

REVIEW ARTICLE

# Stressors and coping mechanisms of family care-givers of older relatives living with long-term conditions in mainland China: a scoping review of the evidence

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(Accepted 5 May 2021; first published online 8 July 2021)

## 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 care-givers. This scoping review therefore aims to explore sources of stress and coping mechanisms adopted by care-givers 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 care-givers 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: care-giving time (N = 22), financial resources (N = 17), role and personal strains (N = 42), preparedness (N = 4), social roles (N = 10) and lack of adequate formal support (N = 22); and one theme captured coping (N = 14). Unmet needs of care-givers 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 care-givers' 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 care-givers by their cultural environment. Having such understanding is crucial to inform the development of competent care, which promotes self-efficacy and self-actualisation in care-givers in mainland China.

**Keywords:** filial piety; self-actualisation; burden; problem-focused coping; emotion-focused coping; family care-givers; 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 care-giving 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 care-givers of older relatives who are living with long-term conditions.

### *Care-giving and existential issues*

The current population aged 60 and above in China is about 230 million, with an expected increase to 490 million by 2050. Likewise, for those aged 80 and above, there is an expected increase from 25 million to about 121 million in the same time-frame (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 care-givers must, of necessity, fend for themselves (Mayston *et al.*, 2017). Research shows that caring poses a number of stressors and existential issues for family care-givers (Kristanti *et al.*, 2018, 2019; Tang, 2020). Also, the unique cultural context of China, with the clear expectation that offspring care for parents, has implications for the way care-givers appraise their role. Stressors in the Chinese context may be changing as a result of societal changes, *e.g.* Zhang *et al.* (2020) 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 care-givers to have high expectations of themselves in relation to their fulfilment of their role, and care-giving stress occurs when there is a perceived mismatch between role performance and ideal role identity or role aspirations (Montgomery and Kosloski, 2009). Factors such as self-efficacy (Crellin *et al.*, 2014), meanings and the motivations attributed to care-giving (Quinn *et al.*, 2010), have implications for care-givers' idiosyncratic views, role adjustment and their social behaviour over time. In the Chinese context, when, for example, a care-giver 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 care-giver.

With reference to the process of care-giving within a social context, McAllum *et al.* (2021) found that taking on a care-giving role involved three aspects, all of which would be affected by culture, namely role acculturation, *i.e.* getting used to the new role; role negotiation and identification, *i.e.* care-givers adapting to care demands within the scope of their own life; and role learning, *i.e.* care-givers

acquiring expertise from health and social care professionals as well as co-care-givers. As care for an older person with progressive needs for support intensifies over time, incongruence between a care-giver's performance and aspirations, levels of care-giving and the nature of support can have adverse implications for role identity. Therefore, factors such as low levels of service support, poor service organisation, care-givers' lack of awareness around their own needs and having to deal with guilt at times when they are unable to manage care demands (Oliveira *et al.*, 2019), result in the personal health needs of care-givers remaining largely unmet (Queluz *et al.*, 2020).

While extensive literature is available on the care-giving process and the implications for care-givers 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, the United Kingdom (UK) and the United States of America (United Nations Department of Economic and Social Affairs, Population Division, 2015). Existing studies have predominantly focused on the influence of shared values and traditions on care-giving, *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 care-giving context varies from one care-giver 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 *et al.*, 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 care-givers of older relatives, a stronger sense of filial obligation was significantly linked with reduced levels of developmental, emotional, social and physical burden (Guo *et al.*, 2019). 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 care-givers (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, care-givers of older relatives may perceive themselves to be in a liminal position, *i.e.* performing care-giving 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 *et al.* (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 *et al.* 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 care-givers. 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 care-givers 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, care-givers 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 wellbeing of those caring for older relatives. This makes it imperative to understand specific stressors and coping mechanisms. The objective of this review was to identify systematically 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:

- (1) What are the stressors experienced by care-givers of older relatives living in the community with long-term health conditions?
- (2) 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 heterogeneous concepts and narratives in order to identify and analyse gaps in knowledge. Hence, a scoping review was identified as the most appropriate method to map out systematically 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 of facilitating future research work (Tricco *et al.*, 2018).

## Eligibility criteria

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

- Conducted with mainland Chinese care-givers 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 care-givers.
- 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 *et al.*, 2012) where the letters refer to: S – sample, PI – phenomenon of interest, D – design, E – evolution, R – research type. The terms were reviewed and discussed between co-authors. 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 the SCOPUS database, see Table S1 in the online supplementary material.

### **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. Ten 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, LY reviewed the studies independently and collaboratively with the other two researchers to reach consensus (for details, see Figure 1). References were managed using EndNote X9.

### **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's 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 and 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 care-giving, with a few capturing coping strategies. The majority were quantitative and employed a range of measures, such as the Caregiving Burden Inventory (CBI) (Chou *et al.*, 2002) and Brief COPE Inventory (Carver, 1997).

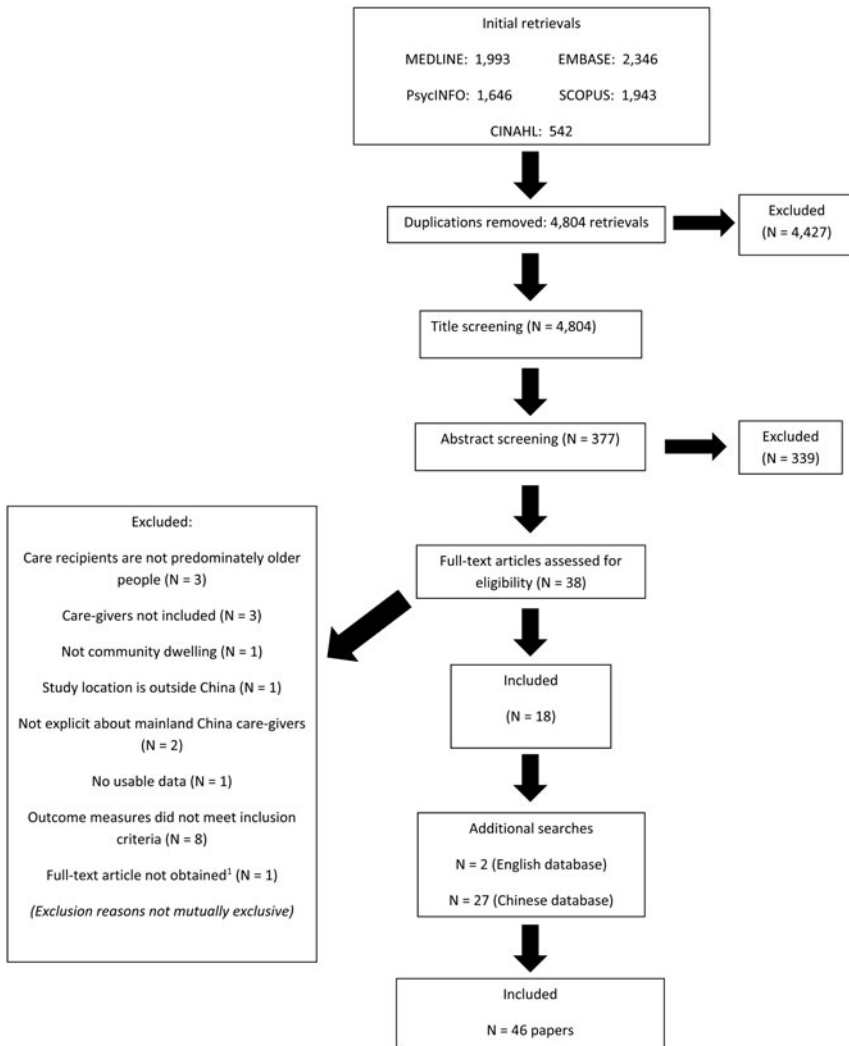


Figure 1. Flowchart of the search strategy.

Specific papers focused on care-givers of older relatives with a range of long-term conditions, including dementia, musculoskeletal conditions, and visual and hearing conditions. Others focused generally on older people with disability and, in some cases, with co-morbidities or multi-morbidities (for details, see Table 1).

### 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 *et al.*, 2010). Following data extraction, data retrieved from relevant studies were sorted and organised under themes. Close attention was paid to cultural nuances and novel issues that related to the research questions. 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 care-giving stressors: care-giving 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.

### **Care-giving time**

Twenty-two papers referred to care-giver stress related to time spent performing care-giving duties. Across all the papers, a longer duration of care-giving was associated with higher levels of personal stress (Tang, 2006; J Liu *et al.*, 2012; Guogui *et al.*, 2017; Lu *et al.*, 2017; H Liu *et al.*, 2018; Song, 2018; Tong, 2018; X Liu *et al.*, 2019), especially as the care recipients' ability to self-care decreased (Lv *et al.*, 2013). Family members involved in care-giving were susceptible to low social functioning and reduced relaxation time (Yu *et al.*, 2013; Qian *et al.*, 2014; Guogui *et al.*, 2017; Wang *et al.*, 2018; Shen *et al.*, 2019b). This was partly due to the time needed to meet the increasing needs of care recipients (Liu *et al.*, 2012; Du *et al.*, 2014; Yu *et al.*, 2015). Consequently, care-givers tended to struggle to meet both care duties and work demands, which tended to impede care-givers' personal lives (Liu and Zhou, 2009; Liu *et al.*, 2015) and career development (Pan *et al.*, 2018). Furthermore, a study that explored experiences of care-givers who were in work (Pei *et al.*, 2017) reported an additional 5 per cent chance of losing a job with every one-hour per 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 care-givers, who moved in with care recipients in order to meet their needs (Wei *et al.*, 2014; Wang *et al.*, 2019).

