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## Stressors and coping mechanisms of family caregivers of older relatives living with long-term conditions in mainland China– A scoping review of the evidence.

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#### Abstract

As the ageing population in China continues to grow, more people will be living with long-term health conditions and require support from family caregivers. This scoping review therefore aims to explore sources of stress and coping mechanisms adopted by caregivers of older relatives living with long-term conditions in mainland China. Literature searches were conducted in English (CINAHL, EMBASE, MEDLINE, PsycINFO and SCOPUS) and Chinese (CNKI, WANFANG DATA, CQVIP and CBM) databases between October and November 2019. The searches focused on the stressors and coping mechanisms utilised by family caregivers residing in the community. Narrative synthesis was used to identify themes within the data. Forty-six papers were included: 20 papers from English and 26 from Chinese databases. Six themes captured stressors: Caregiving time (N=22); Financial resources (N=17); Role and Personal strains (N=42); Preparedness (N=4); Social roles (N=10); Lack of adequate formal support (N=22); and one theme captured coping (N=14). Unmet needs of caregivers of older relatives in mainland China were found to be extensive. Only a few studies had attempted to explore the causal link between stressors, coping and the influence of culture. Findings underscore the significance of adequately capturing intricacies around caregivers' unmet needs, rather than generalising on the basis of culture. Qualitative studies are critical to providing a better understanding of the relationship between stressors, coping and resources afforded to caregivers by their cultural environment. Having such understanding is crucial to inform the development of competent care, which promotes self-efficacy and self-actualisation in caregivers in mainland China.

**Keywords** Filial Piety, Self-actualisation, Burden, Problem-Focused Coping, Emotion-Focused Coping, Family caregivers, Service provision, Long-Term Care.

### Introduction

Due to increasing numbers of older people, urbanisation, the One-Child Policy and the increase in the number of women in employment, there are growing concerns regarding the sustainability of traditional family-based caregiving in China. Considering cultural values such as filial piety, offspring often feel obligated to care for their parents as they grow older. Even though there is extensive research on the increasing need for care as the Chinese population ages, to the best of our knowledge, there has been no recent review drawing together research on stressors and coping mechanisms of Chinese caregivers of older relatives, who are living with long-term condition(s).

#### Caregiving and existential issues

The current population aged 60 and above in China is about 230 million, with an expected increase to 490 million by the year 2050. Likewise, for those aged 80 and above, there is an expected increase from 25 million to about 121 million in the same timeframe (United Nations 2019). With increasing life-expectancy, there will be increased numbers of older people living with adverse health conditions (Hua *et al.* 2019) and multi-morbidities (Wang *et al.* 2014) who are likely to require support. China's increasing population of older people with health conditions is predominantly supported through care provided by family members (Zhu and Walker 2018), sometimes referred to as 'informal care'. In the absence of robust integrated health and social systems, these caregivers must, of necessity, fend for themselves (Mayston *et al.* 2017). Research shows that caring poses a number of stressors and existential issues for family caregivers (Kristanti *et al.* 2019, Kristanti *et al.* 2018, Tang 2020). Also, the unique cultural context of China, with the clear expectation that offspring care

for parents, has implications for the way caregivers appraise their role. Stressors in the Chinese context may be changing as a result of societal changes, for example, Zhang, Clarke and Rhynas (2019) showed that offspring of older relatives felt isolated and disconnected from their communities, especially with younger generations moving to other cities for schooling or employment and becoming estranged from the sense of 'home'.

Societal values lead caregivers to have high expectations of themselves in relation to their fulfilment of their role, and caregiving stress occurs when there is a perceived mismatch between role performance and ideal role identity or role aspirations (Montgomery and Karl 2009). Factors such as self-efficacy (Crellin *et al.* 2014), meanings and the motivations attributed to caregiving (Quinn, Clare and Woods 2010), have implications for caregivers' idiosyncratic views, role adjustment and their social behaviour over time. In the Chinese context, when for example, a caregiver feels weary from having no break from care responsibilities or feels guilt for parents' negative experiences in nursing homes, there will be stress from the discrepancy between their experience and their ideal role identity as a good and dutiful caregiver.

With reference to 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. As care for an older person with progressive needs for support intensifies over time, incongruence between a caregiver's performance and aspirations, levels of caregiving and the nature of support can have adverse implications for role identity. 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, Zarit and Orrell 2019), result in the personal health needs of caregivers remaining largely unmet (Queluz *et al.* 2020).

While extensive literature is available on the caregiving process and the implications for caregivers in developed countries, there is a dearth of equivalent research in China, particularly due to the fact that the nation had a very limited time before transitioning into an ageing society when compared to developed countries like Australia, United Kingdom and the United States (United Nations, Department of Economic and Social Affairs and Population Division 2015). Existing studies have predominantly focused on the influence of shared values and traditions on caregiving, i.e., they have adopted an essentialist view of culture. The above overview indicates that the individual context is also influential. Therefore, in this review, we pay attention to the fact that caregiving context varies from one caregiver to another and include consideration of existential issues.

#### Culture and demographic transitions

A prime Confucian virtue amongst Chinese people is *filial piety* Xiao (孝). This is the obligation of offspring to care for and support their parents, symbolised by showing respect, being obedient and providing emotional and financial assistance (Smith and Hung 2012). Xiao promotes a strong sense of cultural identity and family cohesiveness (Park and Chesla 2007). It plays a significant role in shaping parent-child relationships, thereby informing patterns of care for older people within Chinese communities (Simon *et al.* 2014). The filial support contract, which mandates offspring to oblige their parents (Serrano, Saltman and Yeh 2017), reinforces the need for family members to

look after their own and equally acts as a central endorsement of Confucianism values. Collectivism, where there is interdependence on others with emphasis on fulfilment of social roles, comes with a set of values, attitudes, and behaviours. Cultural context impacts on the social resources that are accessible to individuals and as such, in collectivist societies, people tend to have an external locus of control and are highly influenced by the demands of their environment (Xiao *et al.* 2014). This may explain why care for older people mostly takes place at home and may contribute to low rates of uptake of primary care services (Wu and Lam 2016).

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, Kim and Dong 2019). Conversely, 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). 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). Individuals may feel under pressure to demonstrate willingness to care for their parents and may suppress feelings of stress or struggle (Au 2017). In this context, caregivers of older relatives may perceive themselves to be in a liminal position, i.e. performing caregiving duties that relate to a multiplicity of cultural functions, which can cause them to struggle with their personal identities or role proficiency. The obligation to continue to care in a context of exhaustion or lack of willingness could result in a sense of detachment.

A one-child policy was implemented in China in the late 1970s, as a response to a projected population growth, and rescinded in 2015. This policy has reduced the

number of children available to support ageing parents. In addition, issues which challenge care for older people include the acceleration of 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). Arguably, given China's long history of patrilineality, perhaps one of the unintended consequences of the one-child policy 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. Warmenhoven, Hoebink and Janssens (2018) found that women born after 1978 did not subscribe to norms of patrilineality in comparison to other groups, including men born after 1978. Further, Warmenhoven and colleagues found that, given the skewed sex ratio at birth as a result of the one-child policy, many parents are of the opinion that sons (with a future wife) are in a better position to provide care in comparison to daughters (with a future husband). Therefore, with reference to the rapid societal development of China, Zhou (2019) highlighted problems with the traditional model of care, noting its adverse impact on ageing well and on caregivers. Zhou suggested that the Chinese government has a significant role to play in the development of interventions aimed at promoting contemporary ageing services.

#### Authors' positionality

Burhanullah and Munro (2020) propounded that socio-demographic transitions in Asian countries would have implications for caregivers and the appraisal of their role. Thus, embracing the prospect of uncovering various understandings, the philosophy underpinning this study is that the phenomenon of caring for older relatives is rooted in subjectivist epistemological and relativist ontological foundations. It is timely to move away from global constructs of collectivism and individualism, to focus on

understanding individual appraisal of stressors and coping, within a specific cultural context. As such, caregivers construe their own meanings and understanding within the context of resources afforded to them within their cultural environment.

#### Aims

Drawing on the socio-cultural model of stress and coping (Aranda and Knight 1997), it may be that the socio-demographic changes, in context of the value placed on filial piety (Xiao), negatively affect the well-being of those caring for older relatives. This makes it imperative to understand specific stressors and coping mechanisms. The objective of this review was to systematically identify what is known about stressors and coping mechanisms. Adopting the iterative approach outlined by (Tricco *et al.* 2018), two review questions were designed, taking relevant key concepts into consideration: 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 are used by them?

#### Methods

Bearing in mind our positionality, it followed that social constructivism guided our review methodology. We therefore aimed to conduct an inclusive synthesis of heterogenous concepts and narratives in order to identify and analyse gaps in knowledge. Hence, a scoping review was identified as the most appropriate method to systematically map out key concepts associated with the phenomena of interest and provide 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 synopsis of findings from a range of methods or disciplines with the aim to facilitate future research work (Tricco, *et al.* 2018).

