Article

Living with dementia: Why I am thinking of 'death'

Dementia
2023, Vol. 22(4) 807–819

DOI: 10.1177/14713012231158859
journals.sagepub.com/home/dem
SAGE

Xiubin Zhang
National Heart and Lung Institute, Imperial College London, London, UK

Charlotte Clarke
Social Sciences & Health, Durham University, Durham, UK

Rong Ding
School of Heath in Social Science, The University of Edinburgh, Edinburgh, UK

Abstract

Background and aims: Dementia is recognized globally as a massive burden on public health and wider society. It is a major cause of disability and mortality amongst older people. China has the largest population of people with dementia worldwide, accounting for approximately 25% of the entire global population of people with dementia. The study investigated the perceived experiences of care giving and care receiving in China, with one area identified in the data concerning the extent to which the participants discussed death. The research also explored the meaning of living with dementia in modern China, where the economy, demography and culture are rapidly changing.
Method: The qualitative approach of interpretative phenomenological analysis was used for this study. Semi-structured interviews were used for data collection.
Finding: The paper reports on one specific finding concerning death as a way out of the situation that participants found themselves in.
Conclusion: The study described and interpreted one of the specific issues, 'death', in the participants' narratives. This finding reflects how psychological and social factors, such as stress, social support, healthcare cost, caring burden and medical practice have created the participants' thoughts of 'wishing to die' and the reasons why they believe 'death is a way to reduce burden'. It calls for an understanding, supportive social environment and a reconsideration of a culturally and economically appropriate family-based care system.

Corresponding author:
Xiubin Zhang, National Heart and Lung Institute, Imperial College London, Emmanuel Kaye Building, 1B Manresa Road, White city, London W12 7RQ, UK.
Email: xiubin.zhang@imperial.ac.uk

Keywords
dementia, China, death, interpretative phenomenological analysis

Background

Dementia is a major cause of disability and mortality amongst older people, and it is recognized as a global issue that impacts public health and creates socio-economic burden (Park et al., 2013; Wolters & Ikram, 2018). Dementia has caused a great deal of physical and psychological pressure for the person with dementia and their family caregivers (Brodaty & Donkin, 2022; Xiuxiang et al., 2020; Zhang et al., 2020b). Studies found that rates of depression, stress and suicidal thoughts are higher in family caregivers who are looking after people with dementia (O'Dwyer et al., 2016; Zhang et al., 2021). One study also reported 16% of the caregivers for People with dementia (PWD) experienced suicidal thoughts within the last year (O'Dwyer et al., 2016).

One narrative review shows that older people represent the highest suicide rate in almost all countries, in which mental health issues impacts rates of suicide (Conejero et al., 2018). Suicide amongst old, frail Chinese seniors is well studied (Simon et al., 2013; Zhang et al., 2016), it is reported that suicide risk rates for both men and women raised to more than 100/100,000 in the oldest age groups in rural China (Conwell & Thompson, 2008). However, there is little research in the field of dementia and suicide. China has the largest older population worldwide, and accounts for approximately 25% of the entire global population of people with dementia (Jia et al., 2020). Despite many issues caused by dementia in China, there lacks an understanding of the social environment and support services required to meet with the increasing demand. In addition, numerous studies also reported that the Chinese participants perceived some stigma associated with having dementia (Yang et al., 2021; Zhang et al., 2020a). However, the decline of memory and cognitive ability is often regarded as a normal symptom of ageing in China, which means many people do not seek medical help in time, leading to lack of accessing of professional support (Liu et al., 2019; Zhang et al., 2020a). It is possible that lack of recognition of the need for help may also contribute to deficiency of health services since the true need in society is hidden.

While there is limited evidence from China, studies from other countries with similar cultural views on dementia and suicide can be helpful. Some studies indicate that lack of support and financial stress is associated with suicide thoughts in PWD and their family caregivers (Joling et al., 2018; Zucca et al., 2019). A systematic review found that care burden, dementia severity, and poor approaches to coping are suicide risk factors for South Korean family caregivers whilst losing independence, depression and at home care were identified as suicide risk factors for people with dementia (Kong & Park, 2022). Loneliness, social exclusion, and 'feeling burdened' were also found to be suicide risk factors amongst people with dementia (Álvarez Muñoz et al., 2020). Studies from around the world list many risk factors for suicide, in this study, we intended to find whether these factors also held true for PWD in China through interpretative phenomenological analysis (IPA) analysis.

