited (Arksey 2002). This is even more so in the Chinese context where the role is expected and mandated. As such, it might be a case of preparedness improving over time but in the absence of culturally attuned formal services, caregivers might have no other option but to engage in arbitrary, self-taught interventions, which could have adverse implication for their mental health. For caregivers' needs to be consistently and holistically met, service providers' assessments must acknowledge Xiao's influence on family caregivers' choices and prioritise their concerns. GPs and

other health and social care practitioners could also play a pivotal role in creating an enabling environment for family members to care, which would reinforce autonomy, competence, and kinship (Deci and Ryan 2000).

8.5 Reflexive Juncture: Situating myself in relation to data

Growing up in Nigeria, I had a limited understanding of the influence of culture at the time I was caring for my grandmother. I believe that this and my clinical experience as a mental health nurse led to the pragmatic intention I had going into this study. However, the r-TA approach I adopted for the study had an experiential focus that signified the importance of uncovering how cultural influences shape the process of caregiving and how it applied to my participants. Due to my previous familial and professional experience, I had a complex relationship with my data. On one hand, most of my participants were very positive regarding their caregiving role, and on the other, their narratives reflected normalisation and minimisation of adversities. Hence, unsurprisingly, I lacked confidence initially about the “type of data” I was able to collect. It was extremely difficult for me to separate my emotional (feelings), reasonable (logical) and wise mind (wisdom).

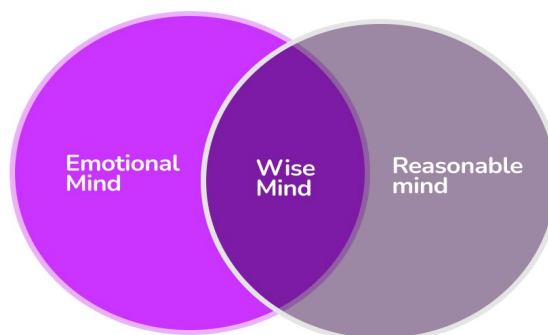


Figure 8.1: States of mind

Source: *States of mind (Walker 2015: 48)*

I soon discovered that the disconnection resulted from an impasse between my pragmatic expectation for the project and the experiential/existential focus of participants' narratives. A crucial part of the learning process, enabled by my supervisory sessions, was mastering the art of analysing, and interrogating the data using the appropriate *state of mind*. For instance, an example to illustrate the concept of minds is how supervisors brought my awareness to my critical position about family caregiving. I was critical of any oversimplification or portrayal of family caregiving as a low skilled role that is suited to anyone; as in my experience as a mental health nurse, this notion is so pervasive and ingrained that it is echoed within professional settings. Therefore, choosing to listen actively, I had to disengage and move beyond negative emotions to avoid negatively interpreting the data from participants' narratives. This played a key role in developing my confidence to articulate or justify adopting my wise mind instead of my reasonable or emotional mind.

8.6 Reflection through the conceptual caregiving lens

Culture has a dynamic influence on caregiving processes and findings from this doctoral study showed that family caregivers in China are subject to a significant level of demands and a high level of societal expectations, which influenced how their stressors and coping responses were appraised. Changing family structures, a rapid rise in the number of older relatives needing daily support (Lu et al. 2021) and the lack of adequate formal support services, alongside the resulting evolution of Xiao, mean the attitudes and motivations of caregivers will have to become more varied and flexible. Consequently, each set of unique caregiving circumstances determined whether caregivers appraised experiences negatively or positively.

In *Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China.*, I highlighted the literature gap and surmised how, due to consistent lack of adequate consideration, existing knowledge had not captured caregivers' needs relating to constructs like selfhood, sociality, embodiment, temporality and spatiality adequately (Ashworth 2006). This doctoral study highlighted the relevance of the key conceptual frameworks (section 1.7), the socio-cultural model of stress and coping (Knight and Sayegh 2010) (section 1.6), and addressed the knowledge gap (section 8.4 Competing pressures: motivation, meanings, and preparedness), substantiating the significance of the constructs highlighted above. Knight and Sayegh (2010) highlighted the importance of paying closer attention to the influence of cultural values on stressors and coping strategies. Supporting this, Burhanullah and Munro (2020) also argued that more attention needs to be paid to the impact of evolving family structures, for instance, as this would have an impact on meanings associated with cultural values, which would, in turn, affect caregivers and their role appraisal. As such, the current findings highlight that, for Chinese caregivers, perception of stressors is significantly influenced by expectations concerning Xiao, the reactions of others in the social context, and the cultural systems of support afforded to individuals (Aldwin 2007). Thus, cultural values have implications for individual coping responses (Knight and Sayegh 2010). Through pin-pointing intersections between Xiao, stressors and coping responses, this doctoral study found that distress could be a more predictive factor for ill-being than caregiving burden (Burhanullah and Munro 2020).

Although Lazarus and Folkman (1984)'s model guided stress and coping research for a long time, the focus has been on caregivers' objective appraisal with limited attention placed on intrapsychic strain, which is a subjective interpretation of appraisals of caregivers in their role. The two models that grounded this doctoral study, Aldwin (2007) and Knight and Sayegh (2010) went further and considered the implications of interdependent self-construal on caregiving process. According to these models, cultural beliefs operate as a function of social responses within and between individuals within their socio-cultural environment, which influences their coping responses. Indeed, the findings from this doctoral study supported the notion that cultural values like Xiao enabled people to benefit from resources available in their sociocultural environment, encouraging the pursuit of being a good person by fulfilling Xiao. Nevertheless, exploring the complexities revealed that the socio-cultural values resulted in tensions for some, between the pressure to fulfil Xiao and their competing but often unspoken wish to reduce caregiver burden or fulfil other aspects of their self. So, everyone can draw on the socio-cultural environment but only if they are in tune with it - they can call on it for motivation and for praise for their role but if they prioritise their own pursuits, they will not be supported by their socio-cultural environment as it does not value individual over collectivist fulfilment.

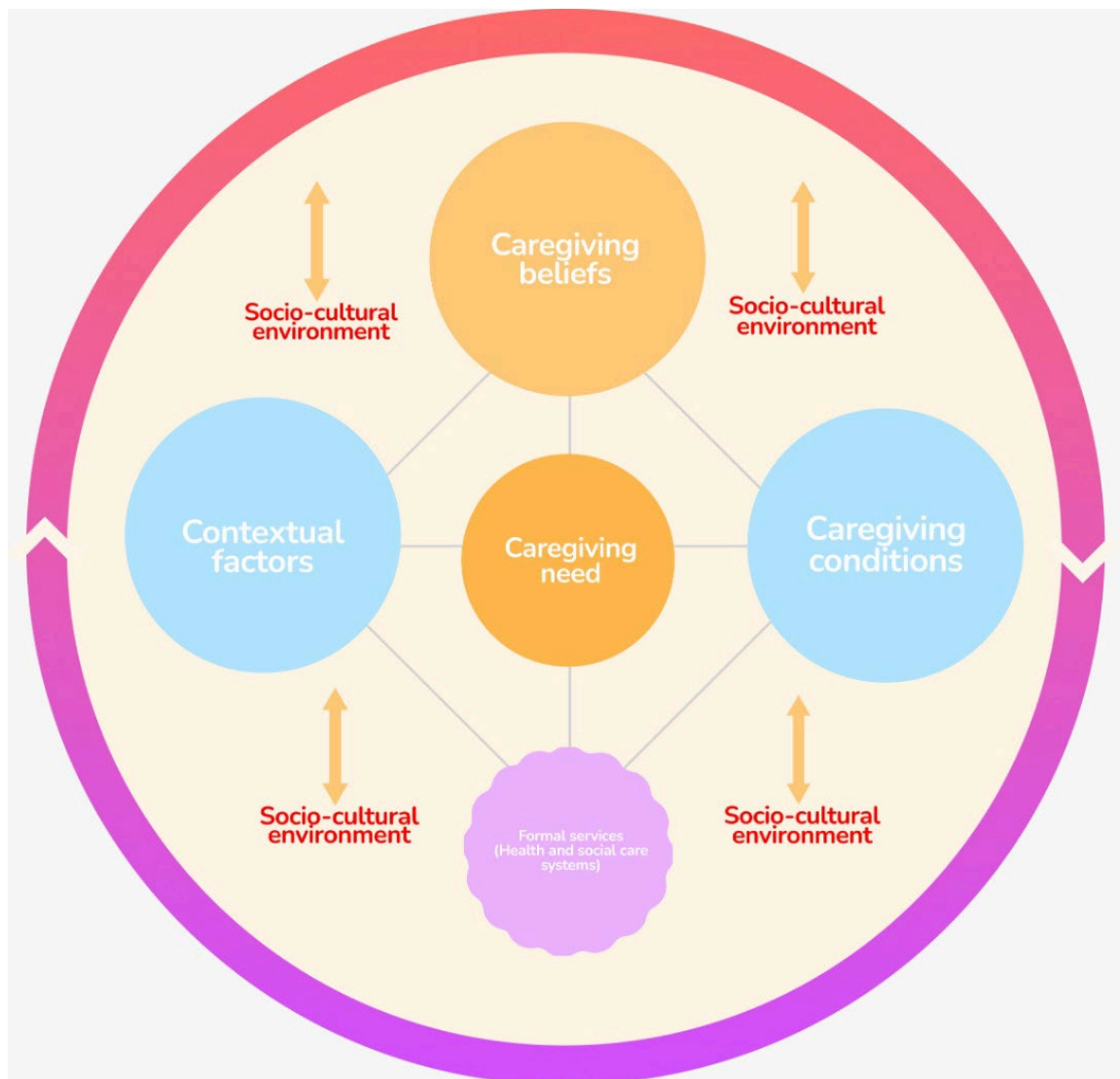


Figure 8.2: Socio-cultural model of understanding caregiving process

Within the context of findings in this doctoral study, figure presented above, shows that in China, in addition to caregivers' socio-cultural environment being a potential coping resource, it could also be a stressor. The expectation that family would provide the care perhaps explains why formal services in China are underdeveloped. When considering participants' sociocultural environment, their values determine the complexities of caregiving. These complexities included, but were not limited to, work-life balance, social pressure, being an only-child, and being a good person. There exists a conundrum of the parent sub-sample in this doctoral study needing to maintain the status-quo of teaching offspring the

important ideal of prioritising older relatives yet understanding that offspring affected by the OCP might not be able to realise this ideal. There is a societal assumption that caregivers naturally possess the technical abilities needed to balance the physical, organisational, emotional, and cognitive facets around caregiving, even though these are often in conflict with each other. This would perhaps explain why recent a qualitative systematic review and meta-synthesis found that researchers are not making a clear distinction between motivation and willingness to provide informal care (Zarzycki et al. 2022). Without consideration for the wider societal context on caregiving process, the continuing efforts of caregivers to balance competing pressures can be counterproductive for the development of adequate services. In the absence of adequate support, caregivers face immense pressures, especially when unprepared for the role. The caregiving models highlighted above articulated coping as an attempt to mitigate caregiving “burden”. Drawing on findings from this doctoral study, coping could be problem-focused, where caregivers adopt active planning strategies and the use of technology to bridge atypical gaps in communication, or where participants would co-opt or co-opted instrumental support from friends or family. Findings from this doctoral study showed that solitude is lacking within the socio-cultural environment and caregivers could feel alienated from what seems like their authentic self. They could abandon other aspects of their personal lives during the ‘caregiving process’ and over time, the degree of absorption in caregiving might make it hard to rediscover other aspects of self later. Hence, coping could also be emotion-focused, with participants engaging in self-blame, positive reframing or relying on social networks for emotional support. Within the wider context of existing sociocultural models of family caregiving, findings from

this doctoral study could inform service provision for Chinese indigenes, not only in mainland China but other countries, for instance, the United Kingdom (UK). People from minority ethnic groups are under-represented within formal services for older people in the UK and Baghirathan et al. (2018) suggested that there is a dearth of evidence regarding the needs of Chinese family caregivers in the UK. However, findings from this doctoral study, for example, that the traditional belief of Xiao can be a motivation to care but can also create pressure resulting in emotional and cognitive dissonance, may have relevance for Chinese populations in the UK. Knight and Sayegh (2010) asserted that cultural values may not necessarily influence the appraisal of burden and Aldwin (2007) hypothesised social support and coping serve as mediators that would impact individuals and their environments. However, conclusively, as illustrated in **Error! Reference source not found.**, the conceptual model developed through this doctoral study's findings, shows that cultural values (*caregiving beliefs*) have a direct influence on caregivers' perception and appraisal of burden, and when considering socio-demographic transitions in current Chinese society (*contextual factors*), social support will be drastically reduced or unavailable and the coping efforts described by participants (*caregiving conditions*) may not be effective in ameliorating caregiving distress (*caregivers need*).

8.7 Strengths and Limitations

A potential limitation of this doctoral study is linked with my outsider status as a non-Chinese researcher, as cultural nuances might have been missed. However, this was also a potential advantage as participants may have been more open in responding to questions. In addition, my Chinese collaborators were able to advise on cultural nuances as they understood Chinese society from the inside.