## Eligibility Criteria

Research papers had to report studies meeting the following inclusion criteria:

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

## Information sources

Electronic databases were searched between October and November 2019. 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.

## Search

The search protocol was discussed in-depth between UK and Chinese researchers to ensure mutual understanding. Key terms were developed and guided by the SPIDER search mnemonic (Cooke, Smith and Booth 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. Terms were further critically reviewed by two university librarians 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 Scopus database, see Supplementary Material Table S1.

#### Selection of Sources of Evidence

For the English papers, the first author (OB) independently reviewed all titles using the eligibility criteria and selected studies eligible for further review. Following this, OB reviewed all abstracts for eligibility alongside CQ, achieving inter-rater agreement of 88 per cent. All disagreements were resolved through discussions and reaching consensus. 10 per cent of the eligible studies (N=4) from the English databases were then subject to full-text screening and independent reviews of eligibility by OB and CQ. Inter-rater reliability was found to be 100 per cent. For the Chinese studies, titles and abstracts were screened independently by two researchers (CW) and (MK) adhering to the eligibility criteria. Following this, they each independently screened full texts for eligibility and reviewed decisions jointly to ensure consistency. In cases of disagreement, a LY reviewed the studies independently and collaboratively with the other two researchers to reach consensus. (See *Figure 1* for detail). References were managed using EndNote X9.

#### [Insert Figure 1 here]

## 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). OB data extraction from two English papers was checked by CQ and considered satisfactory. For the Chinese papers, data extraction and translation into English were conducted by LY, who led a team charting relevant papers. The extraction tables were sent to OB for analysis and to inform write up.

## Results

## Selection of sources of evidence

Forty-six papers were included: 20 from UK databases, 26 from Chinese databases.

## Characteristics of sources of evidence

The majority of the studies were cross-sectional. Most 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 *Caregiving Burden Inventory (CBI) (Chou, Jiann and Chu 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 focused generally on older people with disability and in some cases, with comorbidities or multi-morbidities. (See *Table 1* for details).

## [Insert Table 1 here]

## Synthesis of Results

To accommodate the heterogeneity of the study designs and outcome measures, thematic analysis and narrative reporting were used to synthesise and present the findings (Levac, Colquhoun and O'Brien 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. OB, CW and MK worked collaboratively to group and 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. Six themes were derived that related to caregiving stressors: Caregiving time, financial capabilities, role and personal strains, self-efficacy and social roles and lack of support. Only one theme was identified that focused on coping. Each theme will now be discussed in turn.

#### Caregiving time

Twenty-two 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 (Guogui, Du and Chen 2017, Liu *et al.* 2018, Liu *et al.* 2012, Liu *et al.* 2019, Lu *et al.* 2017, Song 2018, Tang 2006, Tong 2018), 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 (Guogui, Du and Chen 2017, Qian *et al.* 2014, Shen *et al.* 2019b, Wang *et al.* 2018, Yu *et al.* 2013). This was partly due to the time needed to meet the increasing needs of care recipients (Du *et al.* 2014, Liu, *et al.* 2012, Yu *et al.* 2015). Consequently, caregivers tended to struggle to meet both care duties and work demands, which tended to impede caregivers' personal lives (Liu, Zhao and Xiao 2015, Liu and Zhou 2009) and career development (Pan, Li and Zhou 2018).

Furthermore, a study that explored 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 burden 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 (Wang, Chen and Dong 2019, Wei *et al.* 2014).

#### Financial resources

Seventeen papers indicated that there were financial implications to providing care. Liu, Guo and Bern-Klug (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 responsibility, with no financial support from siblings (Liu 2016). In other cases, older caregivers living with long-term conditions, had limited financial resources to meet their own personal needs and that of the care recipient (Lu, et al. 2017, Wang, Chen and Dong 2019). Over time, family caregivers faced financial pressure from the inevitable increase in medical needs of older relatives (Chen 2017, Liu, Chen and Jiang 2017). The high costs of health and social care could be challenging for families with low income (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 due to the exorbitant cost of medical expenses for care recipient. In some cases, this contributed to the psychological burden they experienced (Du, et al. 2014, Du et al. 2017, Jiang et al. 2015, Liu, Guo and Bern-Klug 2013, Liu 2016, Pei, et al. 2017, Song 2018, Yong 2012). 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).

#### Role and personal strains

Forty-two papers referred to either role or personal strains. Role strains were created when the caregiving role precluded the caregiver from fulfilling other obligations, as parent, spouse, or employee. Twenty-three papers showed that caregivers felt stifled due to the demands of caregiving, especially those who themselves had poor health status (Chen 2017, Guogui, Du and Chen 2017, Liu, Zhao and Xiao 2015, Liu and Zhou 2009, Liu 2016, Shen and Wang 2016, Tong 2018). The high dependency of care recipients on caregivers, characterised by the severity of their long-term conditions and poor communication skills, placed particular demands on caregivers (Chen et al. 2017, Li, et al. 2009, Li et al. 2019, Liu, Chen and Jiang 2017, Song 2018). The older the caregivers, the more stress they experienced as the care recipients' ability to self-care reduced (Lv et al., 2013). This may relate to the findings of Wei et al. (2014) and Wang et al. (2019), who both found caregivers who were co-resident with care recipients were expected to meet the needs of their older relative at any time, and this negatively impacted on their well-being. By contrast, Li et al. (2013) found that stress levels were lower in co-resident caregivers, especially those who were competent in nursing care; the better the skillset of caregivers, the better they were at coping with the demands of the role. Further, Qiu, Sit and Koo (2017) noted that caregivers prioritised the well-being of care recipients at the expense of their own health as they felt obliged to expend their own 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, Li and Zhou 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 2016). For instance, caregiving demands created a sense of isolation, leaving caregivers disconnected from other people. Caregivers noted that 'no-one cares' about them, reflecting changes in society (Zhang, Clarke and Rhynas 2019). 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. Societal pressures to hide the existence of dementia, coupled with negative experiences of attempts to use social services and lack of appropriate longterm care facilities, left families caring without outside help and could consequently place strain and cause conflict in family relationships (Sun 2014).

Nineteen 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 both the physical and mental health of caregivers were adversely affected, in cases where caregivers were older people themselves (85 years and above), female, and uneducated, and the care recipient was male. Reduction in physical, cognitive and behavioural capabilities of the care recipient (Jiang, *et al.* 2015, Qian, *et al.* 2014, Sun 2014), as well as older age and poorer health status of caregivers (Liu, *et al.* 2019, Lu, *et al.* 2017, Pan, Li and Zhou 2018, Tong 2018, Wang, Chen and Dong 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, Yue and Liu 2007, Lu,

Liu and Lou 2015, Wang *et al.* 2015, Yu, *et al.* 2015) which disrupted caregivers' plans for social outings or hobbies (Liu, Zhao and Xiao 2015, Zhao 2011). Caregiver stress could precipitate breakdown in family relationships (Liu 2016), especially when caregivers perceived pressure from caring responsibilities (Chen 2017) and had no time to consider personal preferences (Yong 2012).

#### Preparedness

Four papers identified the role of preparedness of caregivers. Caregivers felt unprepared for meeting the needs of care recipients (Liu and Bern-Klug 2016), as they, for instance, were anxious about post-diagnostic management and felt they lacked appropriate skills (Chen 2017, Lian, *et al.* 2017). Wang, *et al.* (2018) suggested caregivers would benefit from psychological counselling to address the consequences of lack of preparedness in order to ease pressure.

#### Social roles

Ten papers considered the influence of gender in the context of caregiving. Women were considered emotionally susceptible to the pressures of caregiving, especially as they were providing most hands-on care (Fu, Yue and Liu 2007, Song 2018, Tang 2006, Wang, *et al.* 2015). Women were also found to experience more physical stress in comparison 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 (Liu, Guo and Bern-Klug 2013, Tang 2006). 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 2016).

#### Lack of adequate formal support

Twenty-two 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, Yue and Liu 2007, Guogui, Du and Chen 2017, Liu, et al. 2018, Liu, Chen and Jiang 2017, Liu, et al. 2019, Liu 2016, Wang, et al. 2015, Wang, et al. 2018, Zhang et al. 2013). 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, 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, in terms of care knowledge and skills, caregivers lacked professional support from primary health workers (Liu, et al. 2012). It was suggested that geographical distance between caregivers and care recipients can be a source of stress (Guogui, Du and Chen 2017) as the lack of local care services leaves caregivers with very limited options for delegation of caregiving tasks. 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 (Shen and Wang 2016, Yong 2012) 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, Liu and Lou 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. This suggests that higher physical burden in caregivers could result in low levels of satisfaction, which could consequently result in conflict between family members, and manifest as low level of support (Zhang, *et al.* 2013). In support, Qiu, Sit and Koo (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).