### **Financial resources**

Seventeen papers indicated that there were financial implications to providing care. Liu *et al.* (2013) found that widowed, unmarried or divorced care-givers, with poor health, reported significant levels of economic stress. One female care-giver, for instance, took on care responsibility, with no financial support from siblings (Liu, 2016). In other cases, older care-givers living with long-term conditions had limited financial resources to meet their own personal needs and those of the care recipient (Lu *et al.*, 2017; Wang *et al.*, 2019). Over time, family care-givers faced financial pressure from the inevitable increase in medical needs of older relatives (Chen, 2017; Liu *et al.*, 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 care-givers were subjected to financial distress due to the exorbitant cost



**Table 1.** Data charted from 46 papers included in the review

Study (publication year)	1. Study design 2. Number of care-givers 3. Care recipients' long-term condition 4. Location: cities or provinces 5. Characteristics of care-givers	Care-givers' stressors and coping mechanisms	Main findings
Davis <i>et al.</i> (1995)	1. Primarily qualitative study 2. 75 3. Series of long-term conditions 4. Beijing, Tianjin and Guangzhou 5. Age range: 23–89. Gender: male 39, female 36. Married 70, widowed 5	<i>Stressors</i> Lack of essential amenities Lack of formal support <i>Coping</i> Attributes of care-givers Finding practical solutions	Women were the main carers of older people and experienced care-giving burden (physical, social, psychological and financial). This was attributed to meeting various needs of care recipients, as care-givers were spouses and older themselves. Care-givers primarily found psychological support through their moral qualities as they found strength in their self-confidence, the sense of duty, responsibility and care obligation. Also, care-givers actively sought practical solutions.
Lian <i>et al.</i> (2017)	1. Qualitative study 2. 20 3. Dementia 4. Chongqing 5. Care-givers had cared for older relative for at least 6 months. Age: mean = 58.0 (SD = 15.1). Gender: male 4, female 16. Married 19, unmarried 1	<i>Stressors</i> Lack of solution Societal perception of condition Early diagnosis Behavioural management Financial difficulties <i>Coping</i> Social support and formal services	Four themes reported addressed: (a) capabilities to detect memory loss at an early stage; (b) perceptions and beliefs about dementia in the community; (c) different journeys towards the diagnosis; (d) expectations of a smooth journey for others. Findings suggest that the transitioning period can be challenging for care-givers of people living with dementia. Care-givers found support through social support and seeking advice from relevant professionals.
Liu (2016)	1. Case study 2. 1 3. Disability 4. Hunan 5. Female family care-givers	<i>Stressors</i> Financial stress Health status of care-giver Personality of care recipient Care-giving role Family conflict Lack of care skills and knowledge <i>Coping</i> Family support	Significant pressure was associated with caring for an older relative. Family members continue to play a central role in providing support based on the values of filial piety. It would require additional support from the government, community services and professional support to reduce the pressure on family care-givers.

Liu and Zhou (2009)	<ol style="list-style-type: none"> <li>1. Qualitative study: (descriptive), in-depth semi-structured interviews</li> <li>2. 15</li> <li>3. Stroke 9, senile dementia 3, Parkinson's disease 1, coronary atherosclerotic heart disease 1, cancer 1. Most care recipients had comorbidity and multimorbidity</li> <li>4. Shanghai</li> <li>5. Family care-givers</li> </ol>	<p><i>Stressors</i> Physical status of care-givers Financial difficulties <i>Coping</i> Not reported</p>	<p>Care recipients with stroke had the greatest care needs. Most care-givers had limited personal time; their physical health deteriorated due to care-giving, resulting in significant psychological burden. Care-givers found medical expenses exorbitant, which contributed to stress. Relationships between care-givers and care recipients were strained.</p>
Qiu <i>et al.</i> (2017)	<ol style="list-style-type: none"> <li>1. Qualitative study</li> <li>2. 25</li> <li>3. Stroke</li> <li>4. Nanjing</li> <li>5. Age range: 45–82. Gender: male 6, female 19. Relationship with care recipient: spouse 16, child or child-in-law 9. Education: primary 4; junior high 10, post-secondary 9, university 2. Care-giving condition: time spent (hours/day) 16; care-givers co-resident with care recipient 23</li> </ol>	<p><i>Stressors</i> Standard of formal services Financial difficulties Accessibility of social support Demands of the role <i>Coping</i> Sense of care obligations</p>	<p>Three coping themes were reported: (a) care-giving role perception: belief that care-giving was the 'right and proper' thing to do, based on reciprocity and cultural/role expectations, influenced by role modelling of other family members; (b) coping strategies: seeking practical support and assistance from family members; (c) self-sacrifice: self-reliance and sacrificing their own health to put the care recipient first. Care-givers were also reluctant to use formal services due to concerns about their quality and costs.</p>
Sun (2014)	<ol style="list-style-type: none"> <li>1. Qualitative study</li> <li>2. 18</li> <li>3. Dementia</li> <li>4. Shanghai</li> <li>5. Age range: 53–82. Gender: female 11, male 7. Relationship with care recipient: spouse 14; adult child 3; daughter-in-law 1. Employment status: employed 3, retired 15</li> </ol>	<p><i>Stressors</i> Attributes of care recipients Demands of the role Family conflict Societal pressure <i>Coping</i> Attributes of care-givers Personal and external resources</p>	<p>Limited physical, cognitive and behavioural abilities of care recipients were directly linked with the increase in the demands of the role. Salient stressors such as the role strain, family conflict and societal pressure were identified. Care-givers coped in various ways, which included drawing on personal experiences, religion, technology and sought support from doctors whilst some planned ahead.</p>
Wang <i>et al.</i> (2018)	<ol style="list-style-type: none"> <li>1. Qualitative study</li> <li>2. 10</li> <li>3. Dementia</li> <li>4. Beijing</li> <li>5. Mean age: 66.9 ± 16.6. Gender: female 9; male 1. Marital status: married 9, widowed 1. Relationship with care recipient: spouse 6, adult children 3, other relative 1</li> </ol>	<p><i>Stressors</i> Low or no level of preparedness Lack of support from both informal and formal services <i>Coping</i> Not reported</p>	<p>Three themes related to care-giver stressors: care knowledge and skills, psychological counselling, collaborative management. Themes reflected lack of support. Participants had negative emotions related to inability to provide adequate care. They considered care-giving as a burden, characterised by lack of professional support and lack of socialising time.</p>

Yong (2012)	<ol style="list-style-type: none"> <li>1. Qualitative study</li> <li>2. 10</li> <li>3. Dementia</li> <li>4. Not specified</li> <li>5. Not specified</li> </ol>	<p><i>Stressors</i></p> <ul style="list-style-type: none"> <li>Financial difficulties</li> <li>Lack of respite</li> <li>Lack of awareness</li> <li>Physical health status of care-givers</li> <li>Inability to balance work and care</li> </ul> <p><i>Coping</i></p> <ul style="list-style-type: none"> <li>Family support</li> </ul>	<p>Three themes reported relate to the mental health status of care-givers of older relatives, feelings associated with caring for older relatives and lack of long-term care services. Care-givers play an integral role in caring for older relatives including prioritising the needs of older relatives ahead of theirs. They were anxious about managing the health of older relatives due to lack of adequate support and still had to provide a high level of hands-on nursing care. Care-givers experienced high levels of burden with negative health outcomes. Care-givers relied on family members for support.</p>
Zhang et al. (2020)	<ol style="list-style-type: none"> <li>1. Qualitative study</li> <li>2. 14</li> <li>3. Dementia</li> <li>4. Shandong</li> <li>5. Age range: 39–78. Relationship status: spouse, parent and offspring</li> </ol>	<p><i>Stressors</i></p> <ul style="list-style-type: none"> <li>Caring at home</li> <li>Care-giving role</li> </ul> <p><i>Coping</i></p> <ul style="list-style-type: none"> <li>Not reported</li> </ul>	<p>Three overarching themes identified that care-givers felt that ‘no one cares’, as a result of changes in society which highlights their state of disconnection. Thus, fearing that ‘home care may create a sense of social isolation’. Care-givers with lack of autonomy over their daily lives and caring duties, felt that ‘home care is a burden’ and could be extremely demanding. Care-givers, 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.</p>
Chen (2017)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 208</li> <li>3. 52.8% ‘disabled elderly’, 47.2% ‘semi-disabled elderly’</li> <li>4. Shanghai</li> <li>5. Gender: female 62.1%, male 37.9%. Relationship status: daughters, spouses, sons, daughters-in-law, other family members, sons-in-law</li> </ol>	<p><i>Stressors</i></p> <ul style="list-style-type: none"> <li>Lack of family support</li> <li>Duration of care</li> <li>Care-givers’ physical health status</li> <li>Financial difficulties</li> <li>Lack of adequate skillset to provide care</li> </ul>	<p>Majority of care recipients lived with dementia. Family care-givers were mostly female, some care-givers were older people and they were spouses to care recipients. Poor physical health status of care-givers made it difficult for them to bear heavy burdens. The long hours needed to provide care adversely contributed to both the physical and psychological wellbeing of care-givers. Family care-givers reported being</p>

		<i>Coping</i> Not reported	under great pressure, as they did not have enough people with whom to share care responsibilities. Care-givers were subjected to financial stress and lacked the skillsets needed to provide adequate care as some received little support from professionals.
Chen <i>et al.</i> (2017)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 203</li> <li>3. Disability</li> <li>4. Zhejiang</li> <li>5. Gender: female 123 (60.6%), male 80 (39.4%). Relationship with care recipient: children 51, spouses 116, other family members 36</li> </ol>	<i>Stressors</i> Age of care-givers Care recipients' self-care ability <i>Coping</i> Not reported	Care-givers were subjected to care-giving burden. When compared with care-givers who cared for relatives aged 75+, care-givers who took care of relatives aged 60–74 presented with higher levels of time-dependence burden, developmental burden and physical burden.
Du <i>et al.</i> (2014)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 744</li> <li>3. Dementia 112 (15.1%), non-dementia 632 (84.9%)</li> <li>4. Beijing</li> <li>5. Gender: male 282 (37.9%), female 462 (62.1%). Age: ≤40: 23 (3.1%), 41–59: 353 (47.4%), ≥60: 368 (49.5%) Relationship with care recipient: spouse 242 (32.5%), child 469 (63.0%), other 33 (4.5%)</li> </ol>	<i>Stressors</i> Lack of social support Financial difficulties Demands of care-giving Relationship status <i>Coping</i> Not reported	Lack of self-efficacy and financial capability on the part of the care-givers contributed to the adverse health outcome (depression). Care-givers with depressive symptoms lacked social support (subjective support and utilisation of support). Based on the relationship with care recipients, spouses spent more time addressing the needs of care recipients.
Du <i>et al.</i> (2017)	<ol style="list-style-type: none"> <li>1. A cross-sectional study</li> <li>2. 766</li> <li>3. Older people living with long-term conditions. Top five conditions are hypertension, stroke, coronary diseases, diabetes and osteoarthritis. Most had more than four chronic conditions</li> <li>4. Beijing</li> <li>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%)</li> </ol>	<i>Stressors</i> Financial difficulties Subjective care-giving burden <i>Coping</i> Not reported	Care-givers were subjected to a moderate amount of burden. Out-of-pocket money was associated negatively to the general wellbeing of care-givers. Time spent providing care, especially with care recipients living with co-morbidity, associated negatively with some aspects of care-givers' HRQoL. Subjective care-giving burden negatively correlated with care-givers' HRQoL.