The similarities between my cultural context and that of the participants could have led to personal bias infiltrating data interpretation. However, I involved other researchers (my supervisors) in the analysis actively to raise awareness of my own assumptions to aid reflexivity. Relatively speaking, participants were mostly from middle or working class. As such, a class bias could have been reflected in the data. Also, given there were more female participants, having a more gender-balanced sample might have provided more insights, which I have not been able to capture within the existing data. Participants did not check the findings (member checking) and therefore did not contribute to the development of the final themes, which could have reduced potential bias from my interpretation. However, this issue was attended to by ensuring that B.Z and L.Y checked the plausibility of the research findings. Additionally, findings within the doctoral study should be adopted with caution as it is limited regarding generalisability.

As highlighted in *Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China.*, I addressed what previous quantitative studies had been unable to, through adopting an interpretative phenomenology, which has helped to identify a relationship between intergenerational solidarity through Xiao and being a current or future caregiver. Qualitative interpretive methodology proved advantageous to understand various aspects of intergenerational solidarity, namely, affectional, associational, consensual, functional, normative, and structural solidarities (Xu et al. 2021), which are necessary for the development of appropriate interventions. As such, future longitudinal and ethnographic studies could further explore the iterative and cyclical relationships between the culture of Xiao, willingness, and preparedness.

Due to limitations resulting from COVID-19, I had access to limited numbers of people. Hence, although it was not my intention at the outset, some parent-child dyads took part in this doctoral research and laid a foundation for dyadic analysis, which provided interesting contributions to understanding patterns of perception, congruence, or incongruence among family care dyads. Future research could focus on dyads for more nuanced understanding in qualitative research where relevant. I have shared findings from *Chapter 2: Scoping review of stressors and coping mechanisms of family caregivers of older relatives living with long-term health conditions in mainland China.* and *Chapter 3: Phase 1: Preliminary Study- Intersections between the Culture of Xiao (孝) and Caring for Older relatives in China: Perspectives of UK-based Chinese students on future care for their parents.* with Chinese communities in the UK via posters, oral presentations, publications, and critique from colleagues, and received positive feedback. I am also producing an animation video in collaboration with working academy at the university of Bradford, which will be shared widely.

8.8 Implications for policy, practice, research, and education.

The findings from this doctoral study indicate that if the lack of adequate health and social support persists, prospective caregivers, especially as very many will be only-children, will be overwhelmed by demands associated with caregiving. Irrespective of their work status, extensive caregiving demands could erode the positive aspects of care, leading to poor quality of care. This assertion is consistent with studies in China and the United States, where some older people have been subjected to abuse and maltreatment by their relatives (Fang et al. 2018; Fang et al. 2019; Gao et al. 2019; Chao et al. 2020). Therefore, the development of culturally attuned health and well-being promoting interventions

for carers with a clear focus on preparedness would be valuable. Bearing in mind constructs like intergenerational solidarity (Xu et al. 2021), future ageing policies in China should foster development of sensitive interventions to promote well-being of both offspring and parents. Ultimately, findings from this doctoral study reinforce the attributes of an intergenerational solidarity framework, including affectional and associational solidarities (i.e., willingness to provide care); consensual, functional, and normative solidarities (i.e., culturally attuned and available options), and finally, structural solidarity(i.e., practicalities of providing day-to-day care) (Silverstein et al. 2002; Xu et al. 2021).

Findings from this study have implications for service development in the UK. Considering how highly esteemed older relatives are to Chinese offspring, the bureaucratic nature of health and social care settings in the UK could dissuade them from using services. The common off-putting barriers include categorising the oversimplification of needs as a “language barrier”, the perception of systems and processes as rigid, and perhaps services being unwilling to embrace “unconventional” ideas, for instance, enabling Chinese relatives bringing their own food to relatives to share as a bonding experience. Therefore, future direction of policy and research in the UK needs to ensure that families of minority ethnic communities are supported in a sensitive and meaningful manner that respects the significance of cultural values on the process of caregiving. This direction would address the need for transformation towards better personalised social care (Alzheimer’s Society 2021). In this respect, family caregivers, health and social care practitioners, service commissioners and service managers in the UK need education and training around the implications of distinctive responses

to fulfilling Xiao, to aid the well-being of current or prospective caregivers and older relatives.

Future investment in ageing and caregiving in mainland China needs to reflect the overlap of independent and interdependent self-construal, especially with the Government pushing to enhance the standard of care services as part of their national ageing strategy (Mca.gov.cn. 2020). For instance, practitioners and service commissioners need to be sensitive to potential difficulties in integrating the dominant traditional understanding of Xiao, with the experience of being an only-child or balancing work with care. Addressing filial discrepancy would have positive implications for achieving the global ambition to promote an inclusive society and improve the quality of life of older people living with long-term conditions and their caregivers (G20 Summit Leaders 2019). Service commissioners, providers and professionals need to gain the confidence to support people to care well for those who are ageing by recognising cultural sensitivities that can improve uptake of services. Drawing on the Admiral Nursing model that is used in the UK as an example, a community case management model may be an effective way of supporting older people and caregivers in China (Bifarin et al. 2020).

Key legislation aims to facilitate the support of carers in the UK to ensure they have necessary information and advice. Legislation including the Care Act (2014) in England and Wales, and (Carers (Scotland) Act 2016) govern services that are intended to delay caregiver stress and prevent their own needs from escalating. Going forward, supportive carer legislation in China may help to ensure that Chinese society can sustain care. Ageing in place enables older people to maintain their sense of attachment and connection to their home and their

community, to strengthen and promote feelings of identity and security and to maintain autonomy, in the context of pre-existing social relationships (Wiles et al. 2012). To support fulfilment of Xiao and sustain ageing in place, attention needs to focus on development of innovative services that support, scaffold, and share caregiving. To be concordant with fulfilment of Xiao, Innovations in care systems and support in China could seek ways to effectively support 'ageing in place' (Wiles et al. 2012), rather than focusing on the provision of specialist residential or nursing home care.

One distinctive facet of family caregiving, as noted earlier, is that it takes place in the context of a pre-existing relationship (Conway et al. 2018). Relationship-centred care, which recognises the influence of the nature and quality of relationships in healthcare on health outcomes, has the potential to diffuse tension within relationships (Morhardt and Spira 2013) to allow living well and caring well for people with dementia. However, whilst keen to preserve their relationship with the person with dementia (Pini et al. 2017), caregivers have been found to struggle to balance their own personal needs with those of their relative (Quinn et al., 2015). As such, Oliveira et al. (2019) and Queluz et al. (2020) showed that caregivers of older relatives living with long-term health condition tended to feel continuous pressure. The current research highlights that caregiving is complex. The intricacies of the caregiving process cannot solely be captured by adopting measures relying on linearity. Recognising that stressors are culturally situated, and interwoven, future research studies need to investigate their impact on coping strategies further, using appropriate qualitative methodologies to enhance discourse around caregivers' coping efforts and responses in mainland China. This would help define the nature of adequate

support and is necessary to enable the development of competent support systems.

8.9 Recommendations

Drawing on findings from this doctoral study, I present key recommendations geared to promote high quality care within the health and social care sector.

How health and social care services, practitioners, policy makers and the government can support family caregivers in China:

- Altruistic reciprocity as a motivator is not enough to provide a high standard of holistic care for older relatives. Therefore, health and social care practitioners should receive adequate and relevant training to support caregivers. They should take the lead on training family caregivers to understand older relatives' diagnosis and work collaboratively with specialist services.
- Inputs of family caregivers and older relatives must be encouraged during the process of planning, implementing, and evaluating care to improve their experiences and ensure psychological safety when providing individualised and evidence-based intervention.
- To relieve family caregivers of the stress of balancing work and care identified in this study, robust respite services need to be available, including community care services such as day centres.
- Considering the societal expectation and meanings associated with caring for older relatives, employers should offer flexible working policies to family caregivers, such as authorised compassionate leave, without consequence for their working status or earnings.

- Specialist services must harness the power of technology in China as offspring, especially the younger generation, seek innovative ways of providing care for their parents.
- Policy makers must drive initiatives that allow older peoples' specialist services to work closely with the government and develop regulated platforms or agencies where caregivers can find trusted paid carers for older relatives in a timely manner whilst also ensuring that the cost of services offered to caregivers are capped or subsidised by the state.
- Provision of funding for research activities is needed for health and social care practitioners and academics for the purpose of supporting family caregivers caring for older relatives, to showcase benefits of collaborative practices.
- Policy to mandate both public and private organisations to pay health and social care workers fairly, to drive recruitment based on value and competence, which would create well monitored start-up companies with opportunities to match paid carers with family caregivers.
- Introduction of lone worker policies and procedures to safeguard paid carers and care recipients would be vital to reduce or mitigate demands placed on caregivers without compromising safety within the caregiving process.
- Promoting the involvement of family caregivers of older relatives living with long-term health conditions in the development of care services and development of training curricula for health and social care practitioners. Employing their expertise would promote culturally sensitive services and increase formal service uptake.

- There must be advocacy for the unmet needs of older relatives and caregivers to receive proportionate care needs assessment that recognises and accounts for the implication of self-construal on the process of caregiving and accommodates individual meanings associated with Xiao. Training of health and social care practitioners such as nurses must start to incorporate topics that would aid adequate and sensitive assessment, which would capture strengths and deficits of caregivers with the view of informing practitioners and service commissioners.
- Continuous professional development should be encouraged for health and social care practitioners with a specific focus on preparing family caregivers for the role with the view of mitigating stigma around long-term health conditions such as dementia and promoting adaptive coping strategies. This would contribute to the development of culturally attuned services that focus on preparedness to build resilience, and not merely to endure hardship.
- Higher education institutions should collaborate with expertise in high income countries in supporting families in the context of ageing well, with a focus on developing a relevant curriculum in social gerontology, to train health and social care practitioners to masters' level. This would enable development of formal services that put individual needs into consideration.

8.10 Conclusion

In summary, I found that the normative values of Xiao permeated the mental representation of cultural beliefs and were held strongly by participants, resulting

in the positive appraisal of family caregiving despite its many challenges. Participants were fully devoted to looking after older relatives and demonstrated compassion towards the reality of ageing. They aimed to preserve the dignity and autonomy of older relatives and were convinced of this as the right or natural thing to do. However, their determination to make necessary sacrifices to fulfil their role expectations resulted in them neglecting their interests and health. This is because most of the participants had inadequate support in their roles despite reciprocity being a shared virtue within Chinese society. Caregiving could have adverse implications for caregivers' self-identity and role identity due to the clash of values between collectivism and individualism in modern China. This study found that future caregivers' decisions could be detrimental for parents and/or themselves whether they decide to co-opt the input of formal services when meeting parents' needs or not. This dilemma makes finding equitable solutions crucial. The findings in this doctoral study help to contextualise how the discrepancy between filial expectations (ideal) and filial performance (actual) might manifest in family caregivers, especially when motivation and meanings associated with Xiao are constrained by finite personal resources and lack of available high-quality formal services. Thus, policymakers, health, and social practitioners need to take the socio-cultural environment into account to sustain both family and cultural values. Aside from cultural competency, the impact of the OCP on current and future caregivers, including how other socio-demographic issues interact with balancing work and care, makes it crucial to address the challenges associated with socio-demographic status, education level, age, occupational risks and access to formal support. Finally, concerning health and social care service design and delivery, resolving issues of availability,

accessibility, and affordability of care services would improve family caregivers' confidence and preparedness to directly support or access the right support for older relatives living with long-term health conditions. Therefore, this doctoral study can inform future work on research and practice by focusing more on an individuals' self-construal. Thus, highlighting the significance of cultural influences on caregiving process for family caregivers of older relatives as it pertains to China's collectivist society.

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Appendices

Appendix A: Scopus search team combination

SPIDER	SPIDER TOOL	SEARCH TERM COMBINATIONS
Sample	S	<p><i>("China" OR "Chinese") AND elderly OR Senior* OR "Old" OR "Older" OR "Geriatric*" OR "aged" OR "dementia" OR "Alzheimer*" OR "long term condition*" OR "Cognitive impairment" OR "Chronic condition*" OR "chronic illness" OR "comorbidity" OR "multicomorbidity" OR "co-morbidity" OR "multi-comorbidity" OR "non communicable disease*" OR "disable*" OR "disability" OR "Parent*" AND "Child of disabled parent*" OR "Child of impaired parent*" OR "Carer*" OR "Caregiv*" OR "family" OR "relative*" OR "Adult Child*" AND communit* OR home W/4 care* OR domestic</i></p>
Phenomenon of Interest	P of I	<p><i>Caregiving OR "burden" OR "distress" OR "Stress" OR "Strain" OR "satisfaction*" OR "experience*" OR "gratification*" OR "support" OR coping OR "positive" OR "negative" OR "cognitive coping" OR emotion focused coping OR Coping W/4 (strategy* OR mechanism* OR style* OR method* OR technique* OR Psychosocial OR maladaptive OR emotional OR adaptive OR religious OR Spiritual OR "problem focus" OR adequate OR restraint) OR manag* OR strategy* OR self manag* OR religio* OR Activit* OR exercise*</i></p>

		<p>OR prayer OR beliefs OR resilience OR mindfulness OR humour OR humor OR planning 409strategy* OR planning OR cop* OR “social support” OR helpless* OR blame OR denial OR accept* OR disengage* OR “substance misuse” OR “Substance abuse” OR reappraisal OR avoid* OR “motivation” OR “impact” OR “ well being” OR well- being OR wellbeing OR “Quality of Life”</p>
Design	D	<p>“questionnaire*” OR “survey*” OR “interview*” OR “focus group*” OR “case study*” OR “obsev*”</p>
Evaluation	E	<p>“view*” OR “experience*” OR “opinion*” OR “attitude*” OR “perce*” OR “belie*” OR “feel*” OR “know*” OR “understand*”</p>
Research Type	R	<p>“qualitative” OR “quantitative” OR “mixed methods”</p>

Appendix B: Ethics Application approval for phase 1 (Preliminary study)



Ethics

10 October 2019 at 16:26

Approved: Ethics Application E763

To: Oladayo Bifarin, Cc: Jan Oyebode, Catherine Quinn, Liz Breen

[Details](#)

 Siri found new contact info Ethics ethics@bradford.ac.uk

[add...](#) 

Dear Oladayo and Jan,

Ethics Application: E763

Title: Supporting Carers in the Chinese workforce

Your ethics submission and documents have now been reviewed by the independent reviewers of the Research Ethics Panel.