#### Coping

Fourteen papers were identified to have explored how caregivers were coping. Studies indicated a range of sources of external support were used. Shen, *et al.* (2019a) found that caregivers sought support from family members, professional care services and care-related government subsidies. From the study, only 5 per cent of respondents found the Government subsidy package somewhat useful. As most caregivers did not engage with professional services (Wei et al., 2014), Pan, Li and Zhou (2018) 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 no other option other than to rely on their family members and neighbours as they had only a few close friends to further assist (Yu, *et al.* 2013). Caregivers' children provided assistance as an act of being filial to parents (Liu 2016). Practical family and social support reduced burden by reducing the time caregivers devoted to caregiving and providing some respite (Li, *et al.* 2009, Shen and Wang 2016). In other cases, family members took the caregiving role in turns (Yong 2012). Conversely, Wang, *et al.* (2015) reported that increased numbers of social support 'helpers' was 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, Sit and Koo 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 senses of duty and responsibility (Davis, *et al.* 1995, Qiu, Sit and Koo 2017). Qiu, Sit and Koo (2017) further stated that caregivers coped by drawing on their inner strength. Offspring of older people were found to need more support compared to spouse 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 2016, Qiu,

Sit and Koo 2017). There was an expectation that immediate family members provided 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 (Qiu, Sit and Koo 2017, Sun 2014, Yu, *et al.* 2013). For example, some caregivers sought advice from social networks and engaged with formal services (Lian, *et al.* 2017) in order to be resourceful by seeking information to ground decisions and explore options. Liu, *et al.* (2012) found that in the absence of general practitioners, caregivers made use of media such as books, television, radio, and newspapers as sources for knowledge and skills acquisition. Some caregivers were found to utilise a distinctive coping strategy namely, a 'family-connected strategy' (Qiu, Sit and Koo 2017). More specifically, Sun (2014) stated that caregivers coped with family obscurities by planning ahead and engaging in direct confrontations. 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.

#### Discussion

The evidence provided in this scoping review, demonstrates the variety of stressors and coping mechanisms described by mainland Chinese people, providing care for older relatives living with long-term health condition(s). Key themes associated with stressors were caregiving time, financial resources, role and personal strains, preparedness, social roles, and lack of adequate formal support. These stressors showed a range of unmet needs for caregivers. These stressors can be continuous, distinct, and inevitably intertwined, as one stressor can be a triggering factor for another. It is important to note that cultural context and societal resources are critical

to understanding the nature and degree of unmet needs. Even though Lu, Zhang and Zhang (2021) asserted that rapid evolution of the principles of filial piety (Xiao) is leading to an increasing number of older people desisting from burdening their children, this review showed that there are various unmet needs of caregivers. With changes to communities and cultural values in China, it is plausible that these unmet needs could result in or exacerbate existing existential crises such as isolation and loneliness of caregivers. This could aggravate breakdown in relationships and even result in abuse of older people by their relatives. Fang *et al.* (2018) found that 42.8 per cent of 1002 older people aged between 55 and 90, were subjected to either physical or psychological abuse over a period of twelve months and victims had increasing odds of developing long-term health conditions. Thus, adequately capturing individual meanings associated with caring for older relatives has the potential to contribute to the body of evidence needed to address issues relating to efficiency and equity of long-term care provision in China (Yang *et al.* 2021).

The majority of papers retrieved for this review were cross-sectional studies, making it difficult to pinpoint meanings associated with cultural values. Therefore, it is unclear how much caregivers subscribed to the fundamental value of Xiao, as it might be that family care continues only from a sense of duty not from a sense of affection (Quinn, Clare and Woods 2010). Caregivers were subject to a significant level of stressors and the societal expectations attached to their role, coupled with the lack of adequate formal support services, appeared to influence the way they appraised their stressors and coping resources. With the evolution of Xiao, changing of family structures and a rapid rise in the number of older relatives needing daily care support (Lu, Zhang and Zhang 2021), it is expected that attitudes and motivations of caregivers will vary, and this will consequently determine if caregivers have negative or positive experiences.

In line with this, Knight and Sayegh (2010) suggested it is important to pay closer attention to the influence of cultural values on stressors and coping strategies instead of grouping caregivers as a monolith. Similarly, Burhanullah and Munro (2020) argued that more attention needs to be paid to the impact of evolving family structures, for instance, as this would impact on meanings associated with cultural values, which in turn, would affect caregivers and the appraisal of their role.

In a systematic review, McCabe, You and Tatangelo (2016) indicated that many unmet needs of caregivers were associated with lack of formal support. In line with this, our findings equally show that caregivers lack adequate support and more specifically, are not well prepared for taking on their caregiving role. Most found it stressful, especially with regard to financial costs and the provision of hands-on care. 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. 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. Future research could usefully develop and evaluate appropriate educational interventions which directly address the lack of preparedness experienced by caregivers. 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.

China is associated with a collectivist culture, which tends to promote interdependence, meaning that self-construal incorporates attention to others' needs and is therefore affected by the demands of the socio-cultural environment. However, even though caring responsibilities are culturally ingrained as paramount, the results

found in this scoping review indicate that little is known about the holistic needs of the caregivers whose services are 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; which could progress to caregivers' suppressing their emotions and consequently, limiting their ability to exercise agency. One of the main gaps in extant research relates to the need to understand how caregivers exercise their individual agency in relation to their personal attitude and capacity for caregiving. For instance, caregiving time was identified as a source of stress, but most papers failed to capture the interaction between caregiving time and time spent on other aspects of life. With rapid socio-demographic transitions, there appears to be an excessive demand placed on caregivers who are employees, due to the highly competitive job market in China. There is also rapid internal migration as people seek out better life opportunities; leading to the strains caused by caring from a distance. In addition, Warmenhoven, Hoebink and Janssens (2018) found that there are still lingering patrilinear values, with some men still expecting women to oblige the traditional model of care, especially with the care of parents-in-law. Given the continuing attitude that women should care, alongside the consequences of the onechild policy, there will be many women who are overloaded with care responsibilities.

As such, dilemmas associated with social roles and lack of adequate formal support have implications for time needed or available for caregiving.

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 are 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, lack of change for caregivers could be detrimental for their well-being. More specifically, with the socio-demographic transitions in China, Generation X and Millennials (those born from year 1965 – 2000) must reconcile the key message on Xiao of their childhood with the need to capitalise on economic opportunities, taking opportunities that life presents alongside managing being solely responsible for their ageing parents.

Although the papers reviewed cover a span of 25 years during which socio-economic and cultural environments in China have evolved rapidly, it was not possible to extract a sense of how care practices and meanings attached to caregiving have changed over this period. However, we noted that only two papers in this review were published between 1995 and 2004, with both focusing on whether there was caregiver stress. In the period from 2005 – 2020, there have been increasing number of publications (2005-2009 – four papers; 2010-2014 – 13 papers; 2015 -2019 – 28 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 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. It is therefore plausible to deduce that caregivers have been under increasing pressure to reconcile their caregiving tasks and care expectations with personal pursuits. Continuously having to adapt 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 with regard 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 significant number of papers showing that caregivers experience stress, only about one-third reported coping strategies which included both problem and emotional focused strategies; whereby caregivers took active steps in acquiring knowledge relating to their role and drew on family and social support to alleviate stressors. Even though the majority of caregivers in this review were dependent on family and social support and reported some level of alleviated stress, it is unclear whether this informal help had long-term benefits for the primary caregivers have to cope with a series of changes and care transitions (Moral-Fernández *et al.* 2018) and because filial responsibility may prevent caregivers from using formal services (Qiu, Sit and Koo 2017). The lack of detailed attention to ways of coping reflects the emphasis that has been placed on describing adverse caregiving experiences rather than exploring how people manage such experiences. It could also suggest that cultural underpinnings such as 'Ren( $\mathbb{Z}$ )' (endurance of hardship) steer researchers

away from exploring coping mechanisms in depth, as they share the belief that people typically get on with hard times (Lam *et al.* 2015).

This review highlights the relevance of the socio-cultural model of stress and coping (Knight and Sayegh 2010), pin-pointing important areas for future research in terms of the intersections between cultural values, such as Xiao, stressors and coping resources. Having established the interweaving features between culture and caregiving for older relatives, future research should explore the influences of Chinese culture on the process of caregiving. Culture is dynamic and its influence on caregiving processes is therefore challenging to measure with standardised quantitative measures. 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 in identifying unmet needs but do not provide insight into the complexities underlying the processes of caregiving. Only nine studies in this review 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. 2021), qualitative methodologies may be useful in providing a contextualised understanding of caregiving that could inform policy for future service development.

Taken together in the context of methodological issues, these findings could be drawn upon to inform service provision for Chinese indigenes in technologically-developed countries like the United Kingdom (UK) for instance. 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 with regards to

the needs of Chinese family caregivers in the UK. It is therefore important that families are supported in a sensitive manner that respects cultural values.