In China, general populations were found to have a low level of knowledge of dementia, especially in less developed regions (Liu et al., 2019). Furthermore, the national healthcare system covers medical costs in clinical settings, but not older care costs. People with dementia and their family caregivers receive very limited support from society, so the person with dementia or his/her family must bear the physical, psychological and financial burden alone (Wang et al., 2019). Along with the traditional cultural norm of filial piety, looking after older and sick family members are expected of by society and the government. However, due to the changing family structure, immigration, sociocultural and economic situation, physically taking care of a family member with dementia has become more challenging than in the past (Zhang et al., 2019). As such, this further increased the burden and care cost on individuals. The study investigated the perceived experiences of care giving and care receiving in China, with one area identified in the data concerning the extent to which the participants discussed death. The research also explored the meaning of living with dementia in modern China, where the economy, demography and culture are rapidly changing.

Methods

Study Design

Smith and colleagues' six steps IPA was used for data analysis (Smith & Shinebourne, 2012). It is a qualitative approach which aims to provide detailed examinations of personal lived experience (Smith & Shinebourne, 2012).

Recruitments

The participants were recruited from a mental health centre that provides in-patient and out-patient services (hospital and clinics) in Shandong, China. This site was chosen because Shandong is the hometown of Confucius, where the traditional culture of 'xiao' (filial piety) originated, so influenced by the filial piety, more old parents were looked after at home by their family. People with dementia and family caregivers who met the inclusion criteria and were interested in the research were recommended by the staff. The research information sheet was initially sent out from the centre by the doctors. Those who expressed an interest in taking part were invited to attend a meeting conducted by the research team in the centre to introduce the study and to have a chance to ask questions privately and sign the consent forms.

Inclusion criteria:

- People with dementia who have been diagnosed with early or middle stage dementia by the psychiatrists in this health centre.
- Family caregivers who were 18 years and older, with more than 6 months of caregiving experience.

Data Collection

A purposive sampling strategy was used. The participants were homogeneous in their ethnicity, cultural context and language. However, their social economic status, household income, education, housing and gender varied. The data collection method used was semi-structured interviews in order to gain a rich, detailed and personal account of participants' experiences. The participants were interviewed individually by the researcher. Each participant was interviewed once. The interviews were conducted in the hospital or in the participant's own home depending on their preferences. The interviews lasted between 30 and 60 min. The interviews were audio recorded using a digital recorder which was agreed upon by the interviewees.

Data Analysis

This study used the six steps of IPA for data analysis (Smith & Shinebourne, 2012):

(A) Familiarisation with the transcripts by repeated reading. This allows the researcher to be involved in active engagement with the data and helps to develop a model of the overall interview structure of the data analysis.
(B) Detailing line-by-line coding of each transcript. In this step, the researchers note anything they found interesting from what the participants said and examined the semantic content and language on an exploratory level; initial notes and comments were made at this stage.
(C) Listing and grouping of codes into initial emerging themes. In this stage, notes and comments were grouped or 'coded' and structured into emerging themes through capturing relationships, connections and patterns.
(D) Searching for connections across emergent themes and identifying patterns between them. In this stage, the researchers listed all the emergent themes in chronological order to summarise and identify patterns between the emergent themes.
(E) Analysing the rest of the transcriptions in the same way.
(F) Developing a master table to present the emerging themes across all the transcripts to identify convergence and divergence, then clustering them into groups and compiling them into superordinate themes.