Fu et al. (2007)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <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>	<p><i>Stressors</i> Behavioural challenges Gender <i>Coping</i> Not reported</p>	<p>Care recipients' pathological behaviours were found to be a stressor and correlated with adverse health outcomes (depression and anxiety). Care-givers 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.</p>
Guogui et al. (2017)	<ol style="list-style-type: none"> <li>1. Quantitative design</li> <li>2. 11,331</li> <li>3. Not specified</li> <li>4. Nationwide</li> <li>5. Gender: 52% male. Age: 31.5% were 60–64, remainder were 65 + . Married: 64.9%. Education: 64.9% primary school and below</li> </ol>	<p><i>Stressors</i> The health status of the care-giver Distance Lack of adequate skillset Lack of time to provide care Financial difficulty <i>Coping</i> Not reported</p>	<p>Care-givers spent an average of 38.3 hours per week caring for care recipients. The main difficulties for care-givers were physical exhaustion, distance, lack of time and dilemmas relating to finances. This partly contributed to the psychological pressure experienced by care-givers, who were older people themselves.</p>
He et al. (1995)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 110</li> <li>3. Dementia</li> <li>4. Shanghai</li> <li>5. More female care-givers. Majority were married. About half were employed and half retired. More than 50% of primary care-givers were children and spouses. More than 30% of spouses were older people themselves</li> </ol>	<p><i>Stressors</i> Demands of care-giving role and individual attributes <i>Coping</i> Not reported</p>	<p>The magnitude of the role was associated with adverse care-giver health outcomes. Characteristics of the care-giver and care recipient affected care-givers' mental health. Older care-givers had 'other types' of work, distant relatives, care recipients with severe dementia. These care-givers experienced higher psycho-social impairment indexes than other groups. Being female, uneducated, with the care recipient being male and over 85 years, affected care-givers' physical health.</p>
Li et al. (2009)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 568</li> <li>3. Chronic diseases (hypertension, diabetes, coronary heart disease, emphysema, asthma, gallbladder and gastrointestinal disease, stroke, glaucoma or cataract,</li> </ol>	<p><i>Stressors</i> Financial difficulties Co-morbidities/multi-morbidities <i>Coping</i> Social support</p>	<p>Of the care-givers, 83.5% 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 care-givers and</p>

	<p>Parkinson's disease, prostatic hyperplasia, cancer, osteoarthritis, rheumatism)</p> <p>4. Fuzhou</p> <p>5. Gender: female 306 (53.9%), male 262 (46.1%). Relationship with care recipient: children 111 (19.5%), spouses 434 (76.4%), other family members 23 (4.1%). Age: <math>\geq 20</math>: 40 (7.0%), <math>\geq 40</math>: 108 (19.1%), <math>\geq 60</math>: 420 (73.9%)</p>		<p>occupation were influencing factors relating to family burden. Care-givers of older relatives with decreased self-care ability and depressive symptoms had a higher burden in comparison to care-givers of older relatives with the ability to self-care and without depressive symptoms. Care-givers of older relatives with two or more chronic conditions had a higher burden. Care-givers found social support useful in terms of reducing care-giving burden with the family.</p>
Li et al. (2013)	<p>1. Cross-sectional study</p> <p>2. 418</p> <p>3. Disability: hypertension (60.3%), heart disease (47.8%), cervical and lumbar disease (21.1%), cerebrovascular disease (19.1%), diabetes (18.7%), tracheitis (17.2%)</p> <p>4. Ji Nan</p> <p>5. Gender: female 180, male 238. Age: 20–40: 16, 40–60: 221, &gt;60: 181. Relationship with care recipient: spouse 114, child 252, other 52; 345 care-givers resided with care recipient; 115 were in employment</p>	<p><i>Stressors</i> Care recipients' characteristics and care-givers' self-efficacy</p> <p><i>Coping</i> Not reported</p>	<p>The care recipients' ADL score, health status, age, availability of spouse, the caring abilities of care-givers and the availability of helpers were associated with the burden of care-givers.</p>
Li et al. (2019)	<p>1. Cross-sectional study</p> <p>2. 291</p> <p>3. Disability: 175 cases (60%) of visual disturbance, 106 cases (36%) of hearing disorders, 91 cases (31%) of communication disorders, 152 cases (52%) of cognitive ability injury, 121 cases (41%) of urinary and faecal incontinence, 107 cases (37%) of severe activity of daily living injury, 25 cases (9%) of pressure sore, 78 cases (27%) of fall in a year, 254 cases (87%) of chronic diseases for disabled older people</p> <p>4. Zhejiang</p> <p>5. Not reported</p>	<p><i>Stressors</i> Demand of care-giving role</p> <p><i>Coping</i> Not reported</p>	<p>Care-givers experienced moderate to high levels of care-giving burden on family members. The results of multi-factor analysis showed that long-term care-givers of care recipients with low overall health perception contributed to care-giving burden.</p>

Liu et al. (2012)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 90</li> <li>3. Diagnosis of dementia or non-dementia chronic diseases (hypertension, diabetes, chronic renal failure, osteoarthritis)</li> <li>4. Beijing</li> <li>5. Mean age: 77.02 ± 3.66. Gender: male 13, female 77. Relationship with care recipient: spouse 48, offspring 10. Co-residence: yes 86, no 4. Employment status: employed 24, unemployed 13, retired 53. Education level: none 7, primary school 17, secondary school 46, tertiary school 20</li> </ol>	<p><i>Stressors</i> Lack of information and guidance <i>Coping</i> Problems solving</p>	<p>There were significant increases in CBI scores between the severe dementia and non-dementia (comparison group). In the dementia group, patients' CDR score was positively correlated with the measure of burden. There was a positive correlation between CBI scores and daily care time. There was a positive correlation between CBI scores and SAS and SDS. Carers of people with dementia reported insufficient involvement of GPs in dementia care. Media was the most important source of knowledge and skills (newspaper 15%, television 13%, radio 12%, books 12%). Only 11% of care-givers were guided by GPs in the daily care of people with dementia.</p>
Liu et al. (2013)	<ol style="list-style-type: none"> <li>1. Survey study</li> <li>2. 895</li> <li>3. Oldest old in China (mean age of 90)</li> <li>4. 31 provinces in China</li> <li>5. Age: mean age: 55.8 (SD = 7.3); most care-givers were in their 50s (46.5%) and 60s (33.4%). Gender: 74.9% of care-givers were males. Living in rural areas: 58.9%</li> </ol>	<p><i>Stressors</i> Financial situation Care-givers' health status Societal expectations <i>Coping</i> Not reported</p>	<p>The income of adult children and the status of being the eldest son were related to economic stress. Economic stress was related to economic capability of care-givers (children of care recipients) as the oldest old parents were financially dependent on their children, due to rarity of pensions. Unmarried care-givers 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.</p>
Liu et al. (2015)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 124</li> <li>3. Disability</li> <li>4. Chong Qing</li> <li>5. Gender: female 89, male 35. Age: 18–35: 18, 36–45: 41, 46–60: 39, &gt;60: 26. Retirement status: retired 59, not retired 65. Marital status: married 118, not married 4, divorced 1, widowed 1. Relationship with care recipient: spouse 42, siblings 3, offspring 79</li> </ol>	<p><i>Stressors</i> Care recipient characteristics Time devoted to care Physical health status of care-givers <i>Coping</i> Not reported</p>	<p>Highest score in terms of care-giving was time-dependent burden, followed by developmental burden and physical burden. Age of older relative, self-reported illness, general health status and health changes, daily care-giving time on the part of care-givers and self-reported illness status indicated that care-givers were subjected to a substantial amount of burden.</p>

Liu <i>et al.</i> (2017)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 80</li> <li>3. Dementia</li> <li>4. Shanghai</li> <li>5. Gender: male 28, female 52. Age range: 38–93. Education: middle school or below 67, college or above 13. Family monthly income (Yuan): &lt;3,000: 31, 3,000~4,000: 37, &gt;4,000: 12. Relationship with care recipient: spouse 23, others 57</li> </ol>	<p><i>Stressors</i>            Nature of long-term condition            Lack of training            Demands of care-giving            Monthly household income (per capita)  <i>Coping</i>            Not reported</p>	<p>Per capita monthly income of families (care-givers), self-care ability and severity of dementia in older relatives, and the demand of care on care-givers were statistically significant. There was a high care demand placed on care-givers of older relatives with dementia especially as they lacked the knowledge and skillsets.</p>
Liu <i>et al.</i> (2018)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 1,000</li> <li>3. Not specified</li> <li>4. 10 cities in 5 provinces in East and Central China</li> <li>5. Average age of the main family care-givers was 42.7 ± 12.7 years old. Female: 339 (48.9%). Education: 61.9% lower or middle school education. Hours of care per day: &lt;2: 25.5%, 2–5: 50.5%, &gt;5: 24.0%</li> </ol>	<p><i>Stressors</i>            Age            Care-givers' own health status            Older relatives' care need            Lack of family support  <i>Coping</i>            Not reported</p>	<p>Care-givers younger than 40, with chronic conditions, who slept for less than seven hours had significantly higher scores for depressive symptoms than those in the other groups. Care-givers who spent less than two hours a day caring for older relatives had significant low scores for depressive symptoms. Likewise, care-givers of older relatives who did not need help with regards to tasks such as housework and transportation had a significant low score for depressive symptoms in comparison to other groups. Care-givers of older people who often or always needed help with their health had a significant high depression score.</p>
Liu <i>et al.</i> (2019)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 316</li> <li>3. Disability</li> <li>4. Ningxia</li> <li>5. Gender: female 223, male 93. Age range: 40–49: 58, 50–59: 87, 60–69: 129, 70–75: 42. Marital status: married 281, not married 1, divorced 26, widowed 8. Education: ≤primary school 75, junior high school 158, high school or technical secondary school 61, college 20, higher education 2. Relationship with care recipient: spouse 192, offspring 119, sibling 5. Daily care time (hours) &lt;6:</li> </ol>	<p><i>Stressors</i>            Age of care-givers            Relationship with care recipient            Health status of care-givers            Low level of training            Duration of care            Financial difficulties and economic income  <i>Coping</i>            Not reported</p>	<p>Of the care-givers of older relatives, 72 (22.8%) had mild burden, 189 (59.8%) had moderate burden, 55 (17.4%) had severe burden; personal burden (30.42 ± 8.82), role burden (17.79 ± 4.35) and total burden (48.32 ± 15.19). There was a significant difference in the burden scores between different ages and care-givers with disability, health statuses, whether they had received relevant care guidance or training, care-giving time, number of assisted care-givers and different economic incomes (<math>p &lt; 0.05</math>). There was also a negative correlation between care-givers' burden and families' care quality, among which personal burden, role burden and total burden are more</p>