#### **Strengths and Limitations**

This review used a rigorous method to capture a wide range of papers by searching nine electronic databases for relevant literature, identifying papers written in English and Chinese. All abstract and full text screening was completed by three independent reviewers. Having the perspective of researchers from several ethnic groups further proved invaluable. Even though Chinese and English peer-reviewed papers were included, it is recognised that a search of grey literature could have generated further relevant papers. In line with scoping review methodology and our positionality, we did not exclude any papers on the basis of their quality but placed emphasis on synthesising existing evidence, in order to give a comprehensive overview (Peters *et al.* 2015). Despite the fact that two experienced librarians and several researchers developed the search strategy, key terms and descriptors used might have limited the numbers of papers retrieved from databases.

#### Conclusions

It is important to understand the needs of Chinese caregivers, particularly as stressors can be interwoven, are culturally situated, and have implications for coping mechanisms adopted by caregivers. Idiosyncratic contexts of caregivers, with respect to their needs, must be understood and used to inform service development. In addition, to enable the development of competent health and social care systems, stakeholders need to acknowledge that culture is multifaceted and 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? Future studies should further explore how caregivers exercise their agency, to enable them to fulfil their responsibilities in a way that best suits their circumstances and the implications of this for stressors and coping mechanisms. This would help define the nature of adequate support. Caregiving is complex and this review has identified areas that require further research, particularly recognising that the intricacies of the process of caregiving cannot solely be captured by adopting measures which rely on linearity. Thus, researchers, policymakers, health, and social care practitioners must endeavour to have more cognisance of the cultural environment whilst elucidating the phenomenon of caring for older relatives, so as to sustain both family and cultural values.

#### Supplementary material

The supplementary material for this article can be found at https://doi.org/10.1017/S0144686X21000817

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#### Author contributions

OB developed the study concept and design, developed and piloted the search strategy, conducted searches, screened articles, performed data extraction, analysed the data and led the writing of the manuscript. CQ contributed to the design of the study, helped develop the search strategy, co-screened the articles, checked the

quality of the data extraction, supported the interpretation of the results and critically reviewed the manuscript. LB contributed to the design of the study, helped develop the search strategy, supported the interpretation of the results and critically reviewed the manuscript. CW searched for eligible studies in the named Chinese databases, captured and translated relevant information into the English language, and reviewed the final draft of the manuscript. MK searched for eligible studies in the named Chinese databases, databases, captured and translated relevant information into the English language, and reviewed the final draft of the manuscript. MK searched for eligible studies in the named Chinese databases, captured and translated relevant information into the English language, and reviewed the final draft of the manuscript. LY identified eligible Chinese studies and critically reviewed the paper to ensure that it reflects and captures the key components of the papers found in the Chinese database, and also to ensure that the cultural nuances were adequately captured. JO contributed to the design of the study, helped develop the search strategy, contributed to the interpretation of the results and critically reviewed the manuscript.

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#### **Conflict of interest**

The authors declare no conflicts of interest.

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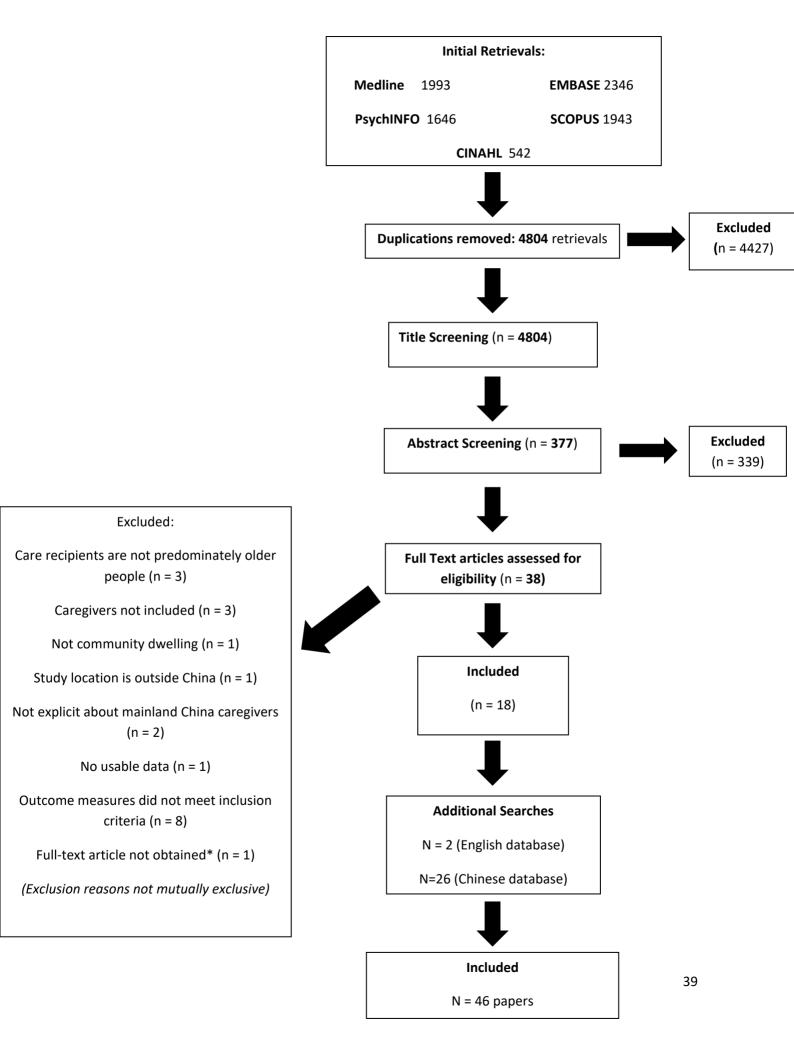


Figure 1: Flowchart of the search strategy

Table 1: Data Charted from 46 Papers Included in the Review

STUDY (PUBLICATION 1. STUDY DESIGN. YEAR)

CAREGIVERS' STRESSORS AND COPING MAIN FINDINGS MECHANISMS.

- 2. NO OF CAREGIVERS (CG)
- 3. CARE RECIPIENTS' LONG-TERM CONDITION (LTC)
- 4. LOCATION- CITIES OR PROVINCES
- 5. CHARACTERISTICS OF CAREGIVERS (CG).

Davis et al. (1995)	1.	Primarily Qualitative study.	Stressors	Women were the main carers of older people and experienced
	2.	75	Lack of essential amenities	caregiving burden (physical, social, psychological and
	3.	Series of long-term conditions.	Lack of formal support	financial). These were attributed to meeting various needs of care recipients, as caregivers
	4.	Beijing, Tianjin and Guangzhou	Coping	were spouses and older themselves. Caregivers
	5.	Age range: 23-89. Gender: Male: 39;	Attributes of caregivers	primarily found psychological support through their moral

	Female: 36. 70 married, 5 widowed.	Finding practical solutions	qualities as they found strength in their self-confidence, the sense of duty, responsibility and care obligation. Also, caregivers actively sought for practical solutions.
Lian et al. (2017)	1. Qualitative study.	Stressors	Four themes reported addressed 1. capabilities to
	2. 20	Lack of solution	detect the memory loss at an
	3. Dementia.	Societal perception of condition	early stage. 2. Perceptions and beliefs about dementia in the
	4. Chongqing	Early diagnosis	community. 3. Different journeys toward the diagnosis.
	<ol> <li>Caregivers had cared for older relative for at least 6 months. Age: Mean (SD) 58.0 (15.1),</li> </ol>	Behavioural management	<ol> <li>Expectations of a smooth journey for others. Findings suggest that the transitioning</li> </ol>
	Gender: Male: 4; Female: 16. 19 Married, 1 Unmarried.	Financial difficulties	period can be challenging for caregivers of people living with dementia. Caregivers found
		Coping	support through social support and seeking advice from
		Social support and formal services	relevant professionals.
Liu, (2016)	1. Case study	Stressors	Significant pressure was associated with caring for an
	2. 1	Financial stress	older relative. Family members continue to play a central role in
	3. Disability	Health status of caregiver	providing support based on the values of filial piety. It would

	4. Hunan 5. Female family caregivers	Personality of care recipient Caregiving role Family conflict Lack of care skills and knowledge	require additional support from the government, community services and professional support to reduce the pressure on family caregivers.
		<b>Coping</b> Family support	
Liu and Zhou (2009)	<ol> <li>Qualitative study: (Descriptive), in-depth semi- structured interviews.</li> <li>15</li> <li>Stroke (N= 9), Senile Dementia (N= 3), Parkinson's disease N=1), Coronary atherosclerotic heart disease (N= 1), Cancer (N= 1). Most care recipients had comorbidity and multimorbidity.</li> </ol>	Stressors Physical status of caregivers Financial difficulties Coping Not reported	Care recipients with stroke had greatest care needs. Most caregivers had limited personal time; their physical health deteriorated due to caregiving, resulting in significant psychological burden. Caregivers found medical expenses exorbitant, which contributed to stress. Relationships between caregivers and care recipients were strained.
	4. Shanghai		