I am pleased to inform you that they have confirmed approval of this study, with no further ethical scrutiny required. Please see comments forms attached which indicate some recommendations you may wish to consider.

NOTE that this approval is for this study only.

Should there be any changes to this study, you must inform ethics@bradford.ac.uk.

Once your changes have been reviewed and you have approval to proceed, only then can you recommence the study.

Failure to do so will render your original approval invalid and withdrawn.

Please add a sentence onto any material you share with participants confirming that ethics approval has been granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 10/10/19.

Thank you
Best Wishes
Deborah

Deborah Hodgson

Grant Applications Coordinator

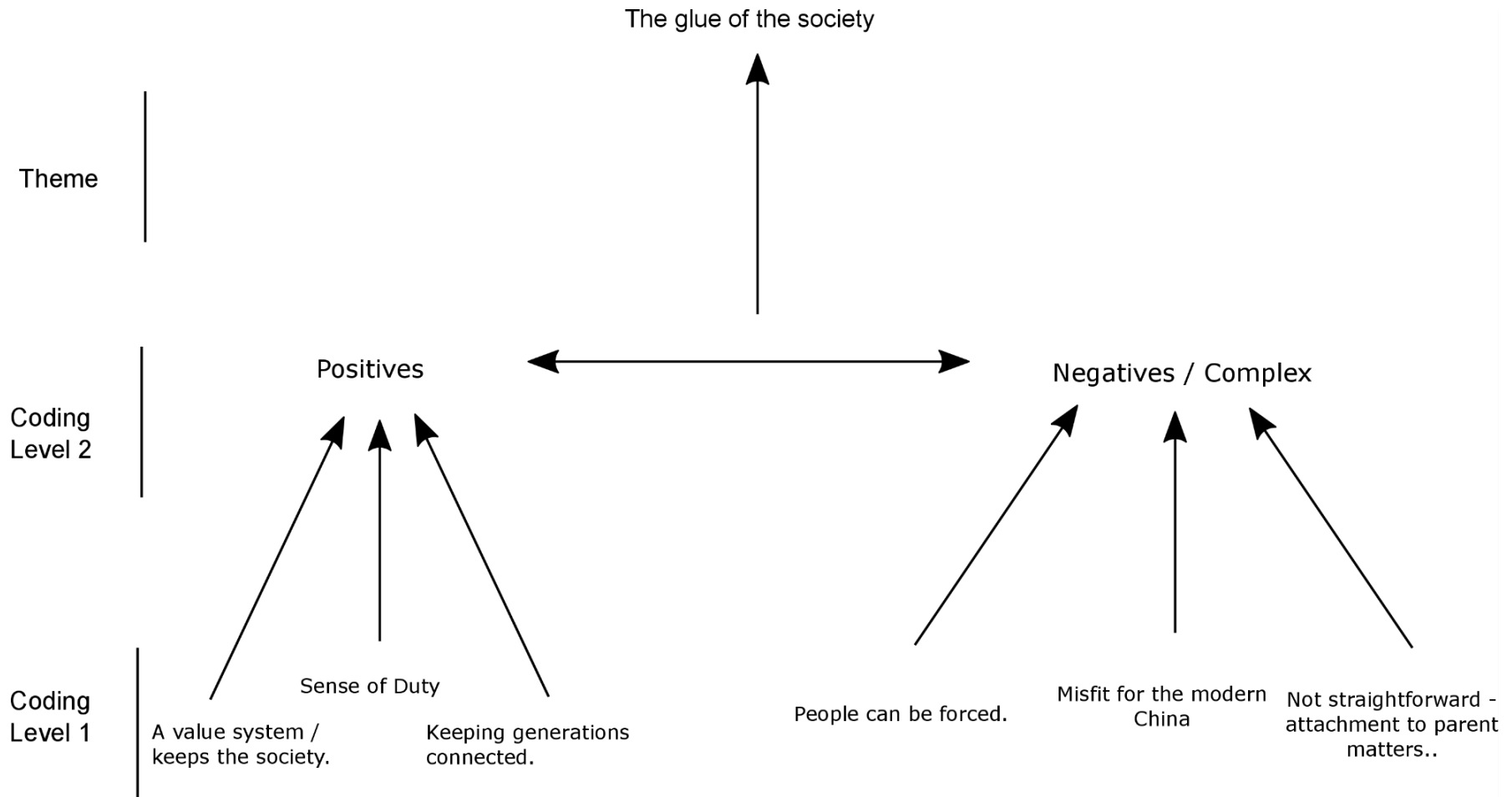
Research and Innovation Services (RaIS), F.24

01274 233196

Appendix C: A sample of the analytic procedure showing connections from data segments to codes, sub-themes, and theme.

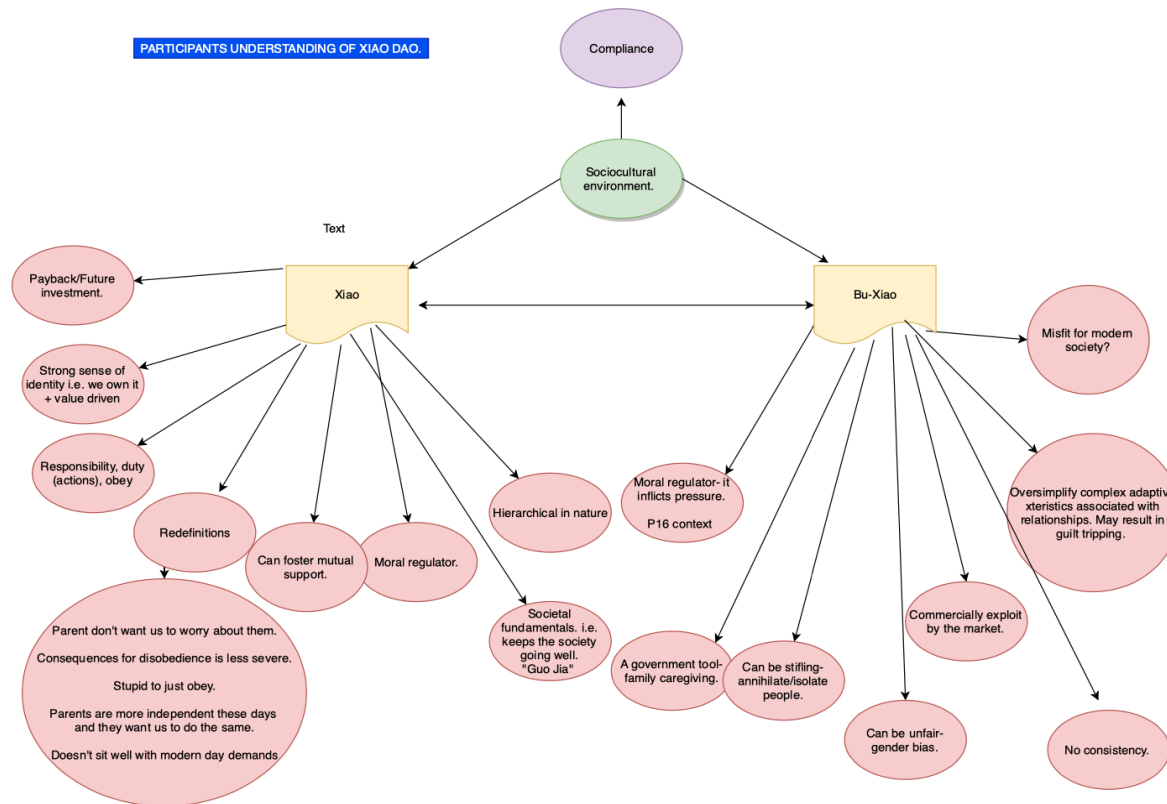
Data extract	Coded for	Subthemes	Themes
<p><i>I think Xiao nowadays helps those people who are not Xiao to force them to treat their parents better. P08</i></p> <p><i>We do feel pressure when the moral aspect comes to us but for the country's development, it plays a more positive role. Letting the country to stay united, not to have too many abuse- because it regulates people's morals tightly, but in another word, it helps the country (Guo Jia) to stay stable. P19</i></p> <p><i>Potentially, if we have Xiao, the next generation, like my son can treat me better, comparing to the western countries without Xiao in the Society. P09</i></p>	<p>Xiao- can mandate better treatment for parents</p> <p>Xiao- fosters togetherness in the country as it regulates people's behaviours</p> <p>Xiao can promote better treatment for parents.</p>	<p>People can be forced.</p> <p>Negative- Leaving people with no other choice</p> <p>A value system/ Keeps the society.</p> <p>Positive- It fosters togetherness in the country</p> <p>Keeping generations connected.</p> <p>Positive- differentiates us from others</p>	<p>The glue of the society</p>

Appendix C: Continuation



Snapshot showing how a selection of codes were turned into a theme.

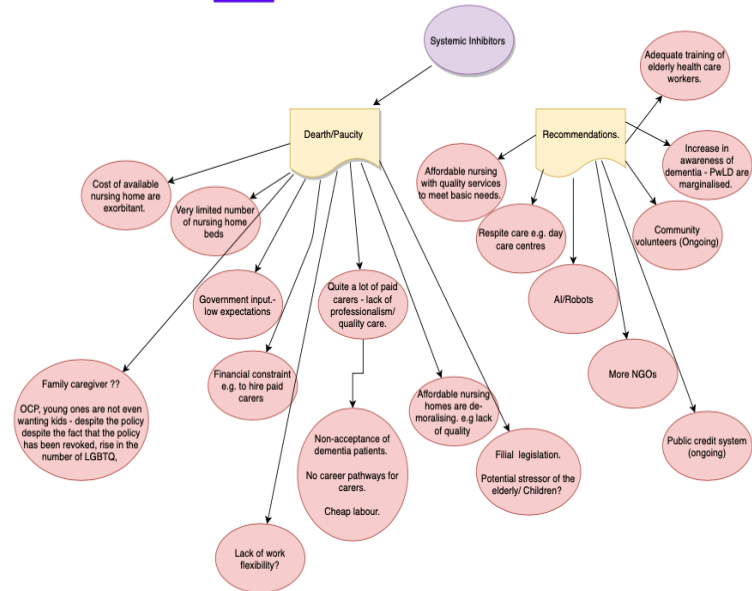
Appendix D: Process of identifying sub-themes and themes (Phase 1: Preliminary Study)



OLDER PEOPLE CAREGIVING ROLE AND RESPONSIBILITIES- ATTITUDE AND PREPAREDNESS.