Throughout the interpretative process, self-reflective notes were used to reflect on the researchers' roles in the study and the data analysis, as well as the final re-reading of the original transcripts to ensure that interpretations were grounded in the participants' accounts. Data collection and analysis was led by the first author who is a nurse and is of the same ethnic background as the participants. Sharing similar beliefs and cultural values may have helped the first author to integrate easily with the participants and to understand the meanings of their experiences. However, these perceived similarities may also be a limitation in discussing some topics that are already known from prior knowledge or previous literature. As a result of this, some meanings may have been lost because implicit assumptions of mutual understanding have been made. Therefore, it is very important to consider how 'cultural intuition' has influenced the process of the study. Two measures were taken to mitigate cultural intuition: firstly, a detailed research diary was kept; secondly, the other authors do not share the same cultural background as the first author or the participants and used this more culturally naïve position to question cultural assumptions. For example, the extent to which participants discussed their own death as a way of resolving their sense of burden on their family (as identified in the Findings section below) was culturally normative to the first author but not to the other authors and would have been relatively 'unnoticed' without discussions between the authors. Iterative procedure checks and going back to the participants' answers ensured the accuracy of data analysis. NVivo 11 software was used to manage the transcripts of the records of the interviews and the field notes.

Findings

Characteristics of the Participants

The participants were from both urban and rural areas in Shandong province. The participants were 10 PWD and 14 family caregivers (participants from either category were not necessarily related to one another). The participants of the dementia group consisted of two females and eight males, whose ages ranged from 67 to 87. Six of the participants with dementia lived with their children, two lived with spouses and two lived with hired home carers. In this group, there were six who retired with varying levels of pensions; four of them did not have pensions. The family caregivers' group consisted of nine females and five males, whose ages ranged from 39 to 78, including five spouses, eight children and one mother. In this group, four participants were retirees (a former teacher, a senior civil servant and two were industrial workers). The other 10 family caregivers were unemployed and had no income or pension.

Death is a Way to End the Meaningless Life, Suffering and Burdens for Us

In the interviews, death was highlighted as an option in coping with the 'altered' life of having dementia as well as by family caregivers. Six of 10 PWD mentioned the topic of death unprompted during their interviews. Yi says:

> 'I don't want to bring pressure to my children. It is a relief for them if I can die soon…' [People with dementia (PWD)2, Yi].

This shows that Yi views death as a way to reduce his children's burden at this stage. This idea might be a consequence of the current health care system in China where the cost of care services needs to be paid for by the family. Again, Xin presents a similar response.

> 'I hope I can die soon. Dying soon, death is an ending for suffering and everything will be gone. It would be better to die now. The children's burden would be reduced if I am dead. They should go to work, but they cannot go to work…' [PWD7, Yin].

In this extract, it seems that death is viewed as a relief for both PWD and family caregivers. There is feeling of depression and despair. Another aspect is associated with the social factor of financial problems. Taking care of Yin has caused financial strain on the family and has limited his children's ability to work, therefore, Yin appears to think that the idea of death is a way to reduce his family's financial and caring burden, and his suffering too.

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

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

In this extract we can see that because of the awareness of the progress of his illness, the desire of death is expressed by Shen. A sense of responsibility of not troubling others can be identified. In addition, being useless to others for Shen means that his life is meaningless.

> '…I am 87 years old, I become older and older, and next year I will be 88 years old. It is just a waste of time to be alive, I cannot contribute anything to the state and children, I cannot give them any help, and there is no meaning to be alive.' [PWD8, Shen].

For Shen, losing the ability to be useful and not contributing leads to thoughts of death. Therefore, death can be interpreted as a responsibility to avoid being useless.

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

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

For Zong, receiving but not giving creates a feeling of guilt. This leads him to question the meaning of his life. In his opinion, it is meaningless if a person cannot be useful or cannot take any responsibility. This also brings a sense of guilt for being a burden and a feeling of being useless. In contrast to other participants' view, Wen's view of death relates to being unable to walk and being dependent on others. He says:

> 'Pessimistic, it's not meaningful to live, there is no meaning to life. I need help from others all of the time. I can only stay on the bed because I cannot walk. I'm never getting well.' [PWD1, Wen].

In the extract, Wen expresses the feeling of sadness and despair which is reflected in the words 'pessimistic', 'meaningful' and 'never'. For Wen, his life has lost meaning because he is dependent on others. His phrase 'not meaningful to live' also links to losing health and losing future perspective. Wen further emphasises his thoughts of death, poor health and negative future perspectives and explains the meaning of 'death as a way out'.

> 'I have been unwell for a long time, I don't want to take any further treatment and I don't want to stay at hospital to wait for death.... I cannot do anything, even get a drink'. [PWD1, Wen].

