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A qualitative study of family caregivers' coping strategies of looking after people with dementia in China

Journal:	<i>Journal of Research in Nursing</i>
Manuscript ID	JRN-19-0060.R2
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Keywords:	Dementia, Family caregivers, Coping strategies, Burden, China
Abstract:	<p>Globally, two thirds of people with dementia are cared for by their families or friends. Family caregivers' coping strategies of managing the caregiving burden of dementia have been studied widely in Western literature. However, few attempts have been made to explore the experience of family caregivers' coping strategies in China. The aim of this study is to explore the family caregivers coping strategies when caring for people with dementia in one city in the province of Shandong, China.</p> <p>Method: Fourteen family caregivers were individually interviewed, and interpretative phenomenological analysis was used to identify themes within different family members.</p> <p>Results: Four key themes were found: (a), 'being filial'. (b), 'changing self and self-care'. (C), 'seeking help'. (d), 'having hope and continuing life'.</p> <p>Conclusion: The study illustrates the different strategies developed by family members in order to cope with their new roles when caring for a relative who has dementia. It shows that cultural belief of filial piety plays a large role across these various coping strategies. It highlights how responsibility has been maintained and influenced by the specific sociocultural context. The results provide a useful foundation for developing interventions that support family caregivers cope with the burden of caring in this population.</p>

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A qualitative study of family caregivers' coping strategies of looking after people with dementia in China

Abstract

Objectives:

Globally, two thirds of people with dementia are cared for by their families or friends. Family caregivers' coping strategies of managing the caregiving burden of dementia have been studied widely in Western literature. However, few attempts have been made to explore the experience of family caregivers' coping strategies in China. The aim of this study is to explore the family caregivers coping strategies when caring for people with dementia in one city in the province of Shandong, China.

Method:

Fourteen family caregivers were individually interviewed, and interpretative phenomenological analysis was used to identify themes within different family members.

Results:

Four key themes were found: (a), 'being filial'. (b), 'changing self and self-care'. (C), 'seeking help'. (d), 'having hope and continuing life'.

Conclusion:

The study illustrates the different strategies developed by family members in order to cope with their new roles when caring for a relative who has dementia. It shows that cultural belief of filial piety plays a large role across these various coping strategies. It highlights how responsibility has been maintained and influenced by the specific sociocultural context. The results provide a useful foundation for developing interventions that support family caregivers cope with the burden of caring in this population.

Keywords

Dementia, family caregivers, coping strategies, burden, China

Introduction

It is estimated that two thirds of people with dementia live and are cared for by their families or friends worldwide (Brodaty & Donkin, 2009 , Yu et al., 2016), especially in China, there are strong traditions of filial piety that demand the Chinese to respect their older family members and take responsibility to care for them when they get old. However, China is currently undergoing a range of sociocultural and demographic changes which have had a significant influence on the capacity and availability of the traditional family support care system. These changes include the increasing trend for migration, urbanization and one child policy which has decreased the size of the older care workforce, isolated older people and resulted in families assuming less responsibility for the care of their older parents. Especially, 4-2-1 family structure (four grandparents, two parents and one child) which resulted from the one child policy has radically changed the traditional version of family-based older care in China.

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3 Dementia care services have been impacted more heavily than care for other diseases due to the
4 fact that dementia care requires more in the way of physical and psychological support (Rosa et al,
5 2010). At the same time as this transition has been taking place in both urban and rural areas,
6 Chinese family caregivers are facing a great challenge in carrying out and coping with their caring
7 responsibility (Zhang et al, 2019a). Previous studies describe different ways that individual
8 characteristics of caregivers predispose their experiences of the burden of care. A number of studies
9 have reported that caring for people with dementia has the potential to cause many negative
10 experiences, such as frustration, anger, disappointment or guilt (De Witt et al., 2009, Williams, 2010,
11 Massimo et al., 2013). Caregiving not only requires a personal commitment of time, energy, and
12 money but also has physical and psychological impacts on the person who takes on the caring role
13 (Moreno et al., 2015, Goren et al., 2016). When care demands become increasingly challenging and
14 stressful, caregivers respond by employing different strategies to meet care demands and decrease
15 the burden of caregiving (Sun, 2013, Chen et al., 2015). For example, Snyder et al (2015) illustrate
16 that caregivers with higher levels of anxiety are more likely to develop self-blaming or wishful
17 thinking coping strategies.