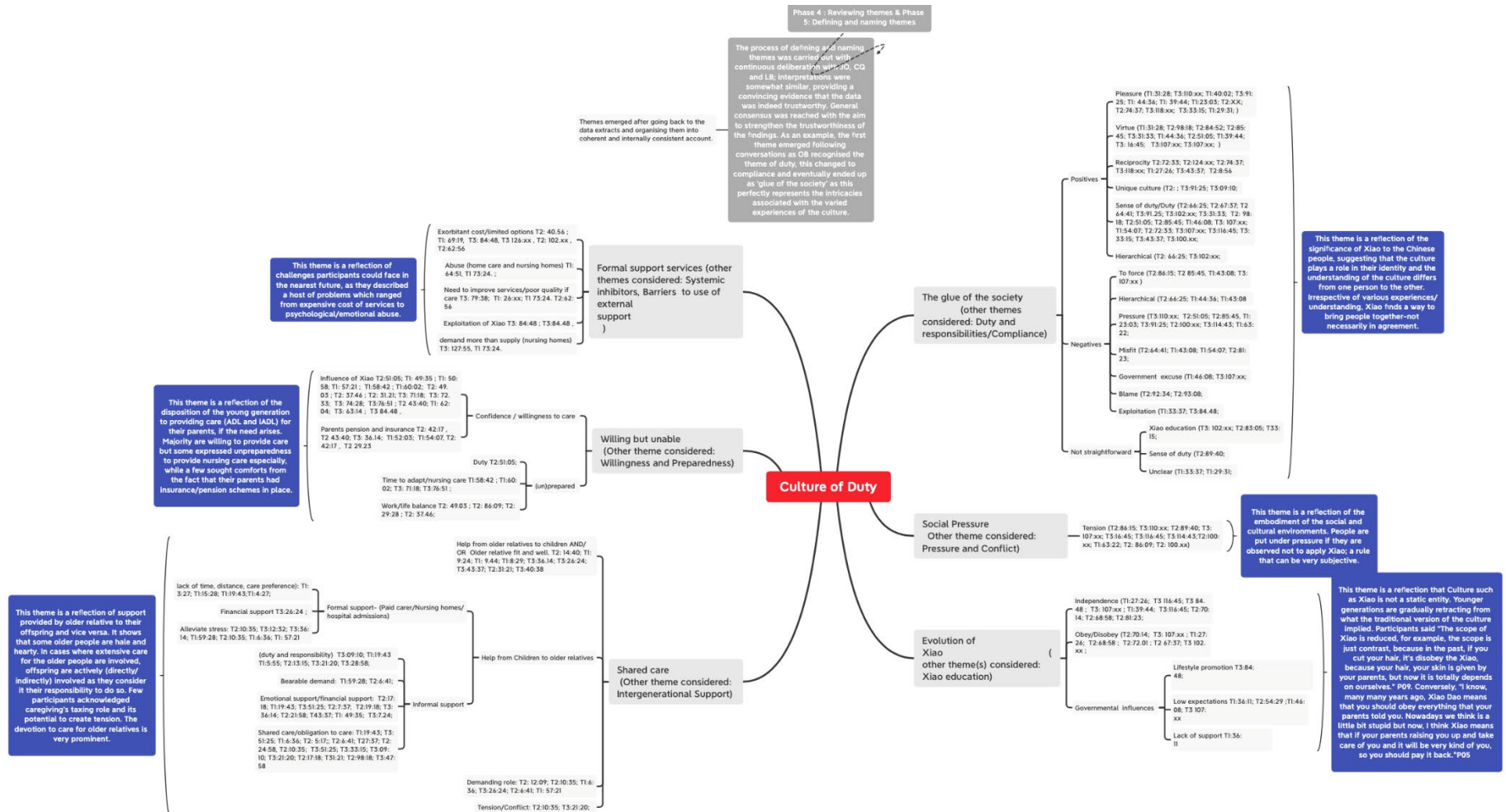


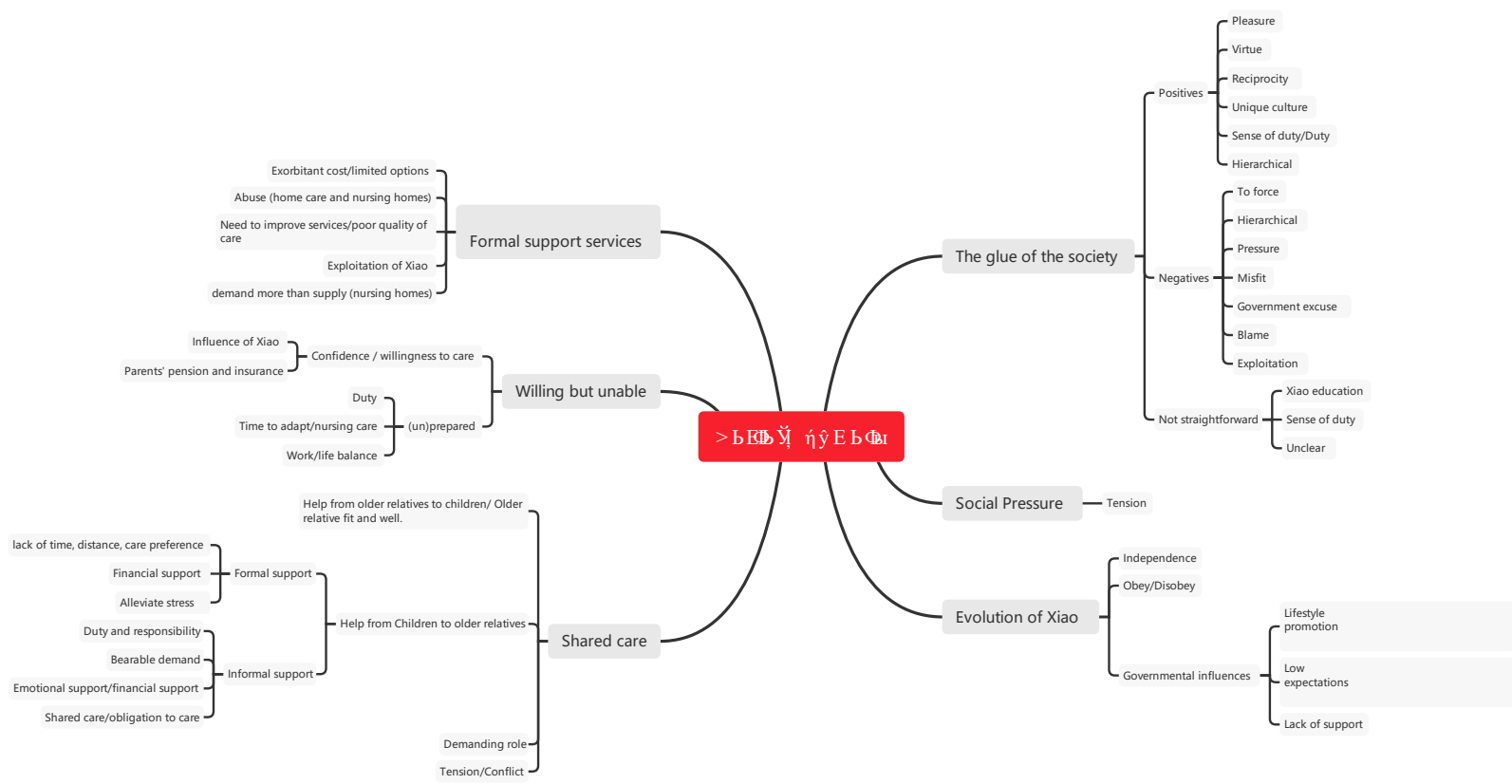
BARRIERS.



Dated January 2020

Dated May 2020





Dated October 2020

Appendix E: Ethics approval for Phase 2 (main study) - University of Bradford



Ethics

****APPROVAL**** Ethics Application E800

To: Oladayo Bifarin, Cc: Jan Oyebode, Liz Breen, Catherine Quinn

6 April 2020 at 23:03



[Details](#)

Dear Oladayo,

Ethics Application: E800

Title: Supporting Carers in the Chinese workforce

Your ethics submission and documents have now been reviewed by the Chair of the Research Ethics Panel.

I am pleased to inform you that the Chair has confirmed approval of this study, with no further ethical scrutiny required.

NOTE that this approval is for this study only.

Should there be any changes to this study, you must inform ethics@bradford.ac.uk.

Once your changes have been reviewed and you have approval to proceed, only then can you recommence the study.

Failure to do so will render your original approval invalid and withdrawn.

Please add a sentence onto any material you share with participants confirming that ethics approval has been granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 06/04/2020.

Best Wishes

Naz



Nazreen Akhtar

Research & Innovation Administrator

Research & Innovation Services (RaIS),

F.24 Richmond Building



+44 (0) 1274 236554



n.akhtar67@bradford.ac.uk

China Medical University: Institutional Review Board (IRB) approval for the main study

关于刘宇同志申报题为“中国慢性病老年人及家庭照顾者长期照护体验的质性研究”的研究项目的医学伦理审查意见

我单位刘宇教授拟申报 2020 年与英国 Bradford 大学 Jan Oyebode 教授合作开展题为“中国慢性病老年人及家庭照顾者长期照护体验的质性研究”的项目，项目负责人刘宇系本校护理学院社区护理教研室教师，多年从事老年护理和社区护理方面的研究。经项目负责人申请并提供有关材料，校医学伦理委员会对本次拟申报项目的研究过程、目的、材料来源，以及受试者的知情同意方案进行了审查。

经初步审核，项目中涉及人的生物医学研究伦理事项符合《赫尔辛基宣言》及国家卫生计生委《涉及人的生物医学研究伦理审查办法（试行）》（[2016]11 号文件）要求，同意该项目按研究计划执行。我校医学伦理委员会将对该项目批准后履行医学伦理研究的有关事项情况予以后续监督。

特此说明。

主任委员签字：

中国医科大学医学伦理委员会

2020 年 3 月 27 日

Appendix F: Posters and Information sheet (English)



DOCTORAL STUDY

UNIVERSITY OF BRADFORD ENGLAND, IN CONJUNCTION WITH CHINA MEDICAL UNIVERSITY SHENYANG.

EXPLORING THE LIVED EXPERIENCES OF
FAMILY CAREGIVERS OF OLDER RELATIVES.

We would like to speak to:

- Parents with one child (with or without older relative caring responsibility).
- An only child within a family (with or without older relative caring responsibility).
- Working family members who also care for an older relative, living with at least one medical long-term condition.

We would like to know more about family carer attitudes and experiences when providing care for older relatives.

(Filial piety, xiao 孝)

You must be age 18 and above to take part in the study.

For more information, please contact

Prof. Liu Yu

China Medical University
School of Nursing

E-mail: liuyu@cmu.edu.cn

WeChat ID: qq113630298

Oladayo Bifarin

University of Bradford
Centre for Applied Dementia Studies

o.o.bifarin@bradford.ac.uk

Bifarin

Ethics

Ethics approval has been granted by the Chair of the Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford on 06/04/20.

IRB approval also granted on 27/03/20 from China Medical University, Shenyang.

Complaints

If you have any complaints, please contact:
Prof. Li, Dean School of Nursing, China Medical University, Shenyang. 110031.
Tel: 86-24-31939546. Email: xhli@cmu.edu.cn

OR

Ms Jane Mallinson. School of Dementia Studies. Faculty of Health Studies, University of Bradford, BD7 1DP. Tel: 01274 233996. Email: j.e.mallinson@bradford.ac.uk

Contact details

If you have any questions or concerns, please contact



Oladayo Bifarin

Ph.D student

Mobile: 07891779428

Email: o.o.bifarin@bradford.ac.uk

WeChat ID: Bifarin

Address: University of Bradford,
Faculty of Health Studies,
Richmond Road, Bradford, BD7 1DP

Liu Yu

Professor of Nursing

Mobile: 86-18640068209

Email: liuyu@cmu.edu.cn

WeChat: 18640068209

Address: China Medical University
School of Nursing
No.77 Puhe Rd. Shenyang North
New Area, Shenyang 110031

Supporting Carers in the Chinese workforce



Information sheet

Background

There are a limited number of children available to take care of older relatives. Until 2015, the One-child Policy had been around in China for over 30 years as a way to reduce the number of its growing citizens. As a result, the older generation in China are growing quicker than there are children to look after them. Many older people are living alone with long-term health conditions like stroke, heart disease, breathing difficulties, lung conditions and Alzheimer's disease.

Given that *filial piety xiao* (孝) suggests that children should pay their parents back, we can understand that the majority of the elderly live at home and are often cared for by family members. Also, the limited numbers of women available to provide care for the older people due to more job opportunities as well as the total increase in internal migration, means that family members will need more support, especially if they are from one-child families.

This study is part 1 of a larger study. In our first study, we spoke with young Chinese students at the University of Bradford, England. It was interesting to hear what they had to say about caring for older family relatives in China today.

Understanding the experiences of family caregivers and those who may support them is very important. It can help us to know what advice we give, to support those caring for older relatives. Part 2 of this study will focus on this area.



Study Aim

The reason for this doctoral study is to understand more about what the Chinese society needs in the future, and in relation to the care available for older people. We would like to speak to people who are currently caring for an older relative while also working full time or part time. Our aim is to learn about their experiences, by seeking the views of parents and children affected by the One-Child Policy.

This study will fill a gap in knowledge because there is little research that gives a deep understanding of this issue.

Why have I been invited?

Those being invited to join this study are carers who are working and care for an older family member who needs some help every day. We also invite parents or children affected by the One Child Policy even if they are not currently looking after an older relative. You must be 18 years or above in age.



What do I have to do?

Before we start, you will have time to ask any questions you have. After this, you can choose to sign a form giving your permission. You will be interviewed, and it should not last longer than 90 minutes. At the end of the interview, a small gift of about £20.00 will be given to people because of your help in the study.

Do I have to take part? NO

You have the choice not to take part. If you choose to take part, you still have the option to change your mind within four weeks of the interview and you do not have to say why. If you decide to stop, the researchers will use the information you have given them up to that point, unless you refuse them permission to do so.

Will my taking part in the study be kept confidential? YES

In line with the UK General Data Protection Regulation (2018), only the team doing the research will have access to the information collected. **ALL** equipment and information collected will be kept safe and secure in a locked cabinet. A password-protected audio-recorder will be used to record the interview. The audio recording will be typed out by a company that is licenced to practice and a 'preferred provider of transcription' of the University of Bradford. As soon as this study is completed, we will delete anything on the recorder. The audio files will be stored on a password-protected computer. Transcriptions will be stored on a password-protected computer. These will be deleted after the completion of the study and associated publications. We will change your personal information, or we won't add your information when typing the recording so that you will be anonymous. No-one will ever be able to identify you personally from anything that we write or say in public about the research.