A feeling of despair as a result of the 'altered' life appears in Wen's descriptions. Death is viewed as a way to escape from the situation of being dependent. In this case, discussing and accepting death as the next step might make it easier for the participant to cope with the 'altered' life and arrange things in advance.

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

> 'I have no plan. I have to live until I stop breathing. I just wait for death day by day …I have no plan now, I am not scared of dying and I really hope one day I don't wake up.' [PWD3, Jing].

For Jing, accepting death is an alternative way to cope with the 'altered' life. In the above extract, death also reflects the natural process of life and the ending of everything. In Chinese traditional culture, one's destiny has already been decided by heaven. This destiny (or fate) is called 'tianming' and how a person shall die has also been decided by 'tianming'. Once a person has been diagnosed with an incurable disease, they would have accepted it as their 'tianming'.

With some of the participants who were family caregivers, the issue of death was relatively less discussed (4 of 12). This may be because the topic of 'death' is too sensitive, and people would be unwilling to talk about it due to Chinese culture. The few views on death were largely associated with financial difficulties and the challenges of caregiving.

> 'I have no thought (about taking care of my wife). I have no income and my son hasn't got money, if she dies, we will just bury her…' [Family caregiver (FC)8, Huai].

Huai and his wife are financially dependent on their children. As his son has a low income, the care burden becomes a huge pressure for him. The statements about his son having no money and that he has no opinion about his role of taking care of his wife reflects that he is in a dependent situation and does not have a lot of power when making decisions to change the situation. His wife's death is the only way for the family to reduce their burden.

One specific phenomenon has been presented by one mother who is looking after her two sons with early-onset dementia. In contrast to other participants, the conversation of death and the perceived caregiving experience from Gui is strong reflected in the drawbacks of the national healthcare system, social minimal security system and social support network.

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

The extract manifests a dilemma between living and death for Gui. The sense of sorrow, helplessness and powerlessness has been emphasised in this extract. The narrative reflects the quality of life for the participants and how it is dependent on the financial support from the government. Again, the request for financial support not being met reveals the limitations of the national healthcare and social security system in China and the reality of the lack of social support which caused the participant to lose hope for the future. This situation makes Gui think of 'death' as the only way to escape from the suffering for both herself and her sons. This also reflected the struggle of how she tries to look after her two sons with dementia and the helplessness of the situation.

One wife who looks after her husband has said that she is too old to look after him and that the only way out may be death, she says:

> '…I have no solution, I am too old. I sometimes cry during the night because of the stress, sometimes I wish he could die soon. I cannot afford to get a private carer. My two sons are both in debt; I cannot get money from them (to pay to hire a carer). Our daily life costs are relying on my husband's pension, which is what we rely on. I want to…' [FC7, Wang].

This extract reveals the reality of Wang's physical inability to look after her husband as she is old and frail while her children cannot provide financial support. In this case, death has been raised as a solution for her. The perceived experiences of stress, helplessness and lack of support from family appear in the extract. On the other hand, the extract also reflects how social factors heavily influence the quality of a family caregiver and PWD's life, such as the lack of a social support network, the unavailability of long-term care services and financial insufficiency.

Gui also manifests that death is a way to give up fighting.

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

In the extract, Gui mentions two life plans: continuing with life and death by suicide. Firstly, the sense of parental responsibility is present when she talks about future life. Secondly, the sense of parental responsibility is present in her talking about bringing her sons together with her in an act intended to take all their lives if life cannot go on. For Gui, death is a kind of responsibility rather than an escape. It is an alternative way to fight against her situation.

Regarding the issue of the value of life, one daughter says:

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

In the extract, the word 'death' isn't mentioned by Mei, but we can see that the thought of death appears in her view about whether her mother should live as her condition is deteriorating. This ambivalence reflects the dilemma of family caregiver towards the issue of whether PWD who lose their ability to understand the world should be alive.

In this study, death is viewed as a way to escape from the situation of being dependent or avoiding being useless to others. The discussions of death also revealed an inability of dementia care services, which were unable provide the social environment, healthcare support and financial security that people need to feel well supported.