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23 However, another study in Taiwan (Che et al., 2006) identified that the difficulty and hardships of
24 caring for people with dementia could inspire caregivers' self-awareness, and this self-awareness
25 gives caregivers self-empowerment to cope with the daily caregiving. This is consistent with Sun's
26 study (2013), in which the author found that self-validation was a common strategy for caregivers to
27 deal with worries and frustration. Ten years on from Che et al (2006), there was a critical review of
28 the positive aspects of caregiving in dementia, reviewing that 'caregiving was identified as an
29 opportunity to learn more about themselves and appeared to give them confidence in their ability to
30 handle difficult situations in the future'(Lloyd et al., 2016, p1554). The authors also claimed that
31 despite studies being conducted in different regions and using methodologies, similar findings can
32 be found in these studies.

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37 In China, looking after parents is not only a social obligation, it is also a legal obligation (Qi, 2015). In
38 2012, the law, called "Protection of the Rights and Interests of Elderly People," emphasised the
39 duties of children and children' obligation to tend to the "spiritual needs of the elderly." This means
40 that the responsibility of caring for older people falls on individuals and families. This legal
41 requirement may change the meaning of filial piety, consequently, caring for older parents has
42 become a legal duty rather than a cultural belief (Zhang et al, 2018). As a result, this may modify the
43 caregiving strategies and experience from other ethnic groups. Therefore, investigating Chinese
44 family caregiver's coping strategies and managing the burden of looking after a family member with
45 dementia is important. Such a concept has been studied widely in Western literature, however,
46 rarely in China. The aim of this study was to explore the coping strategies of family members caring
47 for a relative with dementia in China and discusses the implications for appropriate early
48 intervention.

53 **Methods**

54
55 **Study design:** Interpretative phenomenological analysis (IPA) underpinned the study approach as it
56 allows for in-depth analysis of and engagement with individual accounts (Smith et al., 2009). IPA is
57 particularly concerned with the experience of important events or significant changes in an
58 individual's life. This particular consideration is called ideography because it is interested in
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3 understanding the detailed experience of an individual and the perspective of the individual in a
4 particular context. To ensure idiography, the researcher is normally recommended to have a small
5 sample size (Smith et al., 2009), which allows researchers to conduct detailed analysis of single cases
6 and to examine the similarities and differences within a small sample size. As a result of the detailed
7 single case analysis, it brings a deep understanding of the particular person and their response to the
8 particular experiences. The analysis process involves a 'double hermeneutic', meaning that the
9 participants are encouraged to make sense of their experiences during the interview; and then,
10 through the interpretative exercise, the researcher makes sense of what is happening to the
11 participants by interpreting their perspectives (Smith et al., 2009). It focuses on drawing on the
12 researcher's own interactions with the participants and using that as an interpretative resource –
13 getting insights into the lived experience of the participants. Therefore, this process includes a
14 descriptive meaning of the participants' experiences and an interpretation of the researchers'
15 knowledge and understanding of the context and culture. With the researcher (XZ) having living and
16 working experiences in China, IPA is a better research approach to capture the depth meaning of
17 Chinese family caregivers' experience of looking after a person with dementia specifically, rather
18 than other qualitative methods for this study.
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25 **Participant recruitment:** The participants were recruited from the relative contact list at one Mental
26 Health Centre's outpatient and inpatient units in Shandong province, China. Sampling inclusion
27 criteria were: family caregivers over 18 years old with more than six months of caregiving
28 experience; looking after a person with dementia at their own home. Invitation letters were sent to
29 potential participants and an initial meeting was held to explain the study and answer any questions.
30 Fourteen family members voluntarily participated in the study.
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33 **Data collection:** Individual interviews were undertaken using a semi-structured schedule, based
34 around the research question examining the experience of caring for a person with dementia and
35 the coping strategies used by caregivers. Open-ended questions were designed to provide more
36 space for the participants to express their perceived feeling of caregiving experience. The interview
37 took place in the participants' preferred place. Interviews lasted between 30 - 60 minutes and were
38 audio-recorded for later transcription. Field notes were used to note any important non-verbal or
39 emotional responses or any specific cues that need further action.
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43 **Data analysis**