	25, 6–12: 135, >12:156. Monthly income (Yuan): <1,000: 50, 1,000–1,999: 35, 2,000–2,999: 169, 3,000–3,999: 39, 4,000–4,999: 21, ≥5,000: 2		closely associated to care-givers and care recipients.
Liu and Bern-Klug (2016)	<ol style="list-style-type: none"> <li>1. Survey study</li> <li>2. 895</li> <li>3. Oldest older parents</li> <li>4. 8 coastal provinces in China</li> <li>5. Mean age: 55.83, Gender: female (daughter) 25.14%. Married: 89.61%. Living in rural areas: 58.88%. Retired or not working: 38.97%, part-time workers (18.19%), full-time workers (42.84%)</li> </ol>	<p><i>Stressors</i></p> <p>Self-efficacy</p> <p><i>Coping</i></p> <p>Not reported</p>	Physical and cognitive function scores (ADL, IADL and MMSE) for care recipients indicated care needs were low. Care-givers reported high levels of concerns with regards to their self-efficacy (WAP) in comparison to items on ZBI. Linear regression showed: (a) care-givers who provided long-term care for older people with high IADL needs had a high level of WAP; (b) emotional closeness and sibling support play a crucial role in predicting WAP; (c) care-givers in full-time work reported a low level of WAP; (d) full-time working status was not found to be significantly associated with WAP; (e) higher living standard was significantly associated with higher WAP; (f) higher WAP was reported by care-givers living with the oldest old; (g) daughters were preferred to sons in terms of providing care.
Liu and Lou (2012)	<ol style="list-style-type: none"> <li>1. Cross-sectional</li> <li>2. 720</li> <li>3. Disability</li> <li>4. Shanghai City</li> <li>5. Majority of care-givers were women, middle-aged, older people, retired, with average economic conditions, providing long periods of care</li> </ol>	<p><i>Stressors</i></p> <p>Care-givers' poor health status</p> <p>Financial difficulties</p> <p><i>Coping</i></p> <p>Not reported</p>	Health deterioration of care-givers was associated with caring for older relatives. In response to their financial circumstances in the last six months, 41.0% thought they had barely enough (295), 28.2% thought they had enough (203), 5.0% thought they had enough with spare (36), 19.3% thought they did not have enough (139), 6.4% practically had nothing (46).
Lu et al. (2015)	<ol style="list-style-type: none"> <li>1. Survey study</li> <li>2. 494</li> <li>3. Frail elders with musculoskeletal conditions</li> <li>4. Shanghai</li> <li>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: &gt;60:</li> </ol>	<p><i>Stressors</i></p> <p>Care recipients' functional dependency (ADL), cognitive status and behavioural challenges</p> <p><i>Coping</i></p> <p>Not reported</p>	ADL was significantly associated with depressive symptoms. Depressive symptoms were associated with time dependence, physical and social burden. Both ADL and life satisfaction were mediated by time dependence and developmental burden. Time dependence fully mediated the association between cognitive status and depressive symptoms, the association between behavioural problems and depressive symptoms

250, 60–74: 134, 75–84: 83, 85+: 23.  
 Education: primary school or no formal  
 education 67, secondary school or above  
 426. Lived with care recipient: yes 335, no  
 158

(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 care-givers were more likely to report higher levels of social burden. Care-givers with higher educational attainments were more likely to report higher levels of developmental burden.

Lu <i>et al.</i> (2017)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 375</li> <li>3. Disability</li> <li>4. He Nan</li> <li>5. Gender: male 155, female 220. Age range: 27–87. Average age: 54.23 ± 13.50. Relationship with care recipient: spouse 131, offspring 244</li> </ol>	<p><i>Stressors</i>          Gender          Care-givers' attributes          Care recipient's attributes  <i>Coping</i>          Not reported</p>	<p>The burden of care-givers of older relatives in rural areas was found to be moderate. Gender, age, residential status, subjective support, level of management of care recipients' long-term conditions and emotional state of the care-giver were the main factors that influenced care-giving burden. Social support negatively correlated with the care-giving burden.</p>
Lv <i>et al.</i> (2013)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 119</li> <li>3. Chronic disease, not specific</li> <li>4. Zhejiang</li> <li>5. Gender: male 40, female 79. Relationship with care recipient: spouse 23, offspring 96</li> </ol>	<p><i>Stressors</i>          Financial difficulties          Self-care ability of care recipient          Care-giving time          Low income          Age of care-givers  <i>Coping</i>          Not reported</p>	<p>Young and middle-aged care-givers in rural areas were under a relatively high economic distress as care-giving had impact on their ability to work, which had implications on care-givers meeting care recipients' long-term medical expenses. Spouses of care recipients were under greater pressure due to their special roles and attitudes. Care-givers' occupation was associated with social pressure as care-givers 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 care-giver's age, education level, occupation, patient's self-care ability and mood.</p>
Pan <i>et al.</i> (2018)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 190</li> <li>3. Chronic obstructive pulmonary disease</li> <li>4. Not specified</li> </ol>	<p><i>Stressors</i>          Age of care-givers          Time of care          Occupation</p>	<p>The older the care-giver the more the burden reported. Care-givers in full-time employment reported a higher burden in comparison to part-time workers or those without a job. The</p>

	<p>5. Gender: male 93, female 97. Age: &lt;60: 98, ≥60: 92. Relationship with 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 (Yuan): &lt;5,000: 89, ≥5,000: 101. Occupation: full-time 55, part-time 50, retired or unemployed 85. Daily time for patient care (hours): &lt;5: 75, 5–10: 80, &gt;10: 35</p>	<p>Availability of formal services <i>Coping</i> Social support</p>	<p>longer the time of care-giving per day, the heavier the burden. Care-givers with better access of care reported less care-giving burden and the higher the level of social support received, the less care burden experienced by care-givers.</p>
<p>Pei et al. (2017)</p>	<ol style="list-style-type: none"> <li>Survey study</li> <li>214</li> <li>Not specified</li> <li>Central China</li> <li>Gender: male 116, female 98. Mean monthly income (Yuan) (SD): male 2,933.4 (197.3), female 1,996.0 (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</li> </ol>	<p><i>Stressors</i> Logistics of care-giving Time and financial implications of care-giving Gender <i>Coping</i> Not reported</p>	<p>Lack of support for care-givers in employment was reported, as time and financial dependence on care-givers by care recipients were found to be stressors. There was a 5% chance of experiencing negative employment consequences with an hour increase in care provision. As total care expenses moved up a level (from 1,000 to 1,999 or 2,000 to 2,999 Yuan), care-givers were 33% more likely to experience negative employment consequences. Women were reported to provide more hands-on care, which predisposed them to care-giving burden.</p>
<p>Qian et al. (2014)</p>	<ol style="list-style-type: none"> <li>Cross-sectional survey</li> <li>243</li> <li>Dementia and non-dementia</li> <li>Beijing</li> <li>Gender: male 88 (36.2%), female 155 (63.8%). Age: &lt;60: 132 (54.3%), ≥60: 111 (45.7%). Relationship with care recipient: spouse 79, children 135, other 29</li> </ol>	<p><i>Stressors</i> Age of care recipient Care-givers' characteristics Low social support <i>Coping</i> Not reported</p>	<p>The prevalence rate of anxiety was 29.2% reported by family care-givers. The average score of SAS was 35.6 ± 8.6. The risk factors of care-givers' anxiety included Barthel Index score ≤ 20 (OR = 1.51), SSRS score ≤ 33 (OR = 4.56), no time to relax (OR = 1.57) and poor health status (OR = 3.48). Relatively high levels of anxiety existed in family care-givers, which was found to be a complex process, influenced by diverse care recipients' and care-givers' characteristics. Results showed that the older the care-giver was, the more time spent in providing daily care. The poorer their perceived health condition, the more the absence of daily</p>

			<p>exercises, relaxation time and the higher the detection rate of anxiety among family care-givers with lower social support.</p>
<p>Shen <i>et al.</i> (2019a)</p>	<ol style="list-style-type: none"> <li>1. Survey study</li> <li>2. 601</li> <li>3. Older people with disability</li> <li>4. Nanjing</li> <li>5. Mean age: 48.36 (SD = 16.14). Gender: male 310, female 291. Relationship with care recipient: spouse 514, offspring 53, other 34</li> </ol>	<p><i>Stressors</i> Care-giving role <i>Coping</i> Family, market and governmental support</p>	<p>All participant groups experienced moderate levels of stress, increasing with time with the highest level reported by spouses. Different relatives received different levels of support from the market, family members and the government, with spouses receiving less support from the family members and the market but more subsidy from government. All groups reported psychological stress &gt; financial stress &gt; physiological stress. Most care-givers 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 care-givers sought support from the public service over 75% were very unsatisfied or unsatisfied with the services.</p>
<p>Shen and Wang (2016)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional</li> <li>2. 605</li> <li>3. Over 60 – disability</li> <li>4. Nanjing</li> <li>5. Gender: male 51.41%, female 48.59%. Average monthly economic income (Yuan): 0–1,999: 11.2%, 2,000–3,999: 42.2%, 4,000–5,999: 31.0%, 6,000–7,999: 8.7%, &gt;8,000: 7.0%</li> </ol>	<p><i>Stressors</i> Lack of care information The health status of the care-givers Health status of the care recipient: self-care ability Duration of care <i>Coping</i> Family support</p>	<p>Older care-givers with higher family economic income were willing to buy care services. Care-givers with children were more willing to buy care services. The lower the self-care ability of care recipients, the stronger the willingness of family care-givers to purchase care services. The longer family care-givers took care of care recipients, the stronger their willingness to buy care services, but in cases where someone came to the assistance of care-givers, there was a decline in their willingness to buy care services. The heavier the physical and psychological burden, the greater the willingness to purchase care.</p>
<p>Song (2018)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 219</li> </ol>	<p><i>Stressors</i> Time providing care Individual characteristics Family characteristics and</p>	<p>Care-givers were mostly family members who were older people and were spouses. More than 60% of care-givers who provided long-term care was aged 45 and above. Care-givers' burden was influenced</p>