Discussion

The paper specially reports on the issue of 'death' that appeared in the interviews. The study aimed to understand the lived experience of PWD and their family caregivers in Chinese traditional family-based care. However, the underlying care mechanisms behind Confucius' filial piety has been challenged by industrialization and economic progress, which has led to caregiving and care-receiving being experienced as a burden. The findings about death do not result from direct research questioning about death, but from the participants' narrative responses of their lived experiences. The topic 'death' reflected how social support services were very limited, how life has lost meaning due to dementia for the participants in this study, and how the individual with dementia feels that they have lost their personal value. And revealed too is the care burden perceived by both the PWD and family caregivers.

Firstly, in this study, six out of the 10 participants with dementia claimed that death is a way to reduce burdens for their family. A few also believed that death was a release from the suffering of dementia. Previous studies also showed that PWD may wish to avoid burdening family with their care (Davis, 2014; Richards, 2017; Woo, 2020). A large population study in the United States showed perceived burdensomeness accounts for significant variance in suicide ideation of older adults (Cukrowicz et al., 2011). Research indicates that loss of independence, loss of control, dependence on family and having no hope for the future also lead to rational suicide and self-harm of older people (Conejero et al., 2018; Troya et al., 2019). In a study of factors to Chinese older adults' suicidal thoughts, it was found that suicide is treated as a solution to extremely stressful life situations, especially financial strain (Li et al., 2016). This suicidal ideation is inconsistent with the phenomenology of Confucius' filial piety, however, it reflects the reality of the current industrialization and economic growth that has led to this problem of caring for older people. Therefore, to avoid 'being a burden', in the study, the participants accept their death as a coping mechanism to reduce the care burden for their family.

'Death is a way to reduce burdens for family' also reflected the limitations of the family care services that seems 'responsible' but not 'guaranteed' as it lacks a national welfare regime for support; a person with dementia without an income will become totally financially dependent on their family, which may, in turn, lead to the breakdown of mutual relationships of caregiving (Zhang et al, 2020b). Previous studies also critique informal family-based care without support from formal dementia services provided by the public healthcare system as this may lead to negative healthcare outcomes (Lethin et al., 2020; Wang et al., 2019). This insecure family-based care may also cause suicidal ideation among PWD. One study also indicates that the family-based care system which is based on the phenomenology of Confucius' filial piety may not be applicable in caring for older people in modern economies (Woo, 2020). Therefore, apart from targeting the risk factor associated with suicide in PWD, such as depression, hopelessness, mild cognitive impairment or side effects of anti-dementia drugs in clinical perspectives (Anderson et al., 2019; Haw et al., 2009), rethinking a cultural appropriate dementia care system is also critically needed.

Secondly, the most common issue of the study is the meaning of fulfilment and personal values. Many studies indicate that 'being valuable' is not only critical for the person with dementia to keep life going and maintain social engagements, but is also important in reducing stigma and isolation (Brannelly, 2011; Erlangsen et al., 2020; Jaworska & Chiong, 2021; Seidman, 2009).

In Chinese society, the 'web of interdependence' within a family is a critical element of the continuity of family-based care system (Zhang et al., 2019). In Confucian philosophy, this kind of relationship is reciprocal: parents treat their children with kindness and care; in return, children serve their parents with filial piety and obedience. For instance, grandparents help to look after grandchildren when their adult children go to work, while adult children will provide economic support and care for their parents when their parents get old. Reciprocal or interdependent parent-child relationships exist across generations (Zhang et al., 2019). This interdependent and reciprocal relationship would be changed if the person with dementia lost the capacity to be a contributor within the family. In the study, because of changes in interdependent family relationships, some participants with dementia described being excluded or controlled by their family, and PWD experienced the feeling of 'being a useless person'. This highlights that retaining family responsibility and maintaining personal value is very important for PWD. Therefore, an understanding, supportive community environment and culturally appropriate interventions or programs could potentially promote PWD's contribution within their communities.