What are the risks and benefits of being involved?

We do not think that taking part will cause any trouble or any specific problems for you. We still have to be careful because any question can accidentally cause concern. If you are concerned in any way, we will stop the interview and check if you are willing to continue.

The good part is that you get to tell us what you think and we would be grateful for your help.

I do not speak English. can I still be involved? YES.

We have Liu Yu (Professor of Nursing), or a designated Masters student, who will who will translate and make sure we completely understand what you say.



What will be done with the information?

We will compare the information you provide to us with everyone else in the interviews to have a better understanding of the meanings each person gives to caring for older family members. The results of this study will help us give advice that will be useful for family members of older people living with long term conditions, health care professionals and for policy makers in China.

Who can I contact for more information?

If you are willing to attend this interview, please get in touch with the community worker or Professor Liu Yu, via email, text message, phone call or drop a message on WeChat by using the information provided in the contact details section of this information pack.

Oladayo and Professor Liu Yu will then contact you via email, phone or WeChat. We will provide relevant information and confirm the date, time and location that best suits you.

At the start of the interview, we will answer any questions and obtain your written consent.

Appendix G: Phase 2 (main study) interview guideline



Welcome

- Lead interviewer Oladayo to introduce himself and Prof. Liu Yu or designated Master's student
- Thank participants for taking part in the study, appreciate their contributions in advance and inform them of the time duration (Not longer than 90 minutes).
- Inform participants that discussion will be audio-recorded, explaining that this is for the purposes of having a record of the discussion for later analysis.
- Inform participants that the recorded discussion will be kept confidential and will not be shared with anyone outside the supervisory team and the identified translating/transcribing company. The interview will be transcribed, and pseudo- names will be used (instead of their real name). The audio recording device will be locked in a secure cabinet and audio files will be stored on a password-protected computer.
- Information sheets directly translated to Mandarin will be used with participants and questions will be answered with the assistance of Prof. Liu Yu or designated Master's student.
- Ask participants to sign the consent forms (Mandarin language).

Ground rules

- Inform participants that discussion is being recorded.
- It is essential to state that as much as I am interested in listening to participant's opinions about family caregiving, please ONLY share with us what you are comfortable with.
- If you are distressed or feels uncomfortable by the content of the discussion, please let me know.
- Participants can leave at any point if they change their mind about partaking in the study.
- Happy to have de-brief sessions with participants after the interview- I am in no rush to go anywhere.

Process

Questions have been prepared, and participants willing to share examples will be welcomed to do so, using prompts such as 'Would you explain further?', 'for instance'? 'anything else?', 'please describe what you mean?'

Topic and questions to discuss. (This is only a guideline; the discussion will be in a less structured format).

Today we will be talking about caring for an older relative. Caregivers are family members, friends, or other supporters who provide unpaid help and support to older people. They might help them with... [GIVE EXAMPLES] (ADL and IADL.....)

Only Child: Interview guideline

Quick Exercise: I am interested in learning more about your family. Please draw a family tree indicating three generations G1 (grandparents), G2 (Your parent/Uncle and Aunt), G3 (yourself and cousins) and G4 if this exists. Their age, place/country of residence will also be collected.

Objective 1

To understand the experiences of relatives or friends of participants with older adults caring responsibilities in China. If participants do not have such caring responsibilities themselves. (*Attitude and Knowledge*)

- Do any of your friends or relatives provide care for an older person?
- Can you share with us any experiences (positives and negatives) of your relatives or friends with older adult caring responsibilities?
- Are these relatives or friends working, do they live nearby the person they are supporting? Do they have any other family commitment?
- What do they tell you about their experiences? How are they coping? What helps them to cope?
- Based on the experiences of your friends and relatives, do you have a good idea of what caring for an older relative entail?

Objective 2

To explore the preparedness of participants with regards to their potential future caring responsibilities. (*Preparedness*)

• Imagine your parents or other older relatives start to need support or care. Do you think you would be in a position to provide care for them? What role will other relatives play in this?

- From what you currently know about providing care for older relatives, are you confident about giving care in the future? If not, what will be helpful?
- If you were in the position of supporting an older relative, is there any particular help that you would need what is it? E.g.....
- How prepared do you feel about providing care? For example, personal hygiene care, providing emotional support, helping them with housework, the caring role in general?

Objective 3

To explore the meaning of filial piety to participants and how they anticipate this may influence their lives' or their response if their older

relatives/parents needed support' i.e. to what extent do participants subscribe to this cultural value? (*Motivational/ cultural obligation to care*)

- What does filial piety **xiao** (孝) mean to you? Is it important to you? Is it important to your relatives? (*Filial Piety Law*)
- How have you seen filial piety **xiao** (孝) shown in your family? (e.g. by your parents to their parents? By you to your parents?)
- I understand filial piety gives you an obligation to take care of your older relatives, should they need help. What do you imagine might be involved?
- Is filial piety just as strong now as it used to be? Do you think this is going to change at all and if so, why?
- How strong do you feel families are in China? Do you think this is changing at all? And if so, how and why?
- Would you expect other relatives to support you in potential future caring responsibilities? If so, who do you imagine might help you?
- Describe the expectation placed on younger ones to support older ones in just one word? (if applicable)

Objective 4

To understand participants' attitudes to current or future care for an older relative with needs for ongoing daily care and support, including the influences of social support, filial piety and perceived barriers to providing care. (*Inclination to care*)

- What do you value about filial piety **xiao**? (attributes and influencing factors)
- What sort of disadvantage may result from the value placed upon filial piety?
- What are the likely challenges that could impede your willingness to care in the context of filial piety? What would be your motivations for becoming a caregiver?
- Are there any care-related tasks you would be unwilling to do?
- Do you know of any statutory and non-statutory support services in China for older adults? (Hospitals, day centres, private carers, carer groups, care homes, Charities etc.)
- Do you imagine you might ever arrange for your older relative to use any of these services? (Nursing homes in Shenyang- do you think of them and what are you parent's plan for the future?)
- Are there things you would not be able to do if you took on caring responsibilities; for example, employment, education? Could potential future older parents' responsibilities be an impediment?

Balancing work and care – what can help and support this: Interview guideline

Objective 1

To understand participants' experiences of caring for an older relative in China. (*Attitude and Knowledge*)

1. What job do you do? Working hours? Travelling hours? What is your job like? What are your working hours? What sort of support do you receive from your employer?
2. What sort of care/support do you give your relative? Can you share with us your experiences (positives and negative) of caring for older people in the family?
3. What challenges have you faced caring for your relative?
4. Have you ever taken your relative to a nursing home or hospital? What happened?

(Do you use any support services to provide care or support to your relative? and if so, what do you think of those services – are they good? bad? How might they be improved? What help do they need that they are not getting? What would help with unmet needs?)

5. Are there other relatives or friends who come to your assistance, if need be? Do they live nearby the person you are supporting? Are there any formal support such as day care centres, paid carers etc. available to you and how useful are they?
6. How do you manage your daily work, immediate family commitments, and meeting the needs of the older people you are supporting?
7. How do you cope daily? What helps and what doesn't? What would you like to do differently, and why?
8. Do you feel well informed about how to support your [care recipient living with a long- term condition]. If yes, what knowledge do you have (training?), how did you acquire such knowledge (TV, newspaper, nursing staff)? How do you find the information useful? If No, how do you manage in this caregiving role, e.g. nursing care?
9. What type of support or assistance do you get from your place of work? From your employer's perspective, does it matter if you have to care for an older person and work at the same time? Any mental health training/awareness, paid leave?

Objective 3

To explore the meaning of filial piety to participants i.e. to what extent do participants subscribe to this cultural value? (*Motivational/ cultural obligation to care*)

- What does filial piety **xiao** (孝) mean to you? Is it important to you? Is it important to your relatives? (*Filial Piety Law*)

- How have you seen filial piety **xiao** (孝) shown in your family? (e.g. by your parents to their parents? By you to your parents?)
- Is filial piety **xiao** (孝) just as strong now as it used to be? Do you think this is going to change at all and if so, why?
- What means and measures did/do you use in educating your child/children about filial piety **xiao** (孝)? Any different from how your parent taught you? If yes, how/why? - (Xiao education- questions derived from **phase 1**- preliminary study)
- How strong do you feel families are in China? Do you think this is changing at all? If so, how and why? (what used to happen before that is relatively, no longer evident- any implications for older people caregiving?)
- Would you expect other relatives to support you in potential future caring responsibilities? If so, who do you imagine might help you?
- In the context of filial piety **xiao** (孝), what do you expect from your child/children?
- Do you expect your children to stay close to you (proximity-wise)? If they do, what are your expectations? If they don't (move to Shanghai or the UK for instance), what do you expect from them?
- Do you get any benefits from the government?
- What are your expectations from your children? (Meeting the demands of taking of you.)

Parents of one child policy: Interview guideline

Objective 1

To understand participants' experiences with older people caring responsibilities in China.

(Attitude and Knowledge)

- What are the caring responsibilities that you have? - Can you share with us any of your experiences (positives and negative), caring for older people in the family?
- How do you manage/handle these caring responsibilities? - Are there other relatives or friends who come to your assistance, if need be? Do they live nearby the person you are supporting?
- What challenges have you faced caring for your relative?
- How do you manage your daily work, immediate family commitment, and meeting the needs of the older people you are supporting?
- What do you cope daily? What helps and what doesn't? What will you like to do differently, and why/how?
- Do you think you are well informed about what is needed in supporting someone like your (mother?) living with a long-term condition like (stroke or dementia?). If yes, what knowledge you have (training?), how did you acquire such knowledge (TV, newspaper, nursing staff)? Is knowledge effective? If NO, how do you manage in this caregiving role, e.g. nursing care?

- What type of support or assistance do you get from your place of work? What support do you get from your employer? (Any mental health training/awareness, paid leave in place?)

Objective 3

To explore the meaning of filial piety to participants i.e. to what extent do participants subscribe to this cultural value? (*Motivational/ cultural obligation to care*)

- What does filial piety **xiao** (孝) mean to you? Is it important to you? Is it important to your relatives? (*Filial Piety Law*)
- How do you show filial piety **xiao** (孝) in your family? (e.g. by your parents to their parents? By you to your parents?)
- How did you go about educating your child/children about filial piety **xiao** (孝)? Is this any different from how your own parent taught you? If yes, why? (Xiao education- question derived from **phase 1**- preliminary study).
- In the context of filial piety **xiao** (孝), what do you expect from your child/children?
- What is your view of your child's responsibility to you? - Do you expect your children to stay close to you (proximity-wise)? If they do, what are your expectations? If they don't (move to Shanghai or the UK for instance), what do you expect from them?
- how do they think they will feel if the only child doesn't feel obliged to be close to or provide care for them?
- Is filial piety just as important now as it used to be? Do you think this is going to change at all and if so, why?
- How important do you feel families are in China? Do you think this is changing at all? And if so, how and why? (what used to happen before that is relatively, no longer evident- any implications for older people caregiving?)
- Would you expect other relatives to support you in potential future caring responsibilities? If so, who do you imagine might help you?

Objective 4

To understand participants' attitudes to current or future care for an older relative with needs for ongoing daily care and support, including the influences of social support, filial piety and perceived barriers to providing care. (*Inclination to care*)

- Can you tell me about a time you took your relative to hospital/visited a nursing home? What happened?
- In what ways do you support your older relative, living with a long-term condition?
- Do you use any support services to provide care or support to your relative? and if so, what do you think of those services – are they good? bad? How might they be improved? What help do they need that they are not getting? What would help with unmet needs?

- how would you feel if you need to move to a care home?
- Do you get any benefit from the government e.g. Any One Child Policy incentives?
- Do you ever think about how your child will cope with the demands of life- taking care of you inclusive? / Do you expect this child to care for you? / Would you expect your child to give up work to care for you?
- What will you like to see, in term of service improvement for older people caregivers and care recipients in the nearest future? / how do they feel about using the sort of services they see are available to date?
- What are your motivations for becoming a caregiver? What you think will be the motivation for your child to become a caregiver in the future? What are your expectations for him or her in this regard? If he/she is going to stay around to look after you? I what do you expect from them? If they don't, how do you intend to cope with long-term conditions like stroke or dementia?

Debrief

- Paraphrase the cogent and salient points from the discussion; check if participants are happy and if there are any other issues they want to bring up.
- Reassure participants that confidentiality will be maintained and can withdraw from the study at any time.
- Thank participants for their time.

Appendix H: Blank consent form

Supporting Carers in the Chinese workforce



Consent form

Participant ID _____

	Please initial
I have read and understood the information sheet. I have had the chance to ask questions about this study and had these answered.	
I understand that it is up to me whether to take part. I know I can withdraw at any time without giving a reason.	
I understand that if I withdraw from the study, the researchers will use the information I have provided up to that point, unless I say that I do not want them to.	
I understand that my personal information will be kept safe and secure.	
I agree to take part in this study.	
I agree for the study to be audio recorded.	
I understand that any data or information used in any publications which arise from this study will be anonymised and that no-one will be able to identify me personally in any way.	
I agree to the use of anonymised direct quotes in publications.	