44 Data from the interviews were transcribed and analysed using IPA. Adopting Smith's (2009) six steps,
45 the analysis process initially involved the reading and re-reading of each transcript in order to be
46 familiar with the data. Next, line-by-line coding then examined the semantic content, context and
47 language; key points were noted in the righthand margin of the transcript and categorised into initial
48 themes. After all the transcripts had been individually analysed, the themes in each transcript were
49 then re-examined, and grouped through identifying connections and patterns across the transcripts.
50 Finally, a summary table of themes from each transcript, together with quotations under each
51 theme, were grouped and labelled to create the main themes of family caregivers' experiences
52 (Smith et al., 2009). These inductive and iterative procedures of analysis helped develop an insider's
53 perspective of the research question. The 'one-by-one' analysing allowed us to investigate the
54 detailed experience of each person and the perspective of their particular context giving us the
55 chance to consider both the participants' shared experiences and the issues in which participants'
56 experiences differed.
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5 **Ethical issues:** The research was approved by Edinburgh University and Shandong Mental Health
6 Centre. Consent forms were signed by participants, their details were anonymized and pseudonyms
7 used.
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10 **Results:**

11 Fourteen participants were interviewed: nine females and five males, whose ages ranged from 39 to
12 78; five were spouses, eight were children and one was a mother. In this group, four family
13 caregivers were retirees, and the other ten participants were either unemployed or farmers who had
14 no pensions. All of the participants were of Chinese origin and they represented a range of social,
15 geographical and educational backgrounds.
16

17
18 Family members used different strategies to cope with their caring role. Four main themes reflected
19 the 'coping' experience linking different coping strategies used by family member in their different
20 situations. Cultural beliefs appeared to play a large role across these various coping strategies, in
21 which 'Being filial' reflected the traditional role of filial piety as a social and cultural responsibility,
22 this was described by eight out of fourteen family members. 'Changing self and self-care' illustrated
23 family members perceived experience of how they make themselves 'fit in' with their caring roles,
24 this was claimed by more than half participants. 'Seeking help' has reflected their initiative of
25 seeking informal and formal support as well as their demand of available resources. 'Having hope
26 and continuing life' signalled the positive psychological thinking of their responsibilities, life and
27 wishes, this was told by five family caregivers.
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32 **Being filial**

33 Being filial is embedded in traditional Chinese culture. Filial piety is one of the dominating concepts
34 of Confucian philosophy; the value of filial responsibility regulates the roles and relationships
35 between children and parents (Zhang et al., 2018). Holding on to this belief and accepting the
36 cultural and social role seems to be the most common reason behind family caregivers coping with
37 their caring roles. For example:
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39
40 *'It is my responsibility to look after my parent.... After all, he is my father, whatever difficulties*
41 *I have...I must look after him.'* [Family caregiver (FC)2, Xue]
42

43 *'What is my thought? I have no opinion, she is my mother, what else can I do?'* [FC10, Shou].
44

45 In these two extracts, both Xue and Shou accepted their caring role by saying: 'he is my father' or
46 'she is my mother' in order to cope with their caring roles. It reflects the meaning that looking after
47 their parents has become a cultural-social norm in China.
48

49 Another participant, Yu also perceived the same feeling, he said:

50
51 *'I never think about it (sending mother to care home), she is my mother, it is not reasonable*
52 *to let a care home take the caring responsibility, is it?'* [FC9, Yu].
53

54
55 The above extracts highlight that looking after parents is the children's responsibility. It is necessary
56 and compulsory. This enforced responsibility enhances and encourages family carers to take on a
57 caring role, but it also acts as a coping strategy for the role.
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3 For participant Guang, being filial is a coping strategy *and* a stress reliever while she is looking for her
4 mother.
5

6 *'I think being filial is a thing most are willing to do. Compassion from your heart can create a*
7 *good mood for you too. As a result, the stress will go as well...'* [FC1, Guang].
8

9 Unlike the others, for Xu coping with the caring role was related to the family's financial situation.
10

11 *'I have no difficulty, we have money, my children are working, I have a pension as well. ...The*
12 *payment for children to look after her is free, anyway older people don't need to eat the*
13 *expensive food...'* [FC11, Xu].
14
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16 Xu's description points out that the financial condition of the family reflects a key problem of the
17 current family care services and the relationship of caring responsibility, care burden and coping.
18