Along with the rapid social-economic development, family caregivers experience more extreme stress and challenges of looking after their loved one than ever before (Liu et al., 2022; Yang et al., 2022; Yu et al., 2016). As a result, family caregivers may hold a reluctant attitude toward their caring responsibility, which may bring negative effects into the inter-relationship between caregivers and care recipients. In the study, four out of 10 PWD had no pension and they were financially dependent on their family, in addition, 10 of the family members had no regular income while they were looking after their loved one. So financial burden also seems to be one of the reasons why both PWD and family caregivers think that 'death will relieve their burdens' for them. Therefore, the government and related stakeholders should consider an integrative social support system, such as long-term dementia care cost being included in the national health system, rather than solely paid for by individuals and their family.

Finally, this study found that more than half of the participants with dementia expressed suicidal thoughts or wished to die, and some family caregivers also hoped that the person with dementia whom they looked after would die. It is important to note that while many of the participants expressed a wish to die only one had distinct suicidal ideation in terms of expressing a plan for taking their own life so the findings from this study mainly highlight a strong wish to die among many of the participants rather than suicidal ideation per se. The current small sample size cannot provide a statistically significant conclusion, and whilst the issue of ‘death’ may relate to the current healthcare system and family-based care system, the underlying mechanisms needs to be further explored. However, the finding does highlight the need to reconsider the drawbacks of the current family-based care system and the need to think about how to maintain the sustainability of family-based care for the soaring ageing care demand.

Study Limitations

In this study, IPA approach provides the theoretical underpinnings and guided the process of this qualitative study, which allows an in-depth, detailed experience of living with dementia to be explored. However, due to the requirements of IPA, the study was carried out with a small population and in certain areas, therefore the findings cannot be generalized to other regions where the economic development is different. It does, however, provide a contextualized understanding about life with dementia, explain the meaning of ‘death’ as a topic and provides a base for thinking about the values and the drawbacks of the traditional family-based care system in modern China.

Conclusion and Applications

The study has described and interpreted one of the specific findings concerning ‘death’. This finding reflects how psychological and social factors, such as stress, social support, healthcare cost, caring burden and medical practice have influenced the participants’ thoughts of being ‘ready to die’ and the reason of why they believe ‘death is a way to reduce burdens’. It also highlights PWD’s view of a meaningful life and what they deem as valuable in life. Death also appears to relieve participant burdens, which illuminates the dilemmas and challenges faced by family caregivers. This finding is significant in presenting a specific sociocultural context and how this context has created the cultural concept of death by PWD and family caregivers. It calls for an understanding, supportive social context and also a reconsideration of culturally and economically appropriate family-based care provision.

Acknowledgement

The authors thanks for all the participants and staff at the Mental Health Centre, the study would not be done without their support.

Authors’ contributions

XZ and CC were responsible for the study concept and design, acquisition of data, analysis and interpretation of data. XZ contributed to the data collection and date analysis, and the drafting of the manuscript. All authors were draft, read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

Ethical considerations

Ethical approval was gained from both the University of Edinburgh Ethics Committee and Shandong Mental Health Centre Ethics Committee. Informed consents were signed before conducting the interviews. As the research approach involved vulnerable adults and families of vulnerable people, during the process of interviewing, negative emotions for participants may be provoked as it is likely to touch on sensitive topics such as loss and sadness. In consideration, we ensured that all participants understood the potential risks and were given the opportunity to ask questions which they were concerned about before they signed the consent form. We also informed all participants that they have the right to withdraw at any time, and we prepared alternative solutions if anything were to happen during the interviews such as psychological consultation information and a contact helpline. For example, one mother who takes care her two sons with dementia expressed a strong view during the interview about ending their lives. The village doctor and local leader was contact to discuss with the issue and to support the mother applying for the social minimal allowance with her knowledge and consent. A helpline of China Association for Alzheimer's Disease has provided and a follow up phone call was made. The research team members are registered nurses with expertise in old age mental health research and are experienced in providing psychological supportive if there were signs of distress or other related issues during and after the interview. The researcher who conducted the interviews had also undertaken training in suicide management in the context of research activity

ORCID iDs

Xiubin Zhang https://orcid.org/0000-0003-2660-3937
Charlotte Clarke https://orcid.org/0000-0001-5263-5719