Your name

Date

Signature

Researcher

Date

Signature

Chinese PI

Date

Signature

Appendix I: Blank demographic forms



Participant ID _____

An only Child

Some information about yourself

1. How old are you? _____
2. What is your gender? _____
3. What is your highest level of education/qualification? _____
4. What province are you from? _____
5. Would you consider yourself to be a carer for an older person? Yes No
6. Are any of your relatives a carer for an older person? Yes No
7. Are you an only child? Yes No

Participant ID _____

Parents affected by OCP.

Some information about yourself (Circle your answers where applicable)



1. How old are you? _____
2. What is your gender? _____
3. Highest level of education/qualification _____
4. Are you in a full-time/part-time job? _____
5. What province do you live in China? _____
6. Do you work in Shenyang? If not, where? _____
7. Ethnicity / Religion _____
8. Would you consider yourself to be a carer for an older person? **YES** **NO**
9. Older persons' long term-condition(s) _____
10. What is your occupation? _____
11. How many hours of care do you provide in a day? _____

Participant ID _____ Carers in the Chinese Workforce.

Some information about yourself (Circle your answers where applicable)



1. How old are you? _____
2. What is your gender? _____
3. Highest level of education/qualification _____
4. Are you in a full-time/part-time job? _____
5. Do you work in Shenyang? If not, where? _____
6. Would you consider yourself to be a carer for an older person? **YES** **NO**
7. Older persons' long term-condition(s) _____
8. How many hours of care do you provide in a day? _____
9. Ethnicity / Religion _____
10. What is your occupation? _____
11. How many hours of care do you provide in a week for an older family member?

Appendix J: Typology of meaning and example demonstrating mechanisms aiding reflexivity.

Breakdown of 6 phases of r-TA analytic approach and process drawing on using the sample of offspring affected by OCP:

Phase 1: Data familiarisation

All extracts Below use the transcript for the same individual as an example to give insight into the coding process.

Phase 2: Initial Code Generation

Exploratory process

G1-P02 data analysis

Decided not to focus on linguistics due to the fact that participants were not proficient in English language. Majority could not speak English and had to rely on translator.

Data excerpts	Descriptive (D)/interpretative (I) comments	Codes (Latent-researcher-derived) Conceptual interpretation of data
<p>G1-P02 lines 110-113</p> <p>I guess the <u>most close</u> experience from being a carer to an elder is my parents have to take care of their parents when they are suffering from some disease. My grandfather from my mother's side really did not have a very peaceful retirement stage or kind of thing. He suffered from a lot of disease. I think one is called... let me google that, I'm not sure what it's called in English. [..]Dementia.</p> <p>Lines 117-121</p> <p>Yes, he got that, so he really couldn't recognise anyone, so that's a problem. My mother is a housewife, so apparently of course the reliability lies on her. Yes, she basically had to come to hospital at least every other day or every day, at least when he was at the hospital. They had to hire a lot of nannies, especially my grandfather does not respond well to strangers and therefore there's a lot of adjustment and kind of... it's a hard time, yes, basically it's a hard time.</p>	<ul style="list-style-type: none"> • Grandfather did not have a pleasant time following his retirement due to multimorbidity, in which one of the conditions was dementia. • Retirement is meant to be peaceful but long-term conditions impeded that or disrupted the plan. • Housewife mother had more time in her hands and must take care of father. • Mother had to visit hospital regularly at times when are father was on admission. • Mother required helping hand and employed a lot of nannies (health care assistants). • Grandfather did not get on well with nannies (strangers) and had to keep changing them. (To please the grandfather- my thought) • Caring for older relatives comes with 	<ul style="list-style-type: none"> • Factors (adversely) affecting retirement. • Long-term health conditions disrupt retirement plans. • Retirement not going as envisaged due to health concerns. • inharmonious retirement due to issue relating to health. • Going over and beyond for parents. • Time is not enough • Role of social role <u>i.e.</u> housewife has more time, so can do it. • Decision making • Adjustment

<p>Lines 131-132</p> <p>Yes. We live very close. We are kind of lucky, my family is from military, so in China they gave houses to military families, so our house is <u>really close</u> to each other, yes.</p> <p>Lines 136:138</p> <p>Not <u>really much</u> because my grandfather passed away when I was 15 years old, I suppose, 15 or 16, so not a lot of memories and my mother tends to block those things away from me, so I'm not really sure what's going on. I'm just knowing that hospital is like a normal location for us.</p> <p>Lines 141:144</p> <p>I think I was at a rebelling stage, back then, so I always had a lot of fights with my mother, so I'm not sure how I feel about this. You know, when your family's elder has a chronic disease, it's not really like a very acute thing. It's like a longer term, and so it becomes a normality. You don't suffer from <u>it</u>, you just get used to it.</p>	<ul style="list-style-type: none"> • Military personnel are given houses in China, which tends to benefit the family at large. • Family is privileged being in the military. • I was 15-16 years when grandfather passed away. • Not a lot of memories and mother tend to keep information from her. • Hospital was a regular place to visit. • Not in the clear about experiences of caring for older relatives as mother protected child (good intentions/rationale) • Hospital was a home away from home. • Fighting with mother • No definite feeling relating to be being shielded from having some information. • demands of caregiving: You don't suffer from it; you get used to it. • Meeting the needs of older relatives can be challenging but normal and one of those things that you get used to. 	<ul style="list-style-type: none"> • Process of care transitioning • Creating enabling environment for older relatives. • Taxing caregiving role • Role of social roles • Family members living in close proximities by virtue of their privilege(s). • Limited view of demands of caring for older relatives as mother shielded her from quite a lot. • Hospital: home away from home
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Phase 3 and 4: Identifying themes/ Developing and Reviewing themes – showcasing that theme did not just emerge

An active process- means to an end

Action: Sketch a thematic map for themes and subthemes at this stage

(Final thematic map)

Objectives

- (i) To understand the experiences of relatives or friends of participants with older peoples caring responsibilities in China; if participants do not have such responsibilities themselves. (Attitude and knowledge) **(Consensual, functional and normative solidary- obligation of caregiving)**
- (ii) To explore the preparedness of participants with regards to their potential future caring responsibilities (preparedness) **(Structural solidarity- facilitators and barriers)**
- (iii) To explore the meaning of filial piety to participants and how they anticipate this may influence their lives' or their response if older relatives/parents needed support i.e., to what extent do participants subscribe to this cultural value? **(Associational and affectual solidarities- willingness to care)**

Objective 1: To understand the experiences of relatives or friends of participants with older peoples caring responsibilities in China; if participants do not have such responsibilities themselves. (Attitude and knowledge) **(Consensual (attitude & beliefs), functional (support) and normative solidary (commitment to filial piety)- obligation of caregiving)**

Example showing the active process of identifying, developing, and reviewing themes

THEME 1

Working theme: MEANINGS and MOTIVATION

Social norm

Social role-(change to something that would reflect assumptions of participants around care and free time/ gender) Supervision 27 feedback

Assumed social norm

Housewife has more time in her hands Lines 117-121 (G1-P02)

Yes, he got that, so he really couldn't recognise anyone, so that's a problem. My mother is a housewife, so apparently of course the reliability lies on her. Yes, she basically had to come to hospital at least every other day or every day, at least when he was at the hospital. They had to hire a lot of nannies, especially my grandfather does not respond well to strangers and therefore there's a lot of adjustment and kind of... it's a hard time, yes, basically it's a hard time.

Lines 151-155 (G1-P02)

Yes, so I definitely think compromises has to be made. You couldn't really have a life when you have another person's life just relying on you. My mother is a housewife, so she has a lot of free time. That means she doesn't have to give up her career or anything like that, but her life is definitely disturbed, yes, so I think compromises and a lot of energy or time putting into taking care of him or her is definitely essential.

Retirees have time in their hands Lines 182-186 (g1-P07)

So first I will look for the person from the cousins and relatives, for example, my uncles or maybe my aunts because they are already retired so I think they have time to take care of my parents. If they are not available, I will ask my friends to see if they have someone could introduce to me, for example, if they hired some nursing assistant before and the nursing assistant is really good, so I will like them to introduce that person to me, I will use that person to take care of my parents.

Mother in China complain and still provides care Lines 106-110 (G1-P08)

Oladayo Bifarin

Motivation and meanings (Caregiving context, cultural values, agents, external and internal consequences): it is about commitment to care of parents/older people. Reflection of the inexorably poignant nature of caring for parents, which is call for action within the socio-cultural environment and has consequences. Drivers of care obligation "it" (demographics, socio-cultural context and models of adaption) can easily be ignored, but sooner or later they can catch up and push against "it".

role normalisation and poignant tensions.

Social norm

•**Social role** (cultural value): motivation to care with the socio-cultural context could stem from social norms. These people could care without affection. They are free and or it is their role. Hence, they find themselves doing it ie motivation can be extrinsic and void of affection.

Housewife has more time in her hands; Retirees have time in their hands, Mother in China complain and still provides care, A typical mother: to prioritise the whole family.

Reciprocity

•**Role modelling, preparation, and cultural embeddedness** (parent as agents)
•**adaptations-socio-demo & cultural changes – external and internal consequences.** (government as agent)

Anticipatory filial responsibility and possible consequences caregiving context- situations or conditions where tension might arise.

•**Beliefs of the consequences of Xiao.** (role negotiation and labour domain)



Mother in China complain and still provides care Lines 106-110 (G1-P08)

Yes. I talk with my mum on the phone and usually she will talk something about my grandparents and sometimes she will complain, for example, my grandpa can have some bad words, so he gets angry without any reason and maybe sometimes he is not reasonable but even though he says something like that, even though she complained, she still takes good care of my grandparents. So just like the typical mum in China, you know? They complain and then do the same thing, they still do a good thing even though they complain.

A typical mother: to prioritise the whole family Lines 115-121 (G1-P08)

My mum is a typical mum. That means that usually in the family in traditional China, women usually they take care of the whole family and also teach or take care of the children. So that means the women should do a lot of things for the family, so that kind of tradition of China and for my mum, even though she has to take care of my grandparents, but she still has some time to go out with her friends, for example, she may ask her brother to take care of the grandparents and she will have some time to go out for dinner or for lunch with her friends. Or maybe climb, do some climbing with friends, so it seems just very common, sometimes she complains but she is still trying to do her best to fill out her roles. Everyone has their family roles.

How does G1-P02/07/08 make sense of their experience?

- Housewife, mother, retiree, have time in their hands and can provide care.
- Caring for older people is hard (regular visit to hospital, caregivers must make significant adjustments, make compromises, expend a lot of energy)
- Typical mother will try to fit everything in (care for whole family-women's responsibility) and arrange to have a social life.
- Mother preserve or put up with care demands or doing good against all odds.

Why might G1-P02/07/08 make sense of their experiences in this manner?

- These narratives are mostly due to the influence of socio-cultural environment. What children see regularly, which is influenced by role normalisation, compliance and there are expectations on mothers (who are negotiating within their role) and retirees, housewives (who have free time in their hands).

***A good person will make family a priority* Lines 232-233 (G1-P02)**

I think judging a good person in China includes this criterion of how you are treating your family and how you are taking care of them.

***Care out of love, beyond the demand of Chinese culture* Lines 168-170 (G1-P02)**

Yes, definitely. It's not just from a Chinese culture perspective that you have to care for your parents, **but out of love, yes definitely I would.** It's part of my plan. It's part of how I recognise the world, as always, you know.

***Love, respect and take care of parents* Line 224 (G1-P02)**

I guess it's just love your parents, respect them and take care of them when they need it.

***A moral compass* Lines 228-230 (G1-P02)**

I consider it as like a moral stone, like moral... I guess it's important, but I guess its kind of like already in my blood. It's kind of like a necessity to become a person, so in everyday life, I don't really think about it. If you ask me about my moral values, it's definitely one important part.

***Moral and instinctive* Lines 407-409 (G1-P06)**

I think I don't have special reasons for doing this because in China, being good for parents it is, we can say, we being filial to our parents. It is culture things, almost in every person's opinion, they think that the children should be good to their parents, so I think I just want to filial to my parents. So no other special reasons, I just want to be good to them.

Lines 414-415 (G1-P06)

When I was a boy, I affected with Confucianism in China, so as far as I understand, the Xiào other way filial to the parents is a part of moral things. Moral things.

***Children get used to demands of caring for older relatives* Lines 141:144 (G1-P02)**

I think I was at a rebelling stage, back then, so I always had a lot of fights with my mother, so I'm not sure how I feel about this. You know, when your family's elder has a chronic disease, it's not really like a very acute thing. It's like a longer term, and so it becomes a normality. You don't suffer from it, you just get used to it.

A tradition

Tradition linking generations Lines 281-282 (G1-P05)

It's traditional in Chinese culture, so I can't say it's my favourite. It's just a traditional and so we follow this tradition generation to generation.

Lines 295 (G1-P05)

Yes, it's just like a traditional area, like I said. I have to follow and it's like a habit or something. It is included in our culture, in our traditional culture. So, if I am an only child, I think we should take more responsibilities to be good to our parents. We should take more responsibilities for my parents, for our parents. This is what I think. I think it is just a cultural effect.