#### 5. Family caregivers

Qiu et al. (2017)	1. Qualitative stu	dy Stressors	Three coping themes were reported:
	2. 25	Standard of formal services	
	3. Stroke	Financial difficulties	1. Caregiving role perception: belief that caregiving was the
	4. Nanjing	Accessibility of social support	'right and proper' thing to do, based on reciprocity and
	5. Age range: 45 Gender: Male Female: 19.		cultural/role expectations, influenced by role modelling of other family members. 2.
	Relationship w recipient: Spot		Coping strategies: seeking
	Child or Child- Education: Prii Junior high 10 Postsecondary University 2. Caregiving cor Time spent (hr 16hrs; Caregiv resident with c recipient 23.	in-law 9. Sense of care obligations mary 4; ; y 9; ndition: r/day) vers co- are	practical support and assistance from family members. 3. Self-sacrifice: self- reliance and sacrificing their own health to put the care- recipient first. Caregivers were also reluctant to use formal services due to concerns about their quality and costs.
Sun, (2014)	1. Qualitative stu	dy Stressors	Limited physical, cognitive and behavioural abilities of care
	2. 18	Attributes of care recipients	recipients were directly linked
	3. Dementia		with the increase in the demands of the role. Salient

	4.	Shanghai.	Demands of the role	stressors such as the role
		Age range: 53-82 years. Gender: Female: 11; Male 7.	Family conflict Societal pressure	strain, family conflict and societal pressure were identified. Caregivers coped in various ways, which included
		Relationship with care recipient: Spouse 14; Adult-Child 3; Daughter in-law 1. Employment status: Employed 3; Retired 15.	<b>Coping</b> Attributes of caregivers Personal and external resources	drawing on personal experiences, religion, technology and sought support from doctors whilst some planned ahead.
				_
Wang et al. (2018)	1. 2.	Qualitative study	Stressors Low or no level of preparedness	Three themes related to caregiver stressors: care knowledge and skills,
	3.	Dementia	Lack of support from both informal and formal	psychological counselling, collaborative management.
	4.	Beijing	services	Themes reflected lack of support. Participants had
	5.	Mean age 66.9 +/- 16.6. Gender: Female:	Coping	negative emotions related to inability to provide adequate
		9; Male: 1. Marital status: Married 9; Widowed 1. Relationship with care recipient: Spouse 6; Adult children 3; Other relative 1.	Not reported	care. They considered caregiving as a burden, characterised by lack of professional support and lack of socialising time.
Yong, (2012)	1. Q	ualitative study	Stressors	Three themes reported relates to the mental health status of caregivers of older relatives,

	2. 1	10	Financial difficulties	feelings associated with caring
	3. [	Dementia	Lack of respite	for older relatives and lack of long-term care services. Caregivers play an integral role
	4. N	Not specified	Lack of awareness	in caring for older relatives
	5. 1	Not specified	Physical health status of caregivers	including prioritizing the need of older relatives ahead of theirs.
			Inability to balance work and care	They were anxious about managing the health of older
			Coping	relatives due to lack of adequate support and still had
			Family support	to provide a high-level of hands on nursing care. Caregivers experienced high levels of burden with negative health outcomes. Caregivers relied on family members for support.
Zhang et al. (2019)	1.	Qualitative study	Stressors	Three overarching themes identified that caregivers felt
	2.	14	Caring at home	that 'no one cares', as a result
	3.	Dementia	Caregiving role	of changes in society which highlights their state of
	4.	Shandong		disconnection. Thus, fearing that ' <i>home care may create a</i>
	5.	Age range: 39-78. Relationship status: Spouses, Parent and offspring.	Coping Not reported	sense of social isolation'. 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 'home care versus institutional care', 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)	1. Cross-sectional study	Stressors	Majority of care recipients lived with dementia. Family
	2. 208	Lack of family support	caregivers were mostly female, some caregivers were older
	<ol> <li>52.8% 'disabled elderly', 47.2% 'semi-disabled</li> </ol>	Duration of care	people and they were spouses to care recipients. Poor physical
	elderly'.	Caregivers' physical health status	health status of caregivers made it difficult for them to bear
	4. Shanghai	Financial difficulties	heavy burdens. The long hours needed to provide care,
	5. Gender: Female: 62.1%; Male: 37.9%. Relationship status: daughters, spouses, sons,	Lack of adequate skillset to provide care	adversely contributed to both physical and psychological well- being of caregivers.
	daughters-in-law, other	Coping	Family caregivers reported
	family members, sons-in- law.	Not reported	being under great pressure, as they did not have enough people to share care responsibilities with. Caregivers

were subjected to financial stress and lacked the set-skills

needed to provide adequate care as some received little support from professionals.

Chen et al. (2017)	1. Cross-sectional study	Stressors	Caregivers were subjected to caregiving burden. When
	2. 203	Age of caregivers	compared with caregivers who cared for relatives aged 75+
	3. Disability	Care recipients' self-care ability	and above, caregivers who took care of relatives aged 60-74,
	4. Zhejiang		presented with higher levels of time-dependence burden,
	5. Gender: Female: 123	Coping	developmental burden and
	(60.6%); Male:80 (39.4%). Relationship with care recipient: Children: 51; Spouses: 116; Other family members: 36.	Not reported	physical burden.
Du et al. (2014)	1. Cross-sectional study.	Stressors	Lack of self-efficacy and
	2. 744		financial capability on the part
		Lack of social support	of the caregivers, contributed to
	<ol> <li>Dementia: 112 (15.1%); Non-</li> </ol>	Financial difficulties	the adverse health outcome
	dementia: 632 (84. 9%)	Demands of caregiving	(depression). Caregivers with depressive symptoms lacked

	4.	Beijing	Relationship status	social support (subjective
	5.	Gender: Male: 282(37.9%); Female: 462 (62.1%). Age: $\leq 40: 23 (3.1\%); 41-59:$ $353 (47. 4\%); \geq 60: 368$ (49.5%). Relationship with care recipient: Spouse: 242 (32.5%); Child: 469 (63.0%); Other: 33 (4.5%).	Coping Not reported	support and utilisation of support). Based on the relationship with care recipients, spouses spent more time addressing the needs of care recipients.
Du et al. (2017)	1.	A cross-sectional study.	Stressors	Caregivers were subjected to a moderate amount of burden.
	2.	766	Financial difficulties	Out of pocket money was
	3.	Older people living with long term conditions. Top five conditions are	Subjective caregiving burden	associated negatively to general well-being of caregivers. Time spent
		hypertension, stroke, coronary diseases,	Coping	providing care, especially with
		diabetes and osteoarthritis. Most had more than 4 chronic conditions.	Not reported	care recipient living with co- morbidity, associated negatively with some aspects of caregivers' HRQoL. Subjective
	4.	Beijing		caregiving burden negatively
	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%).		correlated with caregivers HRQoL.
Fu et al. (2007)	<ol> <li>Cross sectional study</li> <li>42</li> </ol>	Stressors	Care recipients' pathological behaviours were found to be a
	<ol> <li>2. 42</li> <li>3. Dementia</li> <li>4. Beijing</li> <li>5. Gender: Male: 27(64.29%); Female: 15 (35.71%). Average age: 73±7.</li> </ol>	Behavioural challenges Gender Coping Not reported	stressor and correlated with adverse health outcomes (depression and anxiety). Caregivers demonstrated 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.
Guogui et al. (2017)	1. Quantitative design 2. 11331	Stressors The health status of the caregiver	Caregivers spent an average of 38.3 hours per week caring for care recipients. The main

3. Not specified	Distance	difficulties for caregivers were physical exhaustion, distance,
4. Nationwide	Lack of adequate skillset	lack of time and dilemma relating to finances. This partly
5. Gender: 52% Male. Age: 31.5% were 60-64.	Lack of time to provide care	contributed to the psychological pressure experienced by
Remainder were 65 years+. 64.9% Married. Education: 64.9% primary school and below	Financial difficulty	caregivers, whom were older people themselves.
Delow.	Coping	
	Not reported	
1. Cross-sectional study	Stressors	The magnitude of the role was associated with adverse
2. 110	Demands of caregiving role and individual	caregiver health outcomes.
3. Dementia	attributes	Characteristics of the care giver and recipient affected
4. Shanghai	Coping	caregivers' mental health. Older caregivers had "other types" of
5. More female caregivers. Majority were married. About half were employed and half retired. More than 50% of primary caregivers were children and spouses. More than 30% of spouses were older people themselves.	Not reported	work, distant relatives, care recipients with severe dementia. These caregivers experienced a higher psychosocial impairment indexes than other groups. Being female, un-educated, with care-recipient being male
	<ol> <li>Not specified</li> <li>Nationwide</li> <li>Gender: 52% Male. Age: 31.5% were 60-64. Remainder were 65 years+. 64.9% Married. Education: 64.9% primary school and below.</li> <li>Cross-sectional study</li> <li>110</li> <li>Dementia</li> <li>Shanghai</li> <li>More female caregivers. Majority were married. About half were employed and half retired. More than 50% of primary caregivers were children and spouses. More than 30% of spouses were older</li> </ol>	<ul> <li>A. Nationwide</li> <li>Lack of adequate skillset</li> <li>5. Gender: 52% Male. Age: 31.5% were 60-64. Remainder were 65 years+. 64.9% Married. Education: 64.9% primary school and below.</li> <li>Choping Not reported</li> <li>Cross-sectional study</li> <li>Stressors</li> <li>110</li> <li>Dementia</li> <li>Dementia</li> <li>Shanghai</li> <li>Coping</li> <li>Not reported</li> <li>Not reported</li> <li>Not reported</li> <li>More female caregivers. Majority were married. About half were employed and half retired. More than 50% of primary caregivers were children and spouses. More than 30% of spouses were older</li> </ul>

Li et.al. (2009)

#### 1. Cross-sectional study

(76.4%); Other family

members: 23 (4.1 %).