	<ol style="list-style-type: none"> <li>3. 24.5% of the older people can take care of themselves, 48.5% are semi-bedridden and 27.0% are completely bedridden</li> <li>4. Shandong</li> <li>5. Gender: female 61.9%. Age: <math>\leq 35</math>: 9.1%, 36–44: 25.6%, 45–54: 47.5%, <math>\geq 55</math>: 14.6%</li> </ol>	<p>cultural value Family support Financial pressure <i>Coping</i> Not reported</p>	<p>by individual characteristics of care-givers, family characteristics and the family support. These factors were found to have had an important impact on care-givers' sense of burden. As care-givers grew older, awareness of their responsibilities for caring increased significantly, showed greater recognition for caring activities and sense of burden decreases significantly. Care-givers living with long-term conditions associated care with a greater burden. Care-givers with better self-rated health tended to have more negative attitudes towards caring for older people and felt more burdened.</p>
Tang (2006)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 300</li> <li>3. Not specified</li> <li>4. Chongqing</li> <li>5. Gender: male 48.7%, female 51.3%. Education: 36.7% graduated from senior high school, 28.1% from junior college, 15.1% were college students or above. All care-givers were offspring (adult children)</li> </ol>	<p><i>Stressors</i> Financial difficulties Time of care-giving Care-givers' psychological status Care-givers' physical status <i>Coping</i> Not reported</p>	<p>Men and women showed statistically significant differences in economic, time and psychological stress. Married and unmarried sons felt more economic pressure, while daughters-in-law and married daughters felt more time and psychological pressure. Time was the most stressful aspect of care, followed by psychological and financial difficulties. Respondents' stress scores were greater than 3, which indicated that they faced a medium level of stress over a short duration of care.</p>
Tong (2018)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 90</li> <li>3. Spinal cord injury</li> <li>4. Shenyang</li> <li>5. Gender: female 67, male 23. Age range: 18–70 years. Average age: <math>45.62 \pm 4.19</math>. Care-givers without help: 67. Care-givers with poor health status: 51. Nursing time range: 4–24 hours</li> </ol>	<p><i>Stressors</i> Health status of care-givers Care-giving time Lack of nursing care support <i>Coping</i> Not reported</p>	<p>Care-givers had moderate nursing burden. The health status, as some care-givers had their own long-term conditions, daily care time and lack of support in terms of nursing care contributed to care-giving burden.</p>
Jiang <i>et al.</i> (2015)	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 64</li> <li>3. Alzheimer's disease</li> <li>4. Chongqing</li> </ol>	<p><i>Stressors</i> Physical health status Financial difficulties <i>Coping</i> Subjective social support</p>	<p>The SCL-90 total scores and the scores of somatisation, compulsion, interpersonal sensitivity, hostility, terror, paranoid, psychotic of family care-givers of care recipients were significantly higher than those of the Chinese</p>

	<p>5. Gender: male 28, female 36. Age: &lt;50: 15, ≥50: 49. Relationship with care recipient: spouse 26, child 33, other 5</p>		<p>norm (<math>p &lt; 0.05</math> or <math>p &lt; 0.01</math>). The SCL-90 scores of family care-givers 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 (<math>p &lt; 0.01</math>). The total scores of SCL-90 of family care-givers were significantly positively correlated with the ZBI total scores (<math>r = 0.924</math>, <math>p &lt; 0.01</math>), significantly negatively correlated with the SSRS total scores (<math>r = -0.288</math>, <math>p &lt; 0.05</math>) and significantly negatively correlated with the subjective support score (<math>r = -0.355</math>, <math>p &lt; 0.01</math>). 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 (<math>\beta = 0.831, 0.186, 0.145, 0.108, 0.089, 0.081, R^2 = 0.892</math>). Home care-givers of patients with Alzheimer's disease had a poor mental health.</p>
<p>Wang <i>et al.</i> (2015)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 152</li> <li>3. Dementia</li> <li>4. A capital city of a province</li> <li>5. Gender: male 43, female 109. Employment status: employed 39, unemployed 113. Relationship with care recipient: spouse 55, non-spouse 97. Co-residence: no 35, yes 117. Financial burden: no 68, yes 84</li> </ol>	<p><i>Stressors</i> Care-giving demands Behavioural management Gender Family support Time dependency Financial difficulties <i>Coping</i> Not reported</p>	<p>Higher levels of stress and prevalence of Behavioural and Psychological Symptoms of Dementia (BPSD) were reported. Women reported higher level of stress in comparisons to male counterpart. The more helpers available to help care-givers, the higher the level of distress experienced. This was attributed to lack of support for care-givers of people living with dementia, <i>i.e.</i> lack of dementia education for care-givers and health-care professionals to help manage from day to day. Some care-givers reported having financial difficulties.</p>
<p>Wang <i>et al.</i> (2019)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 208</li> <li>3. Chronic heart failure</li> <li>4. HaErbing</li> <li>5. Gender: male 51, female 157. Age:</li> </ol>	<p><i>Stressors</i> Financial difficulties Care recipients' ability to self-care Age of care-givers and resident status</p>	<p>The age, residence, work and daily care hours of the carers was associated with level of care-givers' burden. Care-givers whose older relative had to self-fund their treatment experienced a higher level of care-giving burden in comparison to those who had access to public services. Care recipients</p>

	<p>&lt;60 years: 92, 60–70 years: 69, 70 years and above: 47. Marital status: married 173, unmarried 35. Education: middle school and below 89, high school and above 119. Income (Yuan): &lt;3,000: 73, &gt;3,000: 135. Employment status: employed 83, not employed 67, retired 58. Relationship with care recipient: spouse 92, offspring 79, others 37. Care-giving time (hours): &lt;3: 29, 3–6: 74, &gt;6: 105</p>	<p>Care-giving time Coping Not reported</p>	<p>who could barely attend to their needs were highly dependent on care-givers, which in turn increased their burden. Older care-givers experienced higher levels of burden and care-givers who lived with care recipients showed a higher level of burden.</p>
<p>Wei et al. (2014)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 744</li> <li>3. Disability: high blood pressure (72.7%), stroke (50.5%), coronary heart disease (48.4%), diabetes (41.3%), osteoarthritis (30.9%)</li> <li>4. Beijing</li> <li>5. Age range: 26–89.</li> </ol>	<p>Stressors Living arrangement Care-givers' self-reported health status Coping Social support</p>	<p>The prevalence rate of anxiety was 29.2% reported by family care-givers. The average score of SAS was <math>35.6 \pm 8.6</math>. The risk factors of care-givers' anxiety included Barthel Index score <math>\leq 20</math> (OR = 1.51), SSRS score <math>\leq 33</math> (OR = 4.56), no time to relax (OR = 1.57) and poor health status (OR = 3.48). A high level of anxiety exists in family care-givers for the disabled elderly. Care-giver anxiety was a complex process. The results showed that the older the care-giver 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. With regards to social support for family care-givers, difference between care-givers' older relatives with anxiety and those with no anxiety was found to be statistically significant.</p>
<p>Yu et al. (2013)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 121</li> <li>3. Stroke</li> <li>4. A city in central China</li> <li>5. Age: &lt;45: 5, 46–64: 38, &gt;65: 78. Age range: 32–82. Gender: male 33, female 88. Marital status: single 1, married 110,</li> </ol>	<p>Stressors Time dependence Coping Problem solving coping Social support</p>	<p>The MCS correlated with the Barthel Index of care recipients, which showed that functional independence of care was associated with high MCS score. The MCS sub-scale of HrQoL negatively associated with number of care-giving hours per day, as well as the number of care-givers' long-term conditions. Problem-focused coping</p>

	<p>divorced 2, widowed 8. Relationship with care recipient: spouse 96, offspring 15. Employment status: unemployed 5, retired 101, employed 2, other 13</p>		<p>strategies, active coping and planning were found to correlate positively with the mental health of care-givers. Care-givers perceived social support mainly came from family members and neighbours and the least amount of support came from their friends.</p>
<p>Yu <i>et al.</i> (2015)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 168</li> <li>3. Alzheimer's</li> <li>4. Taiyuan</li> <li>5. Gender: male 53, female 115. Relationship with care recipient: spouse 71, offspring 77, others 20</li> </ol>	<p><i>Stressors</i> Attributes of care recipient Time dependency <i>Coping</i> Not reported</p>	<p>Cognitive functioning in care recipients negatively associated with CBI scores: with lower cognitive function in care recipients, higher CBI score was noted. Other sources of stress related to ADLs and behavioural challenges. Care recipients with impaired cognitive functioning reported higher levels of dependency on care-givers with regards to ADL. Behavioural challenges predicted cognitive status of care recipients. Hours of care-giving was reported to be directly proportional to reported CBI scores.</p>
<p>Zhang <i>et al.</i> (2013)</p>	<ol style="list-style-type: none"> <li>1. Survey study</li> <li>2. 58</li> <li>3. Dementia</li> <li>4. Wuhan</li> <li>5. Gender: male 16, female 42. Age range: 42–66. Average age: 49.8 ± 9.2</li> </ol>	<p><i>Stressors</i> Lack of adequate support Lack of skillsets <i>Coping</i> Not reported</p>	<p>Psychiatric distress was found to be associated with lack of adequate understanding and as care-givers lacked the skillset needed to provide care. Family functioning was low and had adverse implications on problem solving and communication skills, affective responsiveness, behavioural control and general functioning.</p>
<p>Zhao (2011)</p>	<ol style="list-style-type: none"> <li>1. Cross-sectional study</li> <li>2. 536</li> <li>3. 157 (29.29%) cases of chronic cardiovascular diseases, 209 (38.99%) cases of cerebrovascular diseases, 138 (25.75%) cases of chronic respiratory diseases, 32 (25.75%) cases of endocrine and immune system diseases</li> <li>4. Shandong</li> </ol>	<p><i>Stressors</i> Personal factors Social pressure Financial pressure Mental stress <i>Coping</i> Not reported</p>	<p>Personal and social strains were the most important pressure faced by care-givers. This was followed by work strain and financial strain. The psychological strain of spouses was relatively lower. Pressure associated with caring responsibilities was found to be responsible for care-givers' anxiety and depression symptoms and made care-givers' health self-evaluation worse. In terms of the needs of care-givers': among the 536 patients' spouses, 88.0% were eager to learn</p>



5. Gender: female 297, male 239. Age range: 60–80. Average age:  $69 \pm 4.23$ . Relationship with care recipient: spouse

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

*Notes:* ADL: activities of daily living. CBI: Caregiver Burden Inventory. CDR: Clinical Dementia Rating Scale. GP: general practitioner. HRQoL: health-related quality of life. IADL: instrumental activities of daily living. MCS: Mental Component Summary. MMSE: Mini-Mental State Examination. OR: odds ratio. SAS: Self Rating Anxiety Scale. SCL-90: Symptom Checklist-90. SD: standard deviation. SDS: Self-rating Depression Scale. SSRS: Social Support Rating Scale. WAP: Worry About Performance. ZBI: Zarit Burden Interview.