How does G1-Pxx make sense of their experience?

- **G3:** caregiving is intergenerationally transmitted from parents (role models) to children. It is implicit; **G4:** Parents acted as role model- in ill-health mother still took care of parent and father passed on a better job opportunity to care for father; imperative action for Xiao-keen to transmit caregiving to generation unborn. **G5:** closely observed parents care for grandparents and will put knowledge to use in the future, **G6:** Xiao is responsible for anticipatory role compliance. **G7:** Intergenerational dependence (an only child); care preferences for parent stems from observing parents care for their own parent. **G8:** Will act in a similar way to mother to provide care **G9:** Parent involving child in discussion about care of older people.

Why might G1-Pxx make sense of their experiences in this manner?

- Care for older people in the environment is very much embedded within culture/driven by cultural values, Parents are seen as assets: knowledgeable and learning from them with the intention of passing this knowledge to generation unborn.

In what different ways do G1-Pxx make sense of the caring for older relatives?

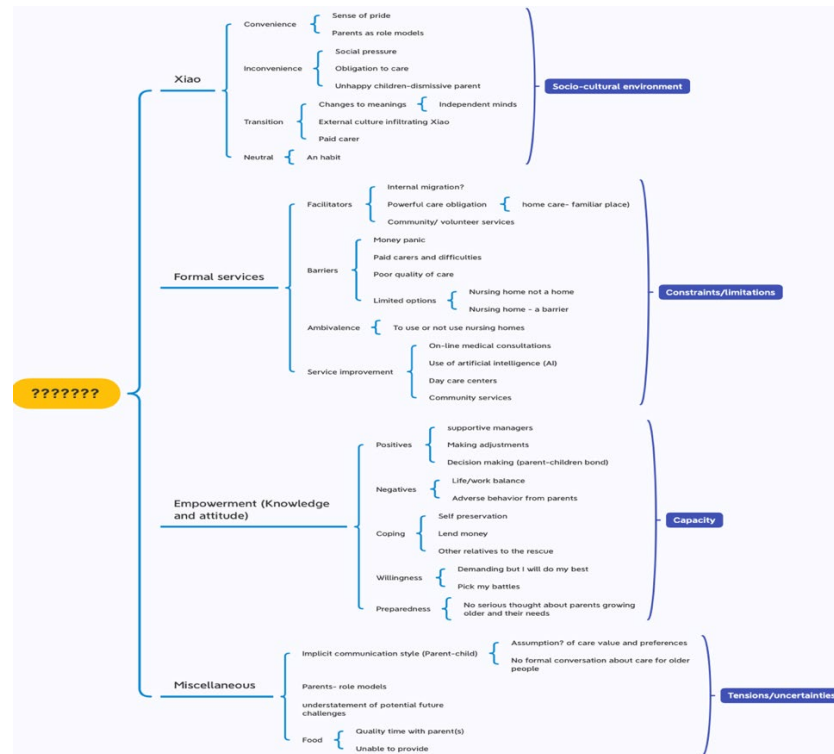
- 2 perspectives: core process involve in caregiving (learning from parents) and Xiao fostering solidarity between generations.

Common-sense association?

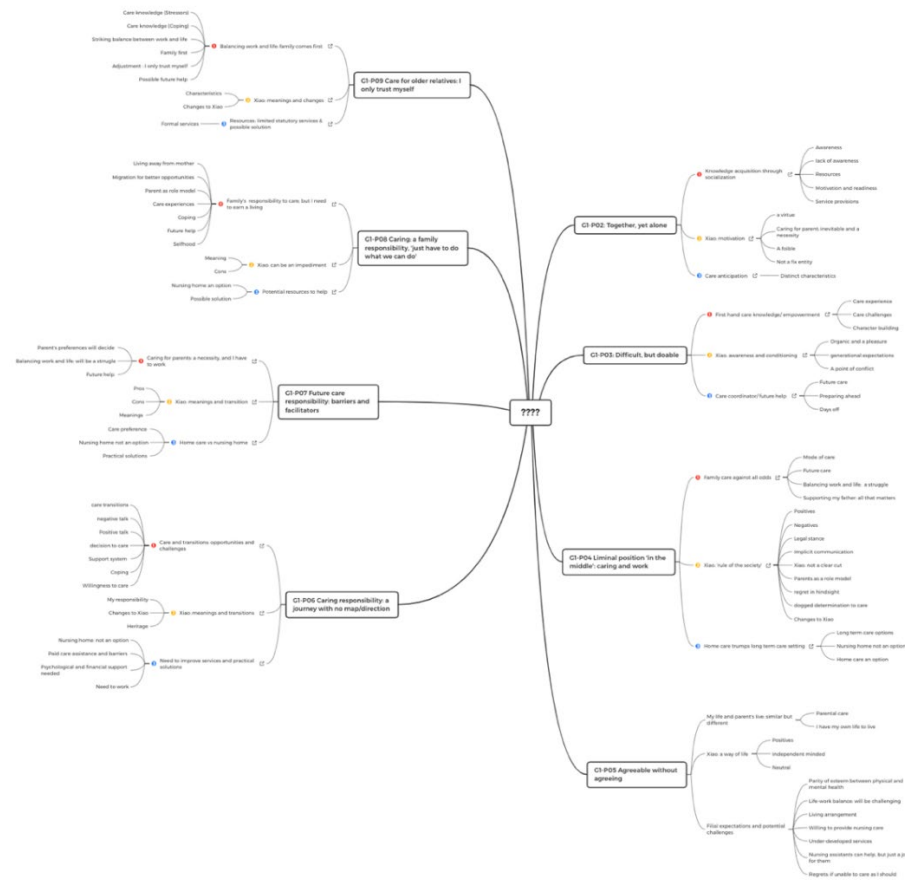
- Make sense to see children to see parents are those who know it all or best at caring for older relative, which would stem from their commitment in difficult times, resulting into caregiving role being normalised. Commitment to care of older relatives (what children see parents do, Xiao) as it is the right thing to do.

Phase 4 and 5: Developing and Reviewing themes/ Refining, defining, and naming themes

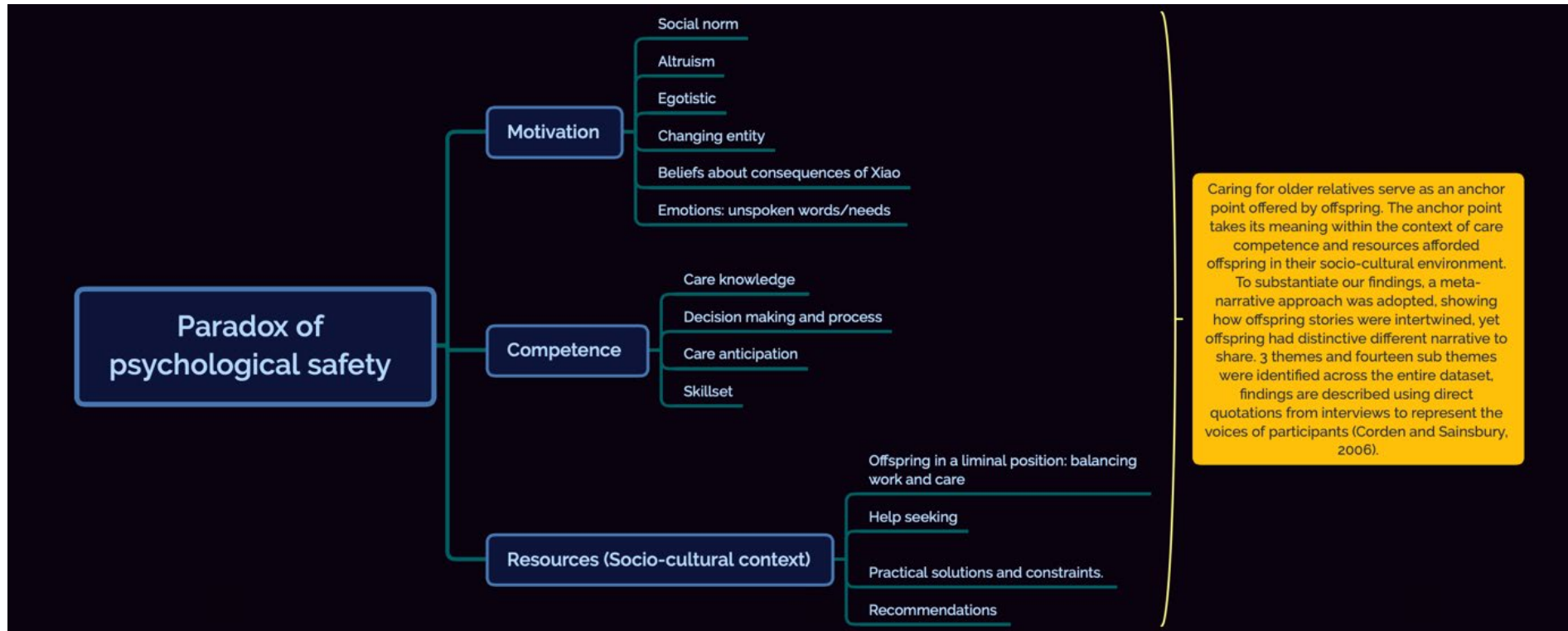
Below are the last set of examples that aided the meaning making process and attached some mind maps to show how themes evolved over time.



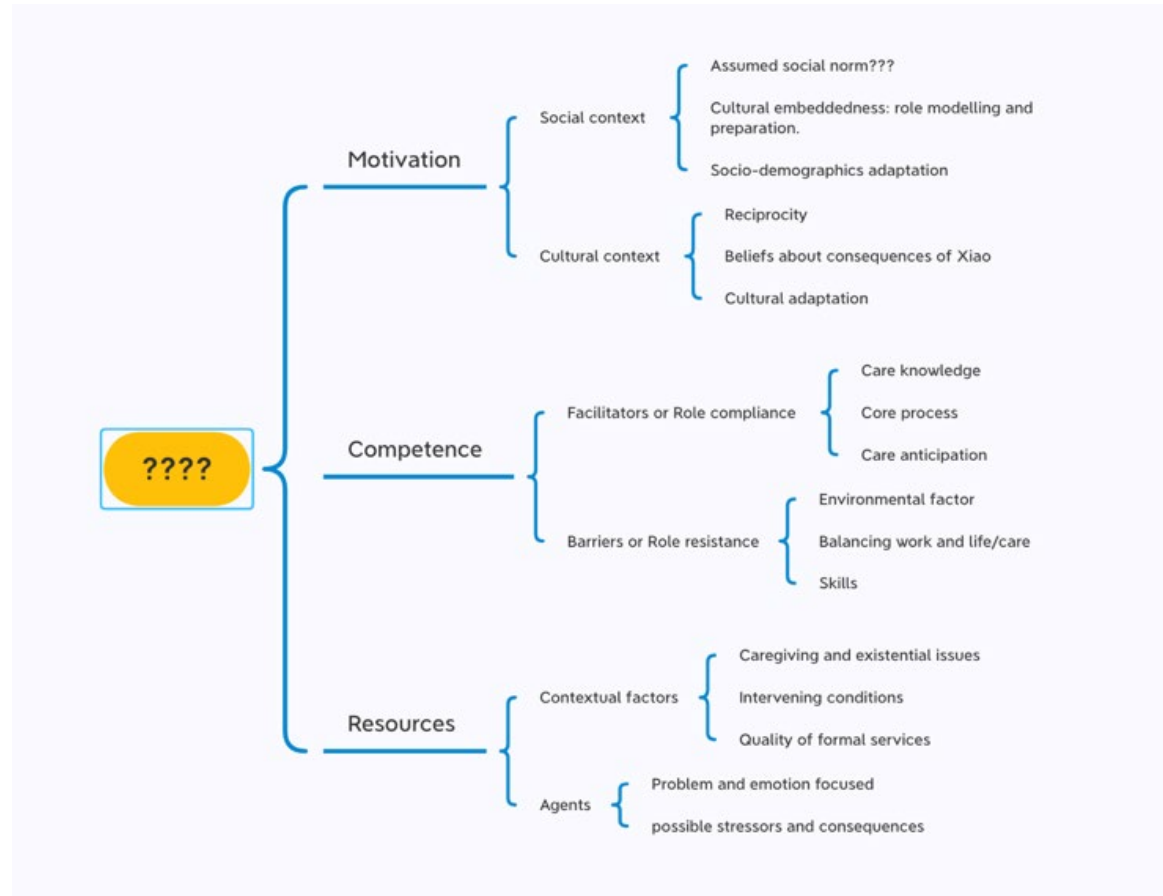
December 2020 - G1- initial thematic analysis