19 Talking about how he hopes to look after his wife, Huai has a different view of his caring role.
20

21 *'I have no choice... My son works all day at the field and my daughters go to work. They*
22 *cannot look after her, who could look after her except me?'* [FC8, Huai].
23

24 The lack of availability of Huai's children meant he had to shoulder the caring role alone. Three out
25 of five of the spouses in this study, have discussed a similar situation. Unlike in the UK, where older
26 people are more likely to be cared by their spouse (Brodaty & Donkin, 2009), in China, caring for
27 older parent is the children's responsibility.
28

29 **Changing self and self-care**

30 In order to adapt into their new roles, some family members illustrated that they had to change
31 themselves by either changing their lifestyle, their personality or increasing their knowledge/skills to
32 'fit' with their caring role. For example, one of the participants who is a family caregiver,
33 acknowledged that coping with the 'new' life is to change herself:
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36 *'I told myself that she cannot change herself, let me change myself. Then slowly I adapted*
37 *myself to the life. I am here now, trying to get into her world and to adapt to her.'* [FC13, Yan].
38
39

40 In Yan's experience, the way of adapting to the new life and building a new relationship between her
41 mother and herself is only achieved by changing herself. This strategy may be associated with
42 changing the environment around her or changing her personal identity or attitude and learning new
43 skills. 'I am here now' refers to the continuity in her present 'coping'. Indeed, this changing herself
44 strategy has helped her to settle into the changed life, as evidenced:
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46

47 *'... I need to get up several times a night. She never goes back to bed by herself unless I get*
48 *up and tell her to go back to bed. I need to gently talk to her and say "Mum, you need go to*
49 *bed because it's too early to get up; you need stay in bed until morning". I need to sing to*
50 *her: "Sleep mum, sleep mum" and treat her like a child.'* [FC13, Yan].
51
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53 Such a role reversal reflects Yan's action on changing the relationship between her and her mother.
54 She has to change herself and become a mother in order to maintain her mother's well-being in
55 order to cope with her caring role. This role reversal, as a coping strategy, was also mentioned by
56 other participants.
57

58 For Mei, having a 'healthy' life is the foundation for her to cope with her role as well as to provide
59 good quality care for her mother. She said:
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3 *'... I enrolled in several training courses, such as dancing course, fitness course and music*
4 *course... I do this because I do not want to drop out of the society. I try to make my life better... I*
5 *am more than 60 years old, I want to keep living a joyful life while I look after my mother...'* [FC6,
6 *Mei].*
7

8
9 Keeping an enjoyable and fit life was key to help Mei cope with the caring role and she tried hard to
10 work out a useful way to do it. The sense of pushing herself to maintain a balance between life and
11 her caring role is identified in the phrase 'I try to make...' Furthermore, when talking about how she
12 manages her mother's swallowing problem she said:
13

14
15 *'I try to persuade her to eat more by using the same method to feed a toddler.... I use many*
16 *ways to persuade her...'* [FC6, Mei].
17

18 This extract reveals that Mei tries hard to find a better way to look after her mother. Similarly, Ying
19 who looks after her husband thinks that leisure activities relieves stress. She said:
20

21 *'I will go outside to have a walk if I get free time, playing poker with others, to release stress...'*
22 *[FC3, Ying].*
23

24 For both Mei and Ying, having a healthy living routine is the foundation for them to provide better
25 caring for their loved one. It also shows that a fit and healthy living routine is a strategy for in coping
26 with the stress experienced from looking after someone with dementia as well as a strategy for life
27 continuity.
28

29 In order to look after her husband better, Liu uses the media to gain more knowledge about
30 dementia. She said:
31

32
33 *'I haven't taken any training courses before. But I was a teacher. I often watch the healthcare*
34 *programme on the television so that I know how to look after him. Some useful knowledge, I*
35 *write down while I am watching. I learned lots of knowledge about healthcare, I use it in*
36 *daily life.'* [FC4, Liu].
37

38 This extract reflects how the participant has striven to adapt to their life changing by learning new
39 knowledge/skills in order to provide better care for her husband and to cope with her caring role.
40

41 **Seeking help**

42 Ten family caregivers acknowledged that the support given by other family members was an
43 important source of maintaining a life and helped them cope emotionally. They spoke about the
44 responsibility of looking after a person with dementia needs to be shared across the family. This idea
45 may be related to traditional family care provision and the sense of family responsibility in Chinese
46 traditional culture of co-residence. For example,
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48