of medical expenses for care recipients. In some cases, this contributed to the psychological burden they experienced (Yong, 2012; Liu *et al.*, 2013; Du *et al.*, 2014, 2017; Jiang *et al.*, 2015; Liu, 2016; Pei *et al.*, 2017; Song, 2018). As such, care-givers 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 care-giving role precluded the care-giver from fulfilling other obligations, as parent, spouse or employee. Twenty-three papers showed that care-givers felt stifled due to the demands of care-giving, especially those who themselves had poor health status (Liu and Zhou, 2009; Liu *et al.*, 2015; Liu, 2016; Shen and Wang, 2016; Chen, 2017; Guogui *et al.*, 2017; Tong, 2018). The high dependency of care recipients on care-givers, characterised by the severity of their long-term conditions and poor communication skills, placed particular demands on care-givers (H Li *et al.*, 2009; Chen *et al.*, 2017; Liu *et al.*, 2017; Song, 2018; P Li *et al.*, 2019). The older the care-givers, 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 care-givers 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 wellbeing. By contrast, Li *et al.* (2013) found that stress levels were lower in co-resident care-givers, especially those who were competent in nursing care; the better the skillset of care-givers, the better they were at coping with the demands of the role. Further, Qiu *et al.* (2017) noted that care-givers prioritised the wellbeing 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 care-giving, some care-givers gave up their jobs or reduced working hours to accommodate care responsibilities, which significantly increased care-giving burden (Pan *et al.*, 2018). The demands or anticipation of providing hands-on care also gave care-givers the impression that they were not in control of their own lives (Davis *et al.*, 1995; He *et al.*, 1995; Liu, 2016). For instance, care-giving demands created a sense of isolation, leaving care-givers disconnected from other people. Care-givers noted that 'no-one cares' about them, reflecting changes in society (Zhang *et al.*, 2020). 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 long-term 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 care-giving. These personal strains were associated with a range of factors. He *et al.* (1995)

found that both the physical and mental health of care-givers were adversely affected, in cases where care-givers 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 (Qian *et al.*, 2014; Sun, 2014; Jiang *et al.*, 2015), as well as older age and poorer health status of care-givers (Lu *et al.*, 2017; Pan *et al.*, 2018; Tong, 2018; Liu *et al.*, 2019; Wang *et al.*, 2019), contributed to higher levels of personal care-giver stress (Shen and Wang, 2016). Particular care-giving activities were found to be personally stressful, especially when care-givers had to manage the care recipient's behaviour (Fu *et al.*, 2007; Lu *et al.*, 2015; Wang *et al.*, 2015; Yu *et al.*, 2015) which disrupted care-givers' plans for social outings or hobbies (Zhao, 2011; Liu *et al.*, 2015). Care-giver stress could precipitate breakdown in family relationships (Liu, 2016), especially when care-givers 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 care-givers. Care-givers 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 care-givers 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 care-giving. Women were considered emotionally susceptible to the pressures of care-giving, especially as they were providing most hands-on care (Tang, 2006; Fu *et al.*, 2007; Wang *et al.*, 2015; Song, 2018). 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 care-giving (Song, 2018), *e.g.* 'eldest sons' were found to be more susceptible to stressors such as financial pressures (Tang, 2006; Liu *et al.*, 2013). Co-residents and daughters, who are societally expected to provide care, often had to provide care unflinchingly and this subjected these care-givers to stress (Liu, 2016; Liu and Bern-Klug, 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 care-givers lacking the knowledge and skills to meet the needs of care recipients and this was associated with adverse health outcomes and negative experiences (Fu *et al.*, 2007; Zhang *et al.*, 2013; J Wang *et al.*, 2015; Liu, 2016; Guogui *et al.*, 2017; X Liu *et al.*, 2017, 2019; H Liu *et al.*, 2018; M Wang *et al.*, 2018). The absence of adequate formal support

implies that relatives had to rally around primary care-givers for support. However, too little or too much relative input could equally be a source of stress (Chen, 2017; Song, 2018). In addition, care-givers expressed concerns about the societal rejection of people living with dementia due to stigma and misunderstanding. The cultural environment did not necessarily afford care-givers 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, care-givers sought advice within their social network, not from professionals (Lian *et al.*, 2017). Similarly, in terms of care knowledge and skills, care-givers lacked professional support from primary health workers (Liu *et al.*, 2012). It was suggested that geographical distance between care-givers and care recipients can be a source of stress (Guogui *et al.*, 2017), as the lack of local care services leaves care-givers with very limited options for delegation of care-giving tasks. Care-givers 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 care-givers to available community resources (Yong, 2012; Shen and Wang, 2016) could perhaps explain the negative impacts of care-giving on health and finances (Liu and Lou, 2012). Depressive symptoms were significantly associated with time dependence, physical burden and social burden (Lu *et al.*, 2015). Lu *et al.* 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 care-givers could result in low levels of satisfaction, which could consequently result in conflict between family members, and manifest as low levels of support (Zhang *et al.*, 2013). In support, Qiu *et al.* (2017) study found that poor social support services and limited access to information tended to impede care-givers from using formal services, resulting in care-givers feeling despondent and isolated. Moreover, in cases where care-givers 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 care-givers were coping. Studies indicated a range of sources of external support were used. Shen *et al.* (2019a) found that care-givers 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 care-givers did not engage with professional services (Wei *et al.*, 2014), Pan *et al.* (2018) found that most care-givers sought support from relatives, friends and society, and that the level of social support was moderate. In some cases, care-givers 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 assist further (Yu *et al.*, 2013). Care-givers' children provided assistance as an act of being filial to parents (Liu, 2016). Practical family and social support reduced burden by reducing the time care-givers devoted to care-giving and providing some respite (Li *et al.*,

2009; Shen and Wang, 2016). In other cases, family members took the care-giving role in turns (Yong, 2012). Conversely, Wang *et al.* (2015) reported that increased numbers of social support ‘helpers’ were associated with higher levels of care-giver distress. In the absence of social support, however, Liu *et al.* (2018) found that some care-givers 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 care-givers.

In terms of emotion-focused coping, care-givers generally accepted their situation (Qiu *et al.*, 2017) and used emotion-focused strategies such as dancing, singing, listening to music and gardening to cope with anxieties and frustrations associated with their role (Sun, 2014). They coped with social pressures through avoidance, escapism and providing justifications for actions. In addition, they coped with the demands of their role and developed self-confidence by drawing upon their moral qualities, including their senses of duty and responsibility (Davis *et al.*, 1995; Qiu *et al.*, 2017). Qiu *et al.* (2017) further stated that care-givers coped by drawing on their inner strength. Offspring of older people were found to need more support compared to spouses and other relatives. Emotional support from their social network reduced the level of burden they experienced (Wei *et al.*, 2014). Care-givers 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 *et al.*, 2017). There was an expectation that immediate family members would provide care for their older relatives, regardless of receiving substantial support or not.

In terms of problem-focused coping, care-givers planned, actively sought care knowledge, mastered care skills and positively reframed their experiences (Yu *et al.*, 2013; Sun, 2014; Qiu *et al.*, 2017). For example, some care-givers 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, care-givers made use of media such as books, television, radio and newspapers as sources for knowledge and skills acquisition. Some care-givers were found to utilise a distinctive coping strategy, namely a ‘family-connected strategy’ (Qiu *et al.*, 2017). More specifically, Sun (2014) stated that care-givers coped with family obscurities by planning ahead and engaging in direct confrontations. To cope with financial difficulties, care-givers actively searched for jobs and sought assistance through governmental agencies. Some combated 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 conditions. Key themes associated with stressors were care-giving 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 care-givers. 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 *et al.* (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 care-givers. 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 care-givers. 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 1,002 older people aged between 55 and 90 were subjected to either physical or psychological abuse over a period of 12 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 care-givers 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 *et al.*, 2010). Care-givers 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 *et al.*, 2021), it is expected that attitudes and motivations of care-givers will vary, and this will consequently determine if care-givers 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 care-givers 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 care-givers and the appraisal of their role.

In a systematic review, McCabe *et al.* (2016) indicated that many unmet needs of care-givers were associated with lack of formal support. In line with this, our findings equally show that care-givers lack adequate support and, more specifically, are not well prepared for taking on their care-giving 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 care-givers were to take on caring. Lack of preparedness of care-givers, found in this review, reinforces the point that care-givers 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 care-givers. Such interventions would need to acknowledge that caring for older relatives in China is multi-dimensional and pay attention to the influence of the individual's socio-cultural environment on the process of care-giving.

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 care-givers 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 care-giving on social identity), sociality (implications of care-giving process on relations with others), embodiment (implications of the process of care-giving for gender, body sensations and 'disability'), temporality (implications of the process of care-giving for time) and spatiality (implications of the care-giving process for place) have not yet been captured adequately (Ashworth, 2006). The association between care-giving and stress implies that care-givers feel excessively taxed; which could progress to care-givers 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 care-givers exercise their individual agency in relation to their personal attitude and capacity for care-giving. For instance, care-giving time was identified as a source of stress, but most papers failed to capture the interaction between care-giving time and time spent on other aspects of life. With rapid socio-demographic transitions, there appears to be an excessive demand placed on care-givers 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 *et al.* (2018) found that there are still lingering patrilineal 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 one-child 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 care-giving.

In the absence of holistic consideration of the needs of care-givers, this scoping review showed that a significant number of papers pertained to personal and role strains. Some care-givers 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 care-givers could be detrimental for their wellbeing. More specifically, with the socio-demographic transitions in China, Generation X and Millennials (those born from 1965 to 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 care-giving



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 care-giver stress. In the period from 2005 to 2020, there have been increasing numbers of publications (2005–2009: four papers; 2010–2014: 13 papers; 2015–2019: 28 papers) focused on a wider range of facets of care-giving. Given that the country had very limited time to prepare for transition into an ageing society, an explanation for the increase in the numbers of papers published could be researchers' response to the increasing prominence of the implications of socio-economic and cultural transitions on the role of care-giving over time. It is therefore plausible to deduce that care-givers have been under increasing pressure to reconcile their care-giving 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 Kosloski, 2009). More specifically, in situations where care-givers are no longer able to cope with increased demands, and having in mind transitions with regard to 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 care-givers when compared to their counterparts in Western societies.