References

Álvarez Muñoz, F. J., Rubio-Aparicio, M., Gurillo Muñoz, P., García Herrero, A. M., Sánchez-Meca, J., & Navarro-Mateu, F. (2020). Suicide and dementia: Systematic review and meta-analysis. *Revista de Psiquiatría y Salud Mental (English Edition)*, *13*(4), 213–227. https://doi.org/10.1016/j.rpsmen.2020.04.006

Anderson, J. G., Eppes, A., & O'Dwyer, S. T. (2019). "Like death is near": Expressions of suicidal and homicidal ideation in the blog posts of family caregivers of people with dementia. *Behavioral Sciences*, *9*(3), 22. https://doi.org/10.3390/bs9030022

Brannelly, T. (2011). Sustaining citizenship: People with dementia and the phenomenon of social death. *Nursing Ethics*, *18*(5), 662–671. https://doi.org/10.1177/0969733011408049

Brodaty, H., & Donkin, M. (2022). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, *11*(2), 217–228.

Conejero, I., Olié, E., Courtet, P., & Calati, R. (2018). Suicide in older adults: Current perspectives. *Clinical Interventions in Aging*, *13*(12), 691–699. https://doi.org/10.2147/CIA.S130670

Conwell, Y., & Thompson, C. (2008). Suicidal behavior in elders. *The Psychiatric clinics of North America*, *31*(2), 333–356. https://doi.org/10.1016/j.psc.2008.01.004

Cukrowicz, K. C., Cheavens, J. S., Van Orden, K. A., Ragain, R. M., & Cook, R. L. (2011). Perceived burdensomeness and suicide ideation in older adults. *Psychology and Aging*, *26*(2), 331–338. https://doi.org/10.1037/a0021836

Davis, D. S. (2014). Alzheimer disease and pre-emptive suicide. *Journal of Medical Ethics*, *40*(8), 543–549. https://doi.org/10.1136/medethics-2012-101022

Erlangsen, A., Stenager, E., Conwell, Y., Andersen, P. K., Hawton, K., Benros, M. E., Nordentoft, M., & Stenager, E. (2020). Association between neurological disorders and death by suicide in Denmark. *JAMA*, *323*(5), 444–454. https://doi.org/10.1001/jama.2019.21834

Haw, C., Harwood, D., & Hawton, K. (2009). Dementia and suicidal behavior: A review of the literature. *International Psychogeriatrics*, *21*(3), 440–453. https://doi.org/10.1017/S1041610209009065

Jaworska, A., & Chiong, W. (2021). Supported decision-making for people with dementia should focus on their values. *The American Journal of Bioethics: AJOB*, *21*(11), 19–21. https://doi.org/10.1080/15265161.2021.1980150

Jia, L., Du, Y., Chu, L., Zhang, Z., Li, F., Lyu, D., Li, Y., Zhu, M., Jiao, H., Song, Y., Shi, Y., Zhang, H., Gong, M., Wei, C., Tang, Y., Fang, B., Guo, D., Wang, F., Zhou, A., & Qiu, Q. (2020). Prevalence, risk factors, and management of dementia and mild cognitive impairment in adults aged 60 years or older in China: A cross-sectional study. *The Lancet. Public Health*, *5*(12), Article e661–e671. https://doi.org/10.1016/S2468-2667(20)30185-7

Joling, K. J., O'Dwyer, S. T., Hertogh, C. M. P. M., & van Hout, H. P. J. (2018). The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: A longitudinal data analysis over 2 years. *International Journal of Geriatric Psychiatry*, *33*(2), 263–270. https://doi.org/10.1002/gps.4708

Kong, J. W., & Park, J. Y. (2022). Understanding suicide risk in people with dementia and family caregivers in South Korea: A systematic review. *Behavioral Sciences*, *12*(4), 97. https://doi.org/10.3390/bs12040097

Lethin, C., Leino-Kilpi, H., Bleijlevens, M. H., Stephan, A., Martin, M. S., Nilsson, K., Nilsson, C., Zabalegui, A., & Karlsson, S. (2020). Predicting caregiver burden in informal caregivers caring for persons with dementia living at home–A follow-up cohort study. *Dementia*, *19*(3), 640–660. https://doi.org/10.1177/1471301218782502