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

52 It appears that sharing the responsibility of care with her siblings makes it easier for Mei. It gives her
53 a break and creates the feeling of being supported. Similarly, Ling expresses a similar view about job
54 sharing:
55

56
57 *'My younger sister and I all help with the daily activities. She is mainly responsible for*
58 *washing the dirty clothes while I take care of our father's personal hygiene and do most of*
59 *the cooking. This is not difficult for us.'* [FC5 Ling].
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3 It is clear that sharing the responsibility of care releases burden for Ling. He is coping well with his
4 caring role with the support of the family. The above two extracts show that by sharing caring tasks
5 the main carer's workload was reduced and made the job easier. This supportive care model likely
6 gives the participant a break as well as a sense of being supported.
7

8 Talking about support from other family members, Yan said:
9

10 *'They all say, "We appreciate to you, Yan (a pseudonym), otherwise it would be a big hassle."
11 They also are very good to me. Last year, when I got allergy on my face, my sisters worried a
12 lot and they took me to the hospital and help me a lot. They treat me very well and they also
13 often come to help me.'* [FC Yan].
14
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16 Support from other family members has not only helped Yan to cope with looking after her mother
17 and has made the family closer, but also makes Yan realise the importance of feeling of being
18 supported, appreciated and valued by her family.
19

20 For Xue, it was the neighbours' support that was most available as other family members were far
21 away:
22

23 *'Sometimes I will ask one of the neighbours to help, but I can't always ask a neighbour for
24 help also sometimes I cannot find a suitable person to help...'* [FC Xue].
25

26 Whilst most of the available informal support is from families or neighbours, most of the participants
27 spoke about their experiences of the lack of any formal support services from either health
28 professionals or society. One typical example is:
29

30 *'I hope there are some staff who can do home visits. They could give some support if some
31 problems appear. You see, most of the children are away from home, only old people are left
32 at home alone. If anything happens, there is no one who can help, it would be better if we
33 have this support. However, there are no such services that exist at the moment. I hope that
34 we will have some social support in the future. Anyway, this would be a social tendency as
35 there are more and more ageing population.'* [FC, Guang].
36
37

38 Here Guang recognizes that ageing is becoming a social problem and talks about the lack of social
39 support services in the field of older care services with an expectation of this kind of support services
40 being available in the future. The feeling of concern with the current situation and worry about the
41 future is also highlighted:
42

43 *'If the community centre can organize something that will make people get together, then
44 people would get to know each other...then people might help each other in some cases...'*
45 [FC, Guang].
46
47

48 Guang describes the changing customs leading people to becoming more private and having less
49 connections with other people than they used to have in the past. Such a trend has become a barrier
50 to creating a friendly community and getting support for people with dementia and family
51 caregivers. Due to this, the participant wanted greater connection and support at the community
52 level.
53

54 **Having hope and continuing life**

55 Having hope and continuing life appeared to be a coping strategy for some participants and reflects
56 the positive psychological thinking of some participants' caring roles and life. It also illustrates their
57 expectations of older care services in China. For example, wishing her mother to have a good later
58 life has stimulated Yan to carry on with her caring responsibility. She said:
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'...My mum has had a hard life since she was married to my dad. She looked after the whole family and worked hard, like a dog. That is also the reason she got ill at this age, therefore as a daughter I need to take my responsibility and look after her. I don't want my mother to have a bad quality of care, I want her to have a good life.' [FC13, Yan].

Furthermore, the mother as a figurehead strengthens Yan's caring responsibility:

'Once we lose her, I will feel like I've lost the supporting pillar of the family, she is the core of the big family. Despite she is not knowing anything, she is the connection among the big family. My sisters and my brother often come to visit her, we can see each other, and this is a connection between us. Once she is gone, the connection would slowly reduce, then the chance for us to be together will become less and less.' [FC13, Yan].

In this extract, we can see that Yan is eager to have a close relationship with her family and this has strengthened her sense of taking a caring responsibility for her mother. As her mother is a spiritual pillar of the family, the caring responsibility has been upgraded to a spiritual level and a hope strategy. These stimulate Yan to provide good care for her mother so that she lives as long as possible. This is consistent with other participants, such as when Xu said:

'...a family has older parents is a happy family...' [FC11, Xu].