Despite the significant number of papers showing that care-givers experience stress, only about one-third reported coping strategies which included both problem- and emotion-focused strategies, whereby care-givers 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 care-givers 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 care-givers and care recipients. Such information is needed, especially given that care-givers have to cope with a series of changes and care transitions (Moral-Fernández *et al.*, 2018) and because filial responsibility may prevent care-givers from using formal services (Qiu *et al.*, 2017). The lack of detailed attention to ways of coping reflects the emphasis that has been placed on describing adverse care-giving experiences rather than exploring how people manage such experiences. It could also suggest that cultural underpinnings such as *Ren* (忍; 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 care-giving for older relatives, future research should explore the influences of Chinese culture on the process of care-giving. Culture is dynamic and its influence on care-giving processes is therefore challenging to measure with standardised quantitative measures. Quantitative measures of care-giving burden and coping, as employed by most papers in this review, can provide researchers or policy makers with a baseline and help in identifying unmet needs, but do not provide insight into the complexities underlying the processes of care-giving. 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 care-giving 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 UK, for instance. People from minority ethnic groups are under-represented within formal services for older people in the UK, and Baghirathan *et al.* (2020) suggested that there is a dearth of evidence with regards to the needs of Chinese family care-givers 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 care-givers, particularly as stressors can be interwoven, are culturally situated and have implications for coping mechanisms adopted by care-givers. Idiosyncratic contexts of care-givers, 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 care-givers' 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 care-givers 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. Care-giving is complex and this review has identified areas that require further research, particularly recognising that the intricacies of the process of care-giving cannot solely be captured by adopting measures which rely on linearity. Thus, researchers, policy makers, and 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>

**Acknowledgements.** The authors are grateful to Maria Introwicz and Mat Andrews, who are the Faculty of Health Studies librarians at the University of Bradford, for their time and effort with regards to refining the search terms.

**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, 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.

**Financial support.** This work was supported by Research England: Quality Related Global Challenge Research Fund (QR-GCRF).

**Conflict of interest.** The authors declare no conflicts of interest.

## References

- Aranda MP and Knight BG (1997) The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. *The Gerontologist* 37, 342–354.
- Arksey H and O'Malley L (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8, 19–32.
- Ashworth PD (2006) Seeing oneself as a carer in the activity of caring: attending to the lifeworld of a person with Alzheimer's disease. *International Journal of Qualitative Studies on Health and Well-being* 1, 212–225.
- Au A (2017) Low mental health treatment participation and Confucianist familial norms among East Asian immigrants: a critical review. *International Journal of Mental Health* 46, 1–17.
- Baghirathan S, Cheston R, Hui R, Chacon A, Shears P and Currie K (2020) A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: balancing the need for support against fears of being diminished. *Dementia* 19, 1672–1691.
- Burhanullah MH and Munro CA (2020) Influences on caregiver distress in Asia: a moving target. *International Psychogeriatrics* 32, 685–687.
- Carver C (1997) You want to measure coping but your protocol's too long: consider the brief COPE. *International Journal of Behavioural Medicine* 4, 92–100.
- Chen R (2017) The burden and supporting mechanism for tenders of households with senior citizens. *Urban Insight* 1, 127–134.
- Chen Y, Zhang C, Qin Q, Li P and Jiang L (2017) Study for the impact on family caregivers' burden by age and self-ability of the disabled elderly. *Journal of Nurses Training* 32, 775–778.
- Chou K, Jiann L and Chu H (2002) The reliability and validity of the Chinese version of the Caregiver Burden Inventory. *Nursing Research* 51, 324–331.
- Cooke A, Smith D and Booth A (2012) Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research* 22, 1435–1443.

- Crellin NE, Orrell M, McDermott O and Charlesworth G** (2014) Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review. *Aging & Mental Health* **18**, 954–969.
- Davis A, Martinson I, Gan L, Jin Q, Liang Y, Davis D and Lin J** (1995) Home care for the urban chronically ill elderly in the People's Republic of China. *International Journal of Aging & Human Development* **41**, 345–358.
- Du J, Qian C, Xu W, Shao S, Zhao Y and Wang H** (2014) Depressive symptoms in family caregivers of disabled elderly in Beijing urban. *Chinese Mental Health Journal* **28**, 506–511.
- Du J, Shao S, Jin G, Qian C, Xu W and Lu X** (2017) Factors associated with health-related quality of life among family caregivers of disabled older adults: a cross-sectional study from Beijing. *Medicine* **96**, e8489.
- Fang B, Yan E, Chan KL and Ip P** (2018) Elder abuse and its medical outcomes in older Chinese people with cognitive and physical impairments. *International Journal of Geriatric Psychiatry* **33**, 1038–1047.
- Fu Y, Yue P and Liu Q-S** (2007) Burdens of spouse caregivers of patients with dementia at home. *Chinese Mental Health Journal* **21**, 267–270.
- Guo L, Zhang J, Ma W, Sha X, Yi X, Zhang B, Wang C and Wang S** (2015) Offspring caregivers' depression affected by intergenerational disagreements on preferred living arrangement for the elderly: a phenomena with Chinese characteristic. *Archives of Gerontology and Geriatrics* **61**, 363–370.
- Guo M, Steinberg NS, Dong X and Tiwari A** (2018) A cross-sectional study of coping resources and mental health of Chinese older adults in the United States. *Aging & Mental Health* **22**, 1448–1455.
- Guo M, Kim S and Dong X** (2019) Sense of filial obligation and caregiving burdens among Chinese immigrants in the United States. *Journal of the American Geriatrics Society* **67**, S564–S570.
- Guogui H, Du P and Chen G** (2017) A study on the current status of taking care of parents among Chinese elderly and its influence on depression. *Scientific Research on Aging* **5**, 15–25.
- He Y, Zhang M, Chou J, Yu W, Wu W, Cui X, Shao H, Grant I and Patterson T** (1995) The psychological and physical health of family members caring for an elderly person with dementia. *Chinese Journal of Clinical Psychology* **3**, 200–203.
- Hua Q, Fan L, Li J, Chen L-Y, Chen W-W, Chen X-P, Guo Y-F, He Q, Hu Y-X, Jiang Y-N, Li N-F, Li W-M, Li Y, Li Y, Li Y, Ma Q-F, Pi L, Song H-Q, Sun X-P, Wang Q, Wang Z-W, Wu H-Y, Wu H-Y, Xie L-D, Yang J-G and Yang W** (2019) 2019 Chinese guideline for the management of hypertension in the elderly. *Journal of Geriatric Cardiology* **16**, 67–99.
- Jiang Z, Tan X, Zhao K, Wen Y, Huang J, Chen F, Jiang P and Hu S** (2015) Analysis on mental health and its influence factors of family caregivers of patients with Alzheimer's disease. *China Medical Herald* **12**, 55–59.
- Knight B and Sayegh P** (2010) Cultural values and caregiving: the updated sociocultural stress and coping model. *Journals of Gerontology: Psychological Sciences and Social Sciences* **65B**, 5–13.
- Kristanti MS, Engels Y, Effendy C, Astuti, Utarini A and Vernooij-Dassen M** (2018) Comparison of the lived experiences of family caregivers of patients with dementia and of patients with cancer in Indonesia. *International Psychogeriatrics* **30**, 903–914.
- Kristanti MS, Effendy C, Utarini A, Vernooij-Dassen MJFJ and Engels YMP** (2019) The experience of family caregivers of patients with cancer in an Asian country: a grounded theory approach. *Palliative Medicine* **33**, 676–684.
- Lam PC, Ng P, Pan J and Young DK** (2015) Ways of coping of Chinese caregivers for family members with schizophrenia in two metropolitan cities: Guangzhou and Hong Kong, China. *International Journal of Social Psychiatry* **61**, 591–599.
- Levac D, Colquhoun H and O'Brien KK** (2010) Scoping studies: advancing the methodology. *Implementation Science* **5**, 69–69.
- Li H, Wang M, Huang H and Zhao H** (2009) Study on family burden in aged patients with chronic disease. *Chinese Journal of Nursing* **44**, 561–564.
- Li M, Yang H, Gao Q and Li S** (2013) Analysis of burden of family long-term caregivers for disabled elders in Jinan city and influencing factors. *Journal of Shandong University (Health Sciences)* **51**, 109–112.
- Li P, Jiang L, Chen Y and Li J** (2019) Effect of health status for disabled elderly on family burden of their long-term caregivers. *Nursing and Rehabilitation Journal* **18**, 30–34.
- Lian Y, Xiao LD, Zeng F, Wu X, Wang Z and Ren H** (2017) The experiences of people with dementia and their caregivers in dementia diagnosis. *Journal of Alzheimer's Disease: JAD* **59**, 1203–1211.
- Lin W** (2019) The relationship between formal and informal care among Chinese older adults: based on the 2014 CLHLS dataset. *BMC Health Services Research* **19**, 1–8.