Li, H., Xu, L., & Chi, I. (2016). Factors related to Chinese older adults' suicidal thoughts and attempts. *Aging & Mental Health*, *20*(7), 752–761. https://doi.org/10.1080/13607863.2015.1037242

Liu, D., Cheng, G., An, L., Gan, X., Wu, Y., Zhang, B., Hu, S., Zeng, Y., & Wu, L. (2019). Public knowledge about dementia in China: A national WeChat-based survey. *International Journal of Environmental Research and Public Health*, *16*(21), 4231. https://doi.org/10.3390/ijerph16214231

Liu, Z., Sun, W., Chen, H., Zhuang, J., Wu, B., Xu, H., Li, P., Chen, X., Li, J., & Yin, Y. (2022). Caregiver burden and its associated factors among family caregivers of persons with dementia in shanghai, China: A cross-sectional study. *BMJ Open*, *12*(5), Article e057817. https://doi.org/10.1136/bmjopen-2021-057817

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2016). Suicidal ideation in family carers of people with dementia. *Aging & Mental Health*, *20*(2), 222–230. https://doi.org/10.1080/13607863.2015.1063109

Park, J.-H., Eum, J.-H., Bold, B., & Cheong, H.-K. (2013). Burden of disease due to dementia in the elderly population of Korea: Present and future. *BMC Public Health*, *13*(1), 1–9. https://doi.org/10.1186/1471-2458-13-293

Richards, N. (2017). Old age rational suicide. *Sociology Compass*, *11*(3), Article e12456. https://doi.org/10.1111/soc4.12456

Seidman, J. (2009). Valuing and caring. *Theoria*, *75*(4), 272–303. https://doi.org/10.1111/j.1755-2567.2009.01049.x

Simon, M., Chang, E.-S., Zeng, P., & Dong, X. (2013). Prevalence of suicidal ideation, attempts, and completed suicide rate in Chinese aging populations: A systematic review. *Archives of Gerontology and Geriatrics*, *57*(3), 250–256. https://doi.org/10.1016/j.archger.2013.05.006

Smith, J. A., & Shinebourne, P. (2012). *Interpretative phenomenological analysis*. American Psychological Association.

Troya, M. I., Babatunde, O., Polidano, K., Bartlam, B., McCloskey, E., Dikomitis, L., & Chew-Graham, C. A. (2019). Self-harm in older adults: Systematic review. *The British Journal of Psychiatry: The Journal of Mental Science*, *214*(4), 186–200. https://doi.org/10.1192/bjp.2019.11

Wang, H., Xie, H., Qu, Q., Chen, W., Sun, Y., Zhang, N., Liu, Y., Li, T., Chan, K. Y., Gauthier, S., & Yu, X.Global Dementia Prevention Program GloDePP. (2019). The continuum of care for dementia: Needs, resources and practice in China. *Journal of Global Health*, *9*(2), 020321. https://doi.org/10.7189/jogh.09.020321

Wolters, F. J., & Ikram, M. A. (2018). Epidemiology of dementia: The burden on society, the challenges for research. In *Biomarkers for Alzheimer's disease drug development* (pp. 3–14). Springer.

Woo, J. (2020). The myth of filial piety as a pillar for care of older adults among Chinese populations. *Advances in Geriatric Medicine and Research*, *2*(2), Article e200012. https://doi.org/10.20900/agmr20200012

Xiuxiang, Z., Zhang, X., & Hockley, J. (2020). A qualitative study of family caregivers' coping strategies of looking after people with dementia in China. *Journal of Research in Nursing: JRN*, *25*(8), 636–649. https://doi.org/10.1177/1744987120925128

Yang, J., Zhang, X., McCormack, B., & Andrew, J. (2022). The life of people with dementia who have multiple children in rural China: A phenomenological case study. *Dementia*, *21*(5), 1669. https://doi.org/10.1177/14713012221089163

Yang, T., Huang, Y., Li, X., Li, M., Ma, S., Xuan, G., Jiang, Y., Sun, S., Yang, Y., Wu, Z., Li, X., & Wang, Y. (2021). Knowledge, attitudes, and stigma related to dementia among Illiterate and literate older adults in Shanghai. *Risk Management and Healthcare Policy*, *14*(4), 959–966. https://doi.org/10.2147/RMHP.S