This extract has reflected the Chinese old saying of 'if the home has an old parent, then it has a treasure' (家有一老，如有一宝). From these two descriptions above, it shows that philosophical strategies enhance family caregivers' caring responsibility, behaviours and attitudes.

Regarding the traditional family responsibility of looking after older parents, another participant says:

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

Here Ling indicates his wish to pass this traditional family responsibility to the next generation by looking after his mother. This belief gives him hope of this good virtue will be continued when it is his time to be taken care of.

While the belief of filial piety gives hope to some participants, Liu believes that Buddhism is a hoping strategy. For example, Liu said:

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

In this extract, the belief of Buddhism is an emotional strategy to cope with Liu's caring role. Buddhism is also a spiritual support and a source for Liu to carry on with the current life and a hope for her future. In this extract, how Liu copes with her caring responsibility is based on her religious belief of fate as she interprets the caring responsibility as something that has already been arranged – her fate. In here, coping with the changed life seems to create a complex relationship of 'responsibility', 'belief', 'coping' and 'hope'. It's also reflected that cultural and religious backgrounds influence Chinese caregivers' experience of looking after family member with dementia. These

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3 findings have the potential to inform policy makers or educational services to think about how to
4 accommodate these cultural beliefs and practices in order to improve services utilization.
5

6 **Discussion and implication**

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8 The findings of this study demonstrate several coping strategies that Chinese family caregivers use
9 when caring for their older relative. It shows that Chinese culture has a strong influence on family
10 caregivers' motivation to help them cope with their caring roles. For example, filial piety was
11 described as a coping strategy by over half of the family caregivers who participated, with phrases
12 such as 'it is my responsibility', 'she is my mother' and 'he is my father' encouraging an acceptance
13 of the reality. For these family caregivers, accepting this filial expectation becomes a coping strategy
14 for them. Participants believed they played a part in continuing a cultural belief by being filial to
15 their parents, continuing a life-cycle of repayment, and believe that their children would be filial to
16 them as they are to their parents. This cultural belief allows them to accept their caring roles more
17 easily and to adjust themselves to the daily caring duties. Consistent with previous studies, filial
18 behaviour through family obligation continues to play significant role in family-based care in China,
19 even though the conventions associated with the relevant expectations, attitudes and emotions
20 have changed (Wang et al., 2009, Laidlaw et al., 2010, Qi, 2015). This suggests that filial piety as a
21 coping strategy provides a useful base for developing cultural-belief-fostering strategies in early
22 interventions. This finding may also can apply to some countries or regions where Confucianism
23 were influenced.
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29 However, with the recent socioeconomic and demographic changes over the last ten years in China,
30 the role of filial piety as well as its significance and content are being challenged (Dong et al., 2012).
31 Such changes are in danger of having a negative influence of family caregivers' capability and
32 availability to look after their older parents (Zhang et al, 2018). Indeed, the conflict between seeing
33 caring as a filial expectation against the pressures of children needing to move away to find work
34 have the potential for increasing psychological stress in those left behind to care (Nie et al., 2011).
35 Interestingly, Yeh and Bedford's (2003) study of authoritarian filial piety in Taiwan indicate that
36 authoritarian filial piety has enforced parent-children responsibility and secured the family care
37 provision in specific cultural and social contexts even though it reduces the individual's
38 opportunities. Fifteen years on from the study by Yeh & Bedford, our study reveals that despite
39 coping strategies, the caring role is highlighting a greater burden than in the last century. This
40 suggestion that filial piety continues to be an influential factor for family-based care services and a
41 coping strategy for family caregivers needs careful consideration as to how to increase its impact on
42 caregiving appraisal and decrease its negative influence in light of changes within Chinese society.
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48 In our study, informal support from family and friends was an important coping strategy for family
49 caregivers. The majority of family caregivers experienced the emotional and physical support from
50 their families and friends. However, as a result of the support from family and friends, the
51 participants have perceived a lack of formal support services within their communities. There was an
52 expectation from some that greater social support service should be available. Previous studies
53 show that family caregivers are less likely to show negative psychological symptoms if they satisfied
54 with their social interactions (Schulz and Martire, 2004, Brodaty and Donkin, 2009). This suggests
55 that more formal support services in communities, such as family/dementia support group to
56 provide sufficient social networks, are important in order to increase social connection and reduce
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3 psychological stress and isolation for this group (Zwaanswijk et al., 2013, Chen et al., 2015, Zhang et
4 al., 2019b).