Age: ≥ 20:40 (7.0%); ≥40:

#### Stressors

2.568 3. Chronic diseases (hypertension, diabetes, coronary heart disease, emphysema, asthma, gallbladder and gastrointestinal disease, stroke, glaucoma or cataract. Parkinson's disease, prostatic hyperplasia, cancer, osteoarthritis, rheumatism). 4. Fuzhou 5. Gender: Female: 306 (53.9%); Male: 262 (46.1%). Relationship with care recipient: Children 111 (19.5%); Spouses: 434

Financial difficulties Co-morbidities/multi-morbidities **Coping** Social support 83.5 % 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, education level of caregivers and occupation were influencing factors relating to family burden. Caregivers of older relatives with decreased self-care ability and depressive symptoms had a higher burden in comparison to 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. Caregivers found social support useful in terms of reducing caregiving burden with the family.

and over 85 years, affected caregivers' physical health.

108 (19.1%); ≥60: 420 (73.9%).

Li et al. (2013)

1. Cross-sectional study The care recipients' Activity of Stressors Daily Living (ADL) score, health 2.418 Care recipients' characteristics and caregivers' status, age, availability of self-efficacy spouse, the caring abilities of 3. Disability: caregivers and the availability of Coping helpers were associated with Hypertension (60.3 %), the burden of caregivers. Heart disease (47.8 %), Not reported 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.

Li et.al. (2019)	<ol> <li>Cross-sectional study</li> <li>291</li> <li>Disability: 175 cases         <ul> <li>(60%) of visual disturbance;</li> <li>106 cases (36%) of hearing</li> <li>disorders; 91 cases (31%)</li> <li>of communication disorders</li> <li>; 152 cases (52%) of</li> <li>cognitive ability injury; 121</li> <li>cases (41%) of urinary and</li> <li>faecal incontinence; 107</li> <li>cases (37%) of severe</li> <li>activity of daily living injury;</li> <li>25 cases (9%) of pressure</li> <li>sore; 78 cases (27%) of fall</li> <li>in a year; 254 cases (87%)</li> <li>of chronic diseases for</li> <li>disabled older people.</li> </ul> </li> <li>Zhejiang</li> <li>Not reported</li> </ol>	Stressors Demand of caregiving role Coping Not reported	Caregivers experienced moderate to high level of caregiving burden on family members. The results of multi- factor analysis showed that long-term caregivers of care recipients with low overall health perception contributed to caregiving burden.
Liu et al. (2012)	<ol> <li>Cross-sectional study.</li> <li>90</li> <li>Diagnosis of dementia or non-dementia</li> </ol>	Stressors	There were significant increases in CBI scores between the severe dementia and non-dementia (comparison group). In the dementia group,

4 5	<ul> <li>(hyp diab failu</li> <li>Beiji</li> <li>Mea 3.66</li> <li>13; I</li> <li>Rela recip offsp resid No: statt</li> <li>Une Retii leve</li> </ul>	nic diseases ertension, etes, chronic renal re, osteoarthritis). ing. in age 77.02 +/- 5. Gender: Male: Female: 77. ationship with care bient: Spouses: 48, bring: 10. Co- dence: Yes: 86, 4. Employment us: Employed: 24, mployed: 13, red: 53. Education I: none: 7, Primary bol: 17, Secondary	Coping Problems solving	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%, radio 12% and book 12%). Only 11% of caregivers were guided by GPs in the daily care of people with dementia
		ool: 46, Tertiary ool: 20.		
Liu et al. (2013)	1.	Survey Study	Stressors	The income of adult-children and the status of being the
	2.	895	Financial situation	eldest son were related to economic stress. Economic
	<ol> <li>Oldest old in China (mean age of 90)</li> <li>31 provinces in China</li> </ol>	China (mean age	Caregivers' health status	stress was related to economic capability of caregivers
		01 90)	Societal expectations	(children of care recipients) as
				the oldest-old parents were financially dependent on their children, due to rarity of
	5.	Age: mean age= 55.8 (SD=7.3).		pensions. Unmarried caregivers

	Most caregivers were in their 50s (46.5 %) and 60s (33.4 %). Gender: 74.9 % of caregivers were males. 58.9% lived in rural areas.	Coping Not reported	reported significant economic stress. Eldest sons were reported to experience more economic stress in relation to caring for the oldest old compared to other siblings.
Liu et al. (2015)	1. Cross-sectional study	Stressors	Highest score in terms of caregiving was time-dependent
	2. 124	Care recipient characteristics	burden, followed by developmental burden and
	3. Disability	Time devoted to care	physical burden. Age of older relative, self-reported illness,
	4. Chong Qing	Physical health status of caregivers	general health status and health changes, daily caregiving time
	5. Gender: Female: 89; Male: 35. Age: 18-35: 18;		on the part of caregivers and self-reported illness status
	36-45: 41; 46-60: 39; >60: 26. Retirement status: 59	Coping	indicated that caregivers were subjected to a substantial
	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.	Not reported	amount of burden.
Liu et al. (2017)	1. Cross-sectional study	Stressors	Per capita monthly income of families (caregivers), self-care

	2 80	Nature of long-term condition	ability and severity of dementia in older relatives, and the
	3 Dementia	Lack of training	demand of care on caregivers were statistically significant.
	4 Shanghai	Demands of caregiving	There was a high care demand placed on caregivers of older
	5. Gender: Male: 28; Female: 52. Age range: 38- 93. Education: Middle school or below: 67;	Monthly household income (per capita)	relatives with dementia especially as they lacked the knowledge and skillsets.
	College or above: 13. Family monthly income:	Coping	
	<ul> <li>&lt;3000 Yuan: 31; 3000~</li> <li>4000 Yuan: 37; &gt;4000</li> <li>Yuan: 12. Relationship with care recipient: Spouse: 23; Others: 57.</li> </ul>	Not reported	
Liu et al. (2018)	1. Cross-sectional study	Stressors	Caregivers younger than 40; with chronic conditions; who
	2. 1000	Age	slept for less than seven hours had significant higher scores for
	3. Not specified	Caregivers' own health status:	depressive symptoms than those in the other groups.
	4. 10 cities in 5 provinces in East and Central China	Older relatives' care need	Caregivers that spent less than two hours a day caring for older
	5. Average age of the main family caregivers was 42.7 ±12.7 years old. Female:	Lack of family support	relatives had significant low scores for depressive symptoms. Likewise, caregivers of older relatives who did not

	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%.	Coping Not reported	need help with regards to tasks such as housework and transportation had a significant low score for depressive symptoms in comparison to other groups. Caregivers of older people who often or always needed help with their health had a significant high depression score.
Liu et al. (2019)	1. Cross-sectional study	Stressors	72 (22. 8%) caregivers of older relatives had mild burden, 189
	2. 316	Age of caregivers	(59. 8%) had moderate burden, 55 (17. 4%) caregivers had
•	3. Disability	Relationship with care recipient	severe burden. Personal burden (30. 42 8. 82), role
	4. Ning Xia	Health status of caregivers	burden (17. 79 4. 35) and total burden (48. 32 ± 15. 19).
	5. Gender: Female: 223; Male: 93. Age range: 40-49:	Low level of training	There was a significant difference in the burden scores
	58; 50-59: 87; 60-69: 129; 70-75:42. Marital status:	Duration of care	between different ages and caregivers with disability, health
	Married: 281; Not married: 1; Divorced: 26; Widowed: 8. Education: <primary school: 75; Junior high school: 158; High school or</primary 	Financial difficulties and economic income.	statuses, whether they had received relevant care guidance or training, caregiving time, number of assisted caregivers
		Coping	and different economic incomes (P<0. 05).
	technical secondary school: 61; College: 20; Higher	Not reported	There was also a negative correlation between caregivers'

35; 2000-2999 Yuan: 169; 3000-3999 Yuan: 39; 4000- 4999 Yuan: 21; ≥5000 Yuan: 2.
Liu and Klug (2016) 1. Survey Study. Stressors Physical and cognitive function scores (ADL, IADL and MMSE)
2. 895 Self-efficacy for care recipients indicated
3. Oldest Older parents.       care needs were low.         Caregivers reported high levels
4. 8 coastal provinces in of concerns with regards to their China Coping self-efficacy (WAP) in
comparison to items on <i>ZBI</i> .
5. Mean age (in years) Not reported 55.83; Linear regression showed:
Gender: Female (daughter):
25.14% Married: 89.61%
Living rural areas: 58.88%. long term care for older people
Retired or not working: with high IADL needs, had a
38.97%;high level of WAP; 2) EmotionalPart-time workers (18.19%);closeness and sibling support
Full-time workers (42.84%).
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 reported by caregivers living with the oldest old; 7) Daughters were preferred to sons in terms of providing care.