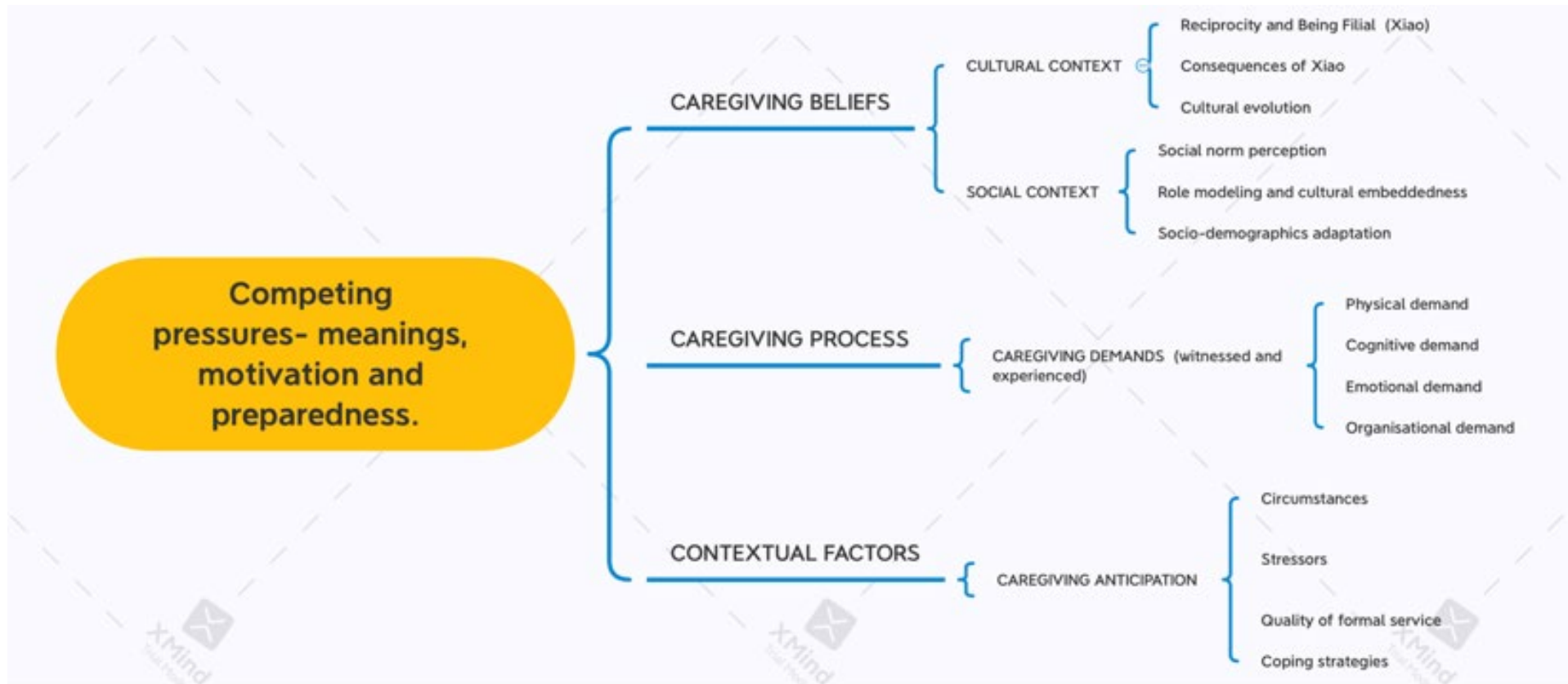
December 2020: *initial thematic analysis* - individual focus on each interview which helped me know them more see convergence and divergence in participants narrative clearer



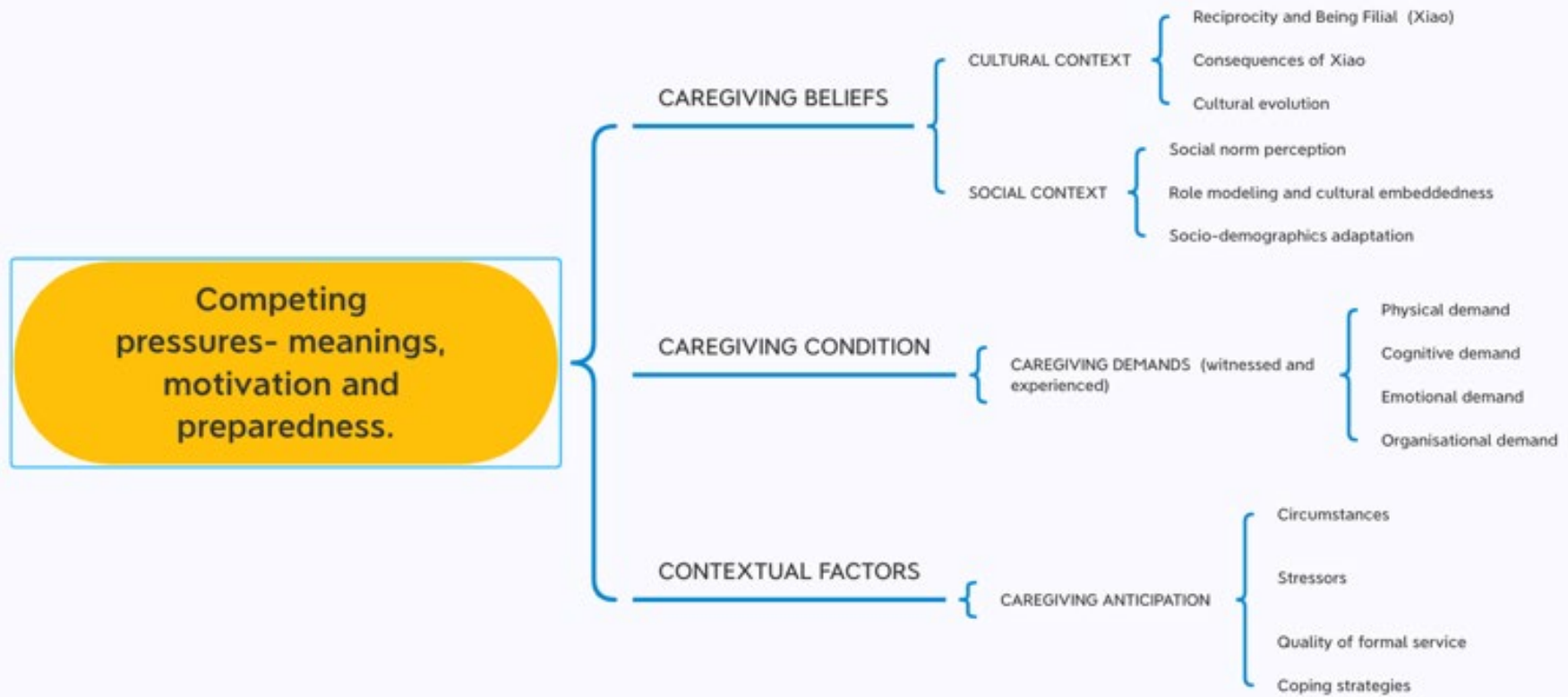
February 2021 – *initial thematic analysis*



May 2021- Developing *thematic analysis*



June 2021- Developing thematic analysis



July 2021- Developing thematic analysis

G3 developing thematic analysis versions 1 and 2 – August 2021



December 2021- G1, G2, G3

January 2022 – G1, G2, G3

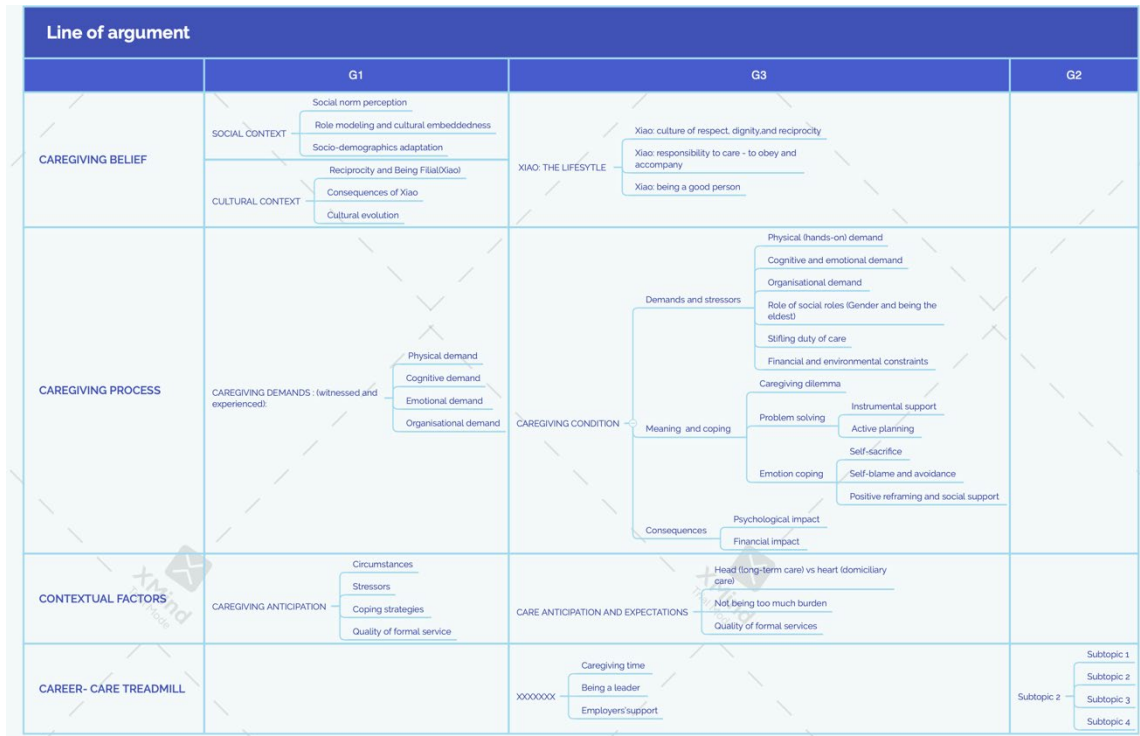


April 2022

Phase 6: Report writing as it pertains to all samples


The writing process started whilst reviewing themes and subthemes, which then progressed into writing for publication using the data from offspring affected by OCP and then, writing the findings section of my thesis. The writing process aided reflexivity, which played a crucial role in conjunction with discussions had with supervisors, in developing deeper understanding of my findings as what was labelled “competence” and “resources” in February had evolved to “caregiving conditions” and “contextual factors”. Influenced by my research positionality and participants interviews, the final labelled themes were more reflective of empathy and exploration, which tells a story of making sense of caregiving phenomenon, attributed to beliefs and demands, which also revealed ways of coping. Evidencing the iterative process of r-TA, whilst writing “consequences” sub-theme was still tweaked to give authority and coherence to participants’ voices.

Developing my lines of arguments: multi-perspectival process adopted



XMind | Trial Mode

POSTER presentation: Alzheimer's Disease international conference, 2022 – London




UNIVERSITY of BRADFORD

Filial discrepancy: the exploration of meaning, motivation, and preparedness to care amongst the One-Child Policy (OCP) generation in China.

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BACKGROUND

An ageing Population¹



Needs for care^{1,2}

- The prevalence of chronic diseases in adults is increasing¹.
- About 9.5 million people are living with dementia in China - 25% of the global population of people living with dementia.
- Family caregivers of older relatives experience distinct, continuous, vicarious, interwoven stressors²

Collectivist Culture³

Chinese culture is driven by interdependent self-construal. "One's sense of self is grounded in one's social relationships, and the most meaningful aspects of oneself are those that emerge in relation to others"³

Socio-cultural Model of Stress, Coping and Adaptation.⁴

- Social environment is embedded within individuals' cultural environments
- Individual stress appraisal is contingent on resources in the cultural environment.
- Appraisal of stress has a direct influence on individual coping resources.


MAIN STUDY RESEARCH AIM

To explore how motivations, meanings, and preparedness could influence caregiving and identify implications for sustaining family caregiving for current and prospective caregivers affected by OCP.

METHODS


- Adopted a constructivist position using a hermeneutic phenomenology approach.
- Interviewed 8 current and prospective caregivers aged 20-35 years about future caregiving responsibilities.
- Data were obtained through in-depth interviews, analysed using latent level reflective thematic analysis (RTA).
- Adopted purposive sampling techniques. § A Chinese researcher (LY) translated interviews and helped capture cultural nuances.

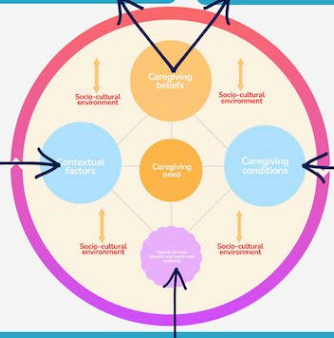
FINDINGS



Xiao (filial piety) remains influential. Offspring expect to repay parents' past sacrifices.

Most viewed long-term care settings as unviable.





Tensions between work, personal and caring responsibilities could manifest as inter-generational conflict, as some might decline caregiving to make life manageable.

Despite recognising the inherent stress, participants saw themselves providing or organising future care to fulfil Xiao

There is a dearth of available formal services for caregivers and participants expressed concerns around older peoples' safety.

CONCLUSIONS & IMPLICATIONS

- Independent and interdependent self-construal can co-exist and have implications for caregiving identity
- The complexity of the concept of Xiao (孝) means it can be a protective factor as well as a risk factor.
- Stressors and coping responses are culturally situated
- Need for culturally attuned services addressing filial discrepancy would have positive implications for achieving the global ambition to promote an inclusive society and improve the quality of life of older people

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