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6 As caring for older people is viewed as a family responsibility in China, the formal dementia care
7 services is consequently undeveloped (Wang et al., 2014). Family caregivers experienced a lack of
8 formal support services from either health professionals or society as shown in the theme 'seeking
9 support'. Participants recognized that ageing is becoming a social problem and there was concern
10 with the current situation and worry about their future care.
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13 As a social support network has both informal and formal elements, it is clear that just informal
14 support from family is not enough for the sustainability of family-based older care services which is
15 currently under threat in China because of changes within society. Whilst family-based care plays a
16 significant role in providing care services for the older population, our research highlights that
17 formal support services such as home-based educational/practical interventions by health
18 professionals or policies/financial support by the local government are important in order for family
19 caregivers to sustain their roles as carers. It also adds to the increasing literature (Robinson et al.,
20 2010), that appropriate support policies, programmes and interventions can help caregivers to
21 develop more effective coping strategies and improve their skills of managing behavioural problems
22 from a Chinese perspective. **Even though the one-child policy has recently been stopped, its effect
23 on the family structure will persist over the coming decades, it means that the family-based care
24 may face a risk of a shortfall of family caregivers and this will also place more pressure on formal
25 care services. Therefore, the government needs to be aware of the impact of the one-child policy on
26 the provision of family-based care and act to prepare for it.**
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32 Even though dementia care services in China are underpinned through an informal support system,
33 this social group is currently ignored by the current Chinese health care services. Therefore, formal
34 support or intervention programmes should not only target in-patients, but also through social care
35 services support people with dementia who live in their own homes along with family/friends who
36 support them. The role of such a support service could include providing basic information about
37 dementia and management skills, arranging further medical health checks, visiting homes and
38 connecting service users with other relevant services such as social workers, support groups, health
39 visitors and voluntary organisations etc. This is re-iterated by Xiao et al (2014) that 'caregiver burden
40 can be reduced by well-designed social structure (policies and resources) in dementia care that meet
41 the needs of people with dementia and their family caregivers' (p6).
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45 This is only a small sample study in one city in one region of China. Therefore, the sample may limit
46 the reliability of the findings and increases the risk of **mistakenly generalising the findings to all of
47 the family caregivers** who look after people with dementia in China. Similarly, the findings cannot be
48 generalized to other regions due to the deference of regional economic development and local
49 social support services. For example, Shandong province is the third economic developed city among
50 the 34 provinces in China, so family caregivers' coping strategies and perceived experiences may
51 different from other less developed regions. Future research could continue to examine **coping**
52 strategies between regions or geographies, and local support services and demographic status.
53 However, it does provide a contextualized understanding of family caregivers' **coping** strategies in
54 China and provides a base for thinking about the value of the traditional culture of filial piety in
55 taking on caring responsibility from a family caregiver's perspective.
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Conclusion

The study illustrates the different strategies developed by family members in order to cope with their new roles when caring for a relative who has dementia. Among them, social and cultural factors play a critical role in the family carers' responsibility. The study highlights how responsibility has been maintained and influenced in a specific sociocultural context. It also states the key problems of family-based dementia care services in China. With the declined capacity of informal support services and unavailability of formal support services. In order to reduce family caregiver stress and strengthen family-based care services, health professionals and policy makers need greater understanding of the individual family carers' experiences and thereby be more in tune with their worries and concerns, so that appropriate care and support can be provided. This study provides a useful foundation for development of interventions that can support family caregivers in coping with the burden of care in caring for relatives with dementia in China.

Key points for policy, practice and/or research

- Development of cultural-belief-fostering strategies for family caregivers in creating meaningful family-based older care services in China requires consideration.
- Despite a history of strong familial piety in China, the capability and availability of family caregivers appears to negatively impact quality of life when caring for frail relatives.
- Commitment to provide formal dementia support care services would decrease family caregiver burden and increase the sustainability of family-based older care services in China
- Providing appropriate support policies, programmes and interventions to help caregivers develop more effective coping strategies and improve their skills of managing behavioural problems of a person with dementia from a Chinese perspective is required.
- More research is required on this topic.

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Conflict of interest

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