Liu and Lou, (2012)	1. Cross-sectional	Stressors	Health deterioration of caregivers was associated with
	2. 720	Caregivers poor health status	caring for older relatives. In response to their financial
	3. Disability	3. Disability Financial difficulties	
	4. Shanghai City		months, 41.0% thought they had barely enough (295), 28. 2% thought they had enough
	<ol> <li>Majority of caregivers were women, middle-aged,</li> </ol>	Coping	(203), 5.0% thought they had enough with spare (36), 19.3%
	older people, retired, with average economic conditions, providing long periods of care.	Not reported	thought they did not have enough (139), 6.4% practically had nothing (46).
Lu et al. (2015)	1. Survey study.	Stressors	ADL was significantly associated with depressive
	2. 494		·

3.	Frail elders with musculoskeletal conditions.	cognitive status and behavior
4.	Shanghai	Coping
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 above: 426. Lived with care recipient: Yes: 335; No: 158.	Not reported

Care recipients' functional dependency (ADL), cognitive status and behavioural challenges.

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 (which was also 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 levels of 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.

Lu et al. (2017)	1. Cross-sectional study	Stressors	The burden of caregivers of older relatives in rural areas
	2. 375	Gender	was found to be moderate. Gender, age, residential status,
	3. Disability	Caregivers attributes	subjective support, level of management of care recipients'
	4. He Nan	Care recipient's attributes	long-term conditions and
	5. Gender: Male: 155; Female: 220. Age range:		emotional state of the caregiver were the main factors that influenced caregiving burden. Social support negatively
	27-87; Average age: 54.23	Coping	
	±13.50. Relationship with care recipient: Spouse: 131; Offspring: 244.	Not reported	correlated with the caregiving burden.
Lv et.al. (2013)	1. Cross-sectional study	Stressors	Young and middle-aged caregivers in rural areas were
	2. 119	Financial difficulties	under a relatively high economic distress as caregiving
	3. Chronic disease, not	Self-care ability of care recipient	had impact on their ability to
	specific.	Caregiving time	work, which had implications on caregivers meeting care

	<ul> <li>4. Zhejiang</li> <li>5. Gender: Male: 40; Female: 79. Relationship with care recipient: Spouse: 23; Offspring: 96.</li> </ul>	Low income Caregiver's age Coping Not reported	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 high 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 level, occupation, patient's self-care ability and mood.
Pan et al. (2018)	1. Cross-sectional study	Stressors	The older the caregiver the more the burden reported.
	2. 190	Age of Caregivers	Caregivers in full time employment reported a higher
	3. Chronic obstructive pulmonary disease	Time of care	of burden in comparison to part time workers or those without a
	(COPD)	Occupation	job. The longer the time of caregiving/ per day, the heavier
	4. Not specified	Availability of formal services	the burden. Caregivers with
	5. Gender: Male: 93; Female: 97. Age: <60: 98; ≥60: 92. Relationship with		better access of care reported less caregiving burden and the higher the level of social

	care recipient: Spouse: 84; Offspring: 59; Others: 47. 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 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.	Coping Social support	support received; the less care burden experienced by caregivers.
Pei et al. (2017)	<ol> <li>Survey study</li> <li>214</li> <li>Not specified</li> </ol>	Stressors Logistics of caregiving	Lack of support for caregivers in employment were reported, as time and financial dependence on caregivers by care recipients
	<ol> <li>Not specified</li> <li>Central China</li> <li>Gender: Male: 116;</li> </ol>	Time and financial implications of caregiving Gender	were found to be stressors. There was a 5% chance of experiencing negative employment consequences with
	Female: 98. Monthly income (Mean SD): Male:		an hour increase in care provision. As total care

	2933.4(197.3); Female: 1996.0 (115.8); Types of employment %: Permanent: Male: 25.9; Female: 25.5; Contract: Male: 66.4; Female:70.4; Other: Male: 7.8; Female: 4.1.	Coping Not reported	expenses moved up a 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 caregiving burden.
Qian et al. (2014)	<ol> <li>Cross-sectional survey</li> <li>243</li> <li>Dementia and non-</li> </ol>	Stressors Age of care recipient	The prevalence rate of anxiety was 29.2% reported by family caregivers. The average score of SAS was 35.6 ± 8.6. The risk
	dementia.	Caregivers characteristics	factors of caregivers' anxiety included Barthel index score ≤
	<ol> <li>Beijing</li> <li>Gender: Male: 88         <ul> <li>(36.2%); Female: 155</li> <li>(63.8%); Age: &lt;60: 132</li> </ul> </li> </ol>	Low social support Coping	20 (OR=1.51), SSRS score ≤ 33 (OR=4.56), no time to relax (OR=1.57) and poor health status (OR=3.48). Relative high levels of anxiety existed in
	(54.3%); ≥60: 111 (45.7%). Relationship with care recipient: Spouse: 79; Children: 135; Other: 29.	Not reported	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 among family caregivers with lower social support.
Shen et al. (2019a)		urvey Study	Stressors	All participant groups experienced moderate levels of
	2. 60	)1	Caregiving role	stress, increasing with time with
		lder people with sability.		the highest level reported by spouses. Different relatives received different levels of
	4. Na	anjing	Coping	support from the market, family members and the government
	16 31 Re re	ean age: 48.36 (SD 5.14); Gender: Male: 10; Female: 291. elationship with care cipient: Spouse: 514; ffspring: 53; Other: 4	Family, market and governmental support.	with spouses receiving less support from the family members and 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 or unsatisfied with the services.

services. The heavier the physical and psychological

Shen and Wang, (2016)	1. Cross-sectional	Stressors	Older caregivers with higher family economic income, were
	2. 605	Lack of care information	willing to buy care services. Caregivers with children were
	3. Over 60- disability	The health status of the caregivers	more willing to buy care services. The lower the self-
	4. Nanjing	Health status of the care recipient: self-care ability	care ability of care recipients, the stronger the willingness of
	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-	Duration of care	family caregivers to purchase care service. The longer family caregivers took care of care recipients", the stronger their willingness to buy care services, but in cases where
	7999 Yuan: 8.7%; > 8000 Yuan: 7.0%.	Family support	someone came to the assistance of caregivers, there was a decline in their willingness to buy care

Song, (2018)

#### 1. Cross-sectional study

3. 24.5% of the older people can take care of themselves, 48.5% are semi-bedridden, and 27.0% are completely bedridden

4. Shandong

2,219

5. Gender: Female: 61.9 %. Age: ≤35: 9.1%; 36-44: 25.6%; 45-54: 47.5%; ≥55: 14.6%. Stressors Time providing care

Individual characteristics Family characteristics and cultural value Family support

Financial pressure

Coping

Not reported

burden, the greater the willingness to purchase care.

Caregivers were mostly family members who were older people and were spouses. More than 60% of caregivers who provided long-term care was 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 had an important impact on caregivers' sense of burden. As caregivers grew older, awareness of their responsibilities for caring increased significantly, showed greater recognition for caring activities, and sense of burden decreases significantly. Caregivers living with long-term conditions associated care with a greater burden. Caregivers with better self-rated health. tended to have more negative attitudes towards caring for

older people and felt more burdened.