- Liu Y (2016) Nursing dilemma and thinking of disabled elderly family caregivers. *Social Sciences Review* **31**, 103–107.
- Liu J and Bern-Klug M (2016) 'I should be doing more for my parent.' Chinese adult children's worry about performance in providing care for their oldest-old parents. *International Psychogeriatrics* **28**, 303–315.
- Liu J and Lou W (2012) Improving the social support system for family caregivers of the disabled old in Shanghai. *Journal of East China Normal University* **44**, 19–25.
- Liu L and Zhou L (2009) Qualitative study on caregiver care experience in elderly patients with chronic diseases. *Journal of Nursing* **16**, 67–69.
- Liu J, Wang L, Tan J, Ji P, Gauthier S, Zhang Y, Ma T and Liu S (2012) Burden, anxiety and depression in caregivers of veterans with dementia in Beijing. *Archives of Gerontology and Geriatrics* **55**, 560–563.
- Liu J, Guo M and Bern-Klug M (2013) Economic stress among adult-child caregivers of the oldest old in China: the importance of contextual factors. *Journal of Cross-cultural Gerontology* **28**, 465–479.
- Liu J, Zhao Q and Xiao M (2015) The current status and influencing factors of caregiver burden among relative caregivers of the disenabled elders in communities. *Chinese Nursing Management* **15**, 925–929.
- Liu X, Chen L and Jiang C (2017) Burden of family caregivers of senile dementia community residents: the influencing factors. *Journal of Nursing Science* **32**, 91–93.
- Liu H, Li X, Ding J and Yang X (2018) A 2017 study on depressive symptoms and influencing factors of elderly caregivers in communities. *Practical Preventive Medicine* **25**, 1501–1504.
- Liu X, Yang Y, Xie X and Si L (2019) Correlation between quality of home care for disabled elderly and burden of caregivers. *Chinese Journal of Gerontology* **39**, 4081–4084.
- Liu N, Liu J and Lou VW (2015) Caring for frail elders with musculoskeletal conditions and family caregivers' subjective well-being: the role of multidimensional caregiver burden. *Archives of Gerontology and Geriatrics* **61**, 411–418.
- Liu X, Li Y, Wang B, Li Y and Chen C (2017) A study on the correlation between the burden of disabled elderly carers in rural areas and social support. *Modern Preventive Medicine* **44**, 843–847.
- Liu J, Zhang L and Zhang K (2021) Care preferences among Chinese older adults with daily care needs: individual and community factors. *Research on Aging* **43**, 166–176.
- Lv Q, Xu S, Sun Y and Chen S (2013) Study on related factors of psychological burden of family caregivers of rural elderly patients with chronic diseases. *Chinese Nursing Research* **27**, 2455–2457.
- Mayston R, Lloyd-Sherlock P, Gallardo S, Wang H, Huang Y, Montes De Oca V, Ezeah P, Guerra M, Sosa AL, Liu Z, Uwakwe R, Guerchet MM and Prince M (2017) A journey without maps – understanding the costs of caring for dependent older people in Nigeria, China, Mexico and Peru. *PLOS ONE* **12**, e0182360.
- McAllum K, Simpson ML, Unson C, Fox S and Kilpatrick K (2021) The socialization of unpaid family caregivers: a scoping review. *Research on Aging*, 1–11 (in print). Doi: 10.1177/01640275211005092.
- McCabe M, You E and Tatangelo G (2016) Hearing their voice: a systematic review of dementia family caregivers' needs. *The Gerontologist* **56**, e70–e88.
- Montgomery RJV and Kosloski K (2009) Caregiving as a process of changing identity: implications for caregiver support. *Generations: Journal of the American Society on Aging* **33**, 47–52.
- Moral-Fernández L, Frías-Osuna A, Moreno-Cámara S, Palomino-Moral PA and Del-Pino-Casado R (2018) The start of caring for an elderly dependent family member: a qualitative metasynthesis. *BMC Geriatrics* **18**, 228.
- Oliveira D, Zarit SH and Orrell M (2019) Health-promoting self-care in family caregivers of people with dementia: the views of multiple stakeholders. *The Gerontologist* **59**, e501–e511.
- Pan D, Li L and Zhou Y (2018) Analysis on the burden of family caregivers of elderly patients with COPD and its influencing factors. *Chinese Journal of Modern Nursing* **24**, 4178–4181.
- Park M and Chesla C (2007) Revisiting Confucianism as a conceptual framework for Asian family study. *Journal of Family Nursing* **13**, 293–311.
- Pei X, Luo H, Lin Z, Keating N and Fast J (2017) The impact of eldercare on adult children's health and employment in transitional China. *Journal of Cross-cultural Gerontology* **32**, 357–372.
- Peters M, Godfrey C, Khalil H, McInerney P, Parker D and Baldini C (2015) Guidance for conducting systematic scoping reviews. *International Journal of Evidence-based Healthcare* **13**, 141–146.
- Qian C, Xu W, Shi T, Shao S, Wang H and Du J (2014) Investigation of the incidence of anxiety and influence factors in family caregivers of disabled elderly in Beijing urban. *West China Medical Journal* **29**, 812–815.

- Qiu X, Sit JW and Koo FK** (2017) The influence of Chinese culture on family caregivers of stroke survivors: a qualitative study. *Journal of Clinical Nursing* **27**, e309–e319.
- Queluz FNFR, Kervin E, Wozney L, Fancey P, McGrath PJ and Keefe J** (2020) Understanding the needs of caregivers of persons with dementia: a scoping review. *International Psychogeriatrics* **32**, 35–52.
- Quinn C, Clare L and Woods RT** (2010) The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics* **22**, 43–55.
- Serrano R, Saltman R and Yeh M** (2017) Laws on filial support in four Asian countries. *Bulletin of the World Health Organization* **95**, 788–790.
- Shen S and Wang Y** (2016) Care pressure community service and purchase care intention of disabled elderly family carers – a case study of Nanjing City. *Labor Security World* **6**, 17–20.
- Shen S, Chen Z, Xue M, Li F and Zhang R** (2019a) How to relieve stress in adult child caregivers of the older adults with disabilities: a survey study from the city of Nanjing, China. *Social Work in Health Care* **58**, 291–303.
- Shen S, Wan Y, Xie Y, Chen Z and Li F** (2019b) Care stress experienced by caregivers of elderly individuals with disabilities and the coping strategies utilized: a survey study in the city of Nanjing, China. *Journal of Family Issues* **40**, 1396–1414.
- Simon MA, Chen R, Chang ES and Dong X** (2014) The association between filial piety and suicidal ideation: findings from a community-dwelling Chinese aging population. *Journals of Gerontology: Biological Sciences and Medical Sciences* **69A**, S90–S97.
- Smith C and Hung I** (2012) The influence of Eastern philosophy on elder care by Chinese Americans: attitudes toward long-term care. *Journal of Transcultural Nursing* **23**, 100–105.
- Song C** (2018) Study on the stress and its influencing factors of elderly family caregivers: evidence from a survey in rural areas of Shandong Province. *Journal of Shandong Technology and Business University* **32**, 107–116.
- Sun F** (2014) Caregiving stress and coping: a thematic analysis of Chinese family caregivers of persons with dementia. *Dementia* **13**, 803–818.
- Tang Y** (2006) Adult caregivers and home care for the elderly. *Journal of Yunnan Finance & Economics University* **21**, 130–132.
- Tang Y** (2020) Experiences of family caregivers with day-care centers for elders in Southern China: a qualitative study. *European Journal of Social Work* **24**, 331–343.
- Tong H** (2018) Nursing burden, quality of life status and influencing factors of caregivers of elderly patients with spinal cord injury. *Guide of China Medicine* **16**, 277–278.
- Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, Moher D, Peters MDJ, Horsley T, Weeks L, Hempel S, Akl EA, Chang C, McGowan J, Stewart L, Hartling L, Aldcroft A, Wilson MG, Garrity C, Lewin S, Godfrey CM, Macdonald MT, Langlois EV, Soares-Weiser K, Moriarty J, Clifford T, Tunçalp Ö and Straus SE** (2018) PRISMA extension for Scoping Reviews (PRISMA-ScR): checklist and explanation. *Annals of Internal Medicine* **169**, 467.
- United Nations** (2019) *World Population Prospects 2019*. New York, NY: United Nations. Available at <https://population.un.org/wpp/Graphs/Probabilistic/POP/80plus/156>.
- United Nations Department of Economic and Social Affairs, Population Division** (2015) *World Population Ageing 2015*. New York, NY: United Nations. Available at [https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/files/documents/2020/May/un\\_2015\\_world-populationageing\\_report.pdf](https://www.un.org/development/desa/pd/sites/www.un.org.development.desa.pd/files/files/documents/2020/May/un_2015_world-populationageing_report.pdf).
- Wang HH, Wang JJ, Wong SY, Wong MC, Li FJ, Wang PX, Zhou ZH, Zhu CY, Griffiths SM and Mercer S** (2014) Epidemiology of multimorbidity in China and implications for the healthcare system: cross-sectional survey among 162,464 community household residents in southern China. *BMC Medicine* **12**, 188.
- Wang J, Xiao LD, Li X, De Bellis A and Ullah S** (2015) Caregiver distress and associated factors in dementia care in the community setting in China. *Geriatric Nursing* **36**, 348–354.
- Wang M, Shao S, Li J, Liu Y, Xu X and Du J** (2018) The needs of informal caregivers and barriers of primary care workers toward dementia management in primary care: a qualitative study in Beijing. *BMC Family Practice* **19**, 201.
- Wang Z, Chen G and Dong Y** (2019) Analysis on the burden and influencing factors of family caregivers for elderly patients with chronic heart failure. *Chinese Journal of Modern Nursing* **25**, 501–504.

- Warmenhoven H, Hoebink PRJ and Janssens JMAM** (2018) The Chinese postreform generation as care-givers: the caregiving intentions toward parents and parents-in-law of the one-child generation. *Journal of Family Issues* **39**, 3690–3712.
- Wei X, Qian C, Ma Y, Shao S, Wang H, Jin G and Du J** (2014) Study on the present situation and influencing factors of the care-taking burden of disabled elderly family caregivers in urban area of Beijing. *Chinese Journal of Disease Control* **18**, 663–666.
- Wu D and Lam TP** (2016) Underuse of primary care in China: the scale, causes, and solutions. *Journal of the American Board of Family Medicine* **29**, 240–247.
- Xiao L, Wang J, He G, De Bellis A, Verbeek J and Kyriazopoulos H** (2014) Family caregiver challenges in dementia care in Australia and China: a critical perspective. *BMC Geriatrics* **14**, 6.
- Xu L, Hsiao H, Denq W and Chi I** (2018) Training needs for dementia care in China from the perspectives of mental health providers: who, what, and how. *International Psychogeriatrics* **30**, 929–940.
- Yang W, Wu B, Tan SY, Li B, Lou V, Chen Z, Chen X, Fletcher JR, Carrino L, Hu B, Zhang A, Hu M and Wang Y** (2021) Understanding health and social challenges for aging and long-term care in China. *Research on Aging* **43**, 127–135.
- Yong T** (2012) The establishment of mental health and long-term care system for the disabled elderly. *Academic Forum* **35**, 168–173.
- Yu Y, Hu J, Efird JT and McCoy TP** (2013) Social support, coping strategies and health-related quality of life among primary caregivers of stroke survivors in China. *Journal of Clinical Nursing* **22**, 2160–2171.
- Yu H, Wang X, He R, Liang R and Zhou L** (2015) Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. *PLOS ONE* **10**, e0132168.
- Zhang H, Xiong R, Hujiken S, Zhang J and Zhang X** (2013) Psychological distress, family functioning, and social support in family caregivers for patients with dementia in the mainland of China. *Chinese Medical Journal* **126**, 3417–3421.
- Zhang X, Clarke C and Rhynas S** (2020) A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China. *Dementia* **19**, 2821–2835.
- Zhao Y** (2011) Investigation on the caring pressure of the spouses of patients on the aged chronic disease and the corresponding nursing intervention. *Chinese Journal of Modern Nursing* **17**, 1638–1641.
- Zhou G** (2019) The smart elderly care service in China in the age of big data. *Journal of Physics: Conference Series* **1302**, 42008.
- Zhu H and Walker A** (2018) The gap in social care provision for older people in China. *Asian Social Work and Policy Review* **12**, 17–28.

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**Cite this article:** Bifárin O, Quinn C, Breen L, Wu C, Ke M, Yu L, Oyebode J (2023). Stressors and coping mechanisms of family care-givers of older relatives living with long-term conditions in mainland China: a scoping review of the evidence. *Ageing & Society* **43**, 952–989. <https://doi.org/10.1017/S0144686X21000817>