Tang, Y. (2006)	1. Cross-sectional study	Stressors	Men and women showed statistically significant
	2. 300	Financial difficulties	differences in economic, time
	3. Not specified	Time of caregiving	and psychological stress. Married sons and unmarried
	4. Chongqing	Caregivers psychological status	sons felt more economic pressure, while daughter-in-law
	5. Gender: Male: 48.7%; Female: 51.3%. Education: 36.7%	Caregivers physical status	and married daughters felt more time and psychological pressure. Time was the most
	graduated from senior high school; 28.1% from junior college; 15.1% were college students or above. All caregivers were offspring (adult- children).	Coping Not reported	, followed by psychological and financial difficulties. Respondents stress scores were greater than three, which indicated that they faced a medium level of stress over a short duration of care.
Tong, (2018)	1. Cross-sectional study	Stressors	Caregivers had moderate nursing burden. The health
	2. 90	Health status of caregivers	status as some care givers had
	3. Spinal cord injury	Caregiving time	their own long-term conditions; daily care time and lack of support in terms of nursing care
	4. Shenyang	Lack of nursing care support	support in terms of nursing care

	Mal yea 4.1 helj poc	Gender: Female :67, le: 23. Age range: 18 -70 ars; Average age: 45.62± 9. Caregivers without p: 67. Caregivers with or health status 51. rsing time range: 4 -24 urs.	Coping Not reported	contributed to caregiving burden.
Jiang et al. (2015)	1. 2. 3. 4. 5.	Cross-sectional study 64 Alzheimer's disease Chongqing Gender: Male: 28; Female: 36. Age: <50: 15; ≥50: 49. Relationship with care recipient: Spouse: 26; Child: 33; Other: 5.	Stressors Physical health status Financial difficulties Coping Subjective social support	The SCL-90 total scores and the scores of somatisation, compulsion, interpersonal sensitivity, hostility, terror, paranoid, psychotic 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 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 of common type of dementia (P < $0.01$ ). The total score of SCL- 90 of family caregivers were significantly positively correlated with 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 ( $ \beta $ ) =0.831, 0.186, 0.145, 0.108, 0.089, 0.081, R2=0.892. Home caregivers of patients with AD had a poor mental health.
Wang et al. (2015)	1.	Cross-sectional study.	Stressors	Higher level of stress and prevalence of Behavioural and
	2.	152	Caregiving demands	Psychological Symptoms of Dementia (BPSD) was
	3.	Dementia	Behavioural management	reported. Women reported
	4.	A capital city of a province	Gender	higher level of stress in comparisons to male counterpart. The more the
	5.	Gender: Male: 43; Female: 109.	Family support	helpers available to help caregivers, the higher the level
		Employment status: Employed: 39; Unemployed: 113.	Time dependency	of distress experienced. This was attributed to lack of support

	Relationship with care recipient: Spouse: 55; Non spouse: 97. Co- residence: No: 35; Yes: 117. Financial burden: No: 68; Yes 84.	Financial difficulties Coping Not reported	for caregivers of people living with Dementia i.e. lack of dementia education for caregivers and health care professionals to help manage from day to day. Some caregivers reported having financial difficulties.
Wang et al. (2019)	1. Cross-sectional study 2. 208	Stressors Financial difficulties	The age, residence, work and daily care hours of the carers was associated with level of caregivers' burden. Caregivers
	3. Chronic heart failure	Care recipient ability to self-care	whose older relative had to self- fund their treatment
	4. HaErbing	Age of caregivers and resident status	experienced a higher level of caregiving burden in
	<ol> <li>Gender: Male: 51; Female: 157. Age:</li> <li>&lt;60 years: 92; 60-70 years: 69; 70 years and above:</li> <li>47. Marital status: Married: 173; Unmarried: 35. Education: Middle school and below: 89; High school and above: 119. Income: &lt; 3000 Yuan: 73; &gt; 3000</li> </ol>	Caregiving time Coping Not reported	comparison to those who had access to public services. Care recipients who could barely attend to their needs were highly dependent on caregivers, which in turn increased their burden. Older caregivers experienced higher levels of burden and caregivers who lived with care recipients

	Yuan: 135. Employment status: Employed: 83; Not employed: 67; retired: 58. Relationship with care recipient: Spouse: 92, Offspring: 79, Others: 37. Caregiving time (hrs): < 3: 29; 3-6: 74; > 6: 105.		showed a higher level of burden.
Wei et al. (2014)	1. Cross-sectional study	Stressors	The prevalence rate of anxiety was 29.2% reported by family
	2. 744	Living arrangement	caregivers. The average score of SAS was $35.6 \pm 8.6$ . The risk
	3. Disability (High blood	Caregiver's self-reported health status	factors of caregivers' anxiety included Barthel index score ≤
	pressure (72.7 %). Stroke	caregivers	20 (OR=1.51), SSRS score ≤ 33 (OR=4.56), no time to relax
	(50.5%). Coronary heart disease (48.4%). Diabetes		(OR=1.57) and poor health status (OR=3.48). A high level
	(41.3 %). Osteoarthritis (30.9%)	Coping	of anxiety exists in family caregivers for the disabled
	4. Beijing	Social support	elderly. Caregiver anxiety was a complex process. The results showed that the older the
	5. Age range: 26 - 89 years.		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.

Yu et. al (2013)	1.	Cross sectional study.	Stressors	MCS correlated with Barthel index (BI) of care recipients,
	2.	121	Time dependence	which showed that functional
1	3.	Stroke.		independence of care was associated with high MCS
	4.	A city in central China		score. The Mental Component
	5.	Age (years): <45: 5;	Coping	Summary (MCS) sub-scale of
		46–64: 38; >65: 78.		HrQoL negatively associated
		Age range: 32-82.	Problem solving coping	with number of caregiving hours
		Gender: Male: 33;		per day, as well as the number
		Female: 88. Marital	Social support	of caregivers' long-term
		Status: Single: 1,		conditions. Problem focused
		Married: 110,		coping strategies, active coping
		Divorced: 2, Widowed:		and planning were found to
		8. Relationship with		positively correlate with the
		care recipient: Spouse:		mental health of caregivers.
		96; Offspring: 15.		Caregivers perceived social
		Employment status:		support mainly came from
		Unemployed: 5;		family members and neighbours
		Retired: 101;		and the least amount of support
		Employed: 2; Other:		came from their friends.
		13.		

With regards to social support for family caregivers, difference between caregivers' older relatives with anxiety and those with no anxiety was found to be statistically significant.

Yu et al. (2015)	1.	Cross-sectional study	Stressors	Cognitive functioning in care
	2.	168	Attributes of care recipient	recipients negatively associated with caregiving burden Inventory (CBI) scores: with
	3.	Alzheimer's	Time dependency	lower cognitive function in care recipients, higher CBI score
	4.	Taiyuan		was noted. Other sources of stress related to Activities of
	5.	Gender: Male: 53, Female: 115.	Coping	daily living (ADL) and behavioural challenges. Care
		Relationship with care recipient: Spouse: 71; Offspring: 77; Others: 20.	Not reported	recipients with impaired cognitive functioning reported higher level of dependency on caregivers with regards to ADL. Behavioural challenges predicted cognitive status of care recipients. Hours of caregiving was reported to be directly proportional to reported CBI scores.
Zhang et al. (2013)	1.	Survey study	Stressors	Psychiatric distress was found to be associated with lack of
	2.	58	Lack of adequate support	adequate understanding and as caregivers lacked the skill set
	3.	Dementia	Lack of skillsets	needed to provide care. Family functioning was low and had
	4.	Wuhan		adverse implications on problem solving and communication skills, affective

	5. Gender: Male: 16; Female: 42. Age range (Years): 42–66. Average age: 49.8±9.2 years.	Coping Not reported	responsiveness, behavioural control and general functioning.
Zhao, (2011)	1. Cross-sectional study	Stressors	Personal and social strains were the most important
	2. 536	Personal factors	pressure faced by caregivers. This was followed by work
	3. 157(29, 29%) cases of chronic cardiovascular	Social pressure	strain and financial strain. The psychological strain of spouses
	diseases; 209 (38.99%) cases of cerebrovascular	Financial pressure	was relatively lower. Pressure associated with caring
	diseases; 138(25.75%) cases of chronic respiratory diseases; 32(25.75%) cases of endocrine and	Mental stress	responsibilities was found to be responsible for caregivers' anxiety and depression
	immune system diseases.	Coping	symptoms and made caregivers' health self-
	4. Shandong.	Not reported	evaluation worse. In terms of the needs of caregivers': among the 536 patients' spouses,
	5. Gender: Female: 297; Male :239. Age range: 60-80; Average: 69±4.23. Relationship with care recipient: Spouses.		<ul> <li>88.0% were eager to learn about how to nurse older relatives, 91% wanted to communicate with nurses, 27.6% wanted to communicate with nurses generally, 57% wanted to communicate with nurses about patients'</li> </ul>

conditions, and 66% wanted to communicate with nurses about nursing knowledge, as most caregivers struggled with daily management of their loved ones.

Note: CBI = Caregiver Burden Inventory; CDR = Clinical Dementia Rating Scale; SAS= Self Rating Anxiety Scale; SDS = Self-Rating Depression Scale; WAP= Worry about Performance;

ZBI= Zarit Burden Interview; ADL= Activities of Daily Living; IADL= Instrumental Activities of Daily Living; MMSE= Mini-Mental State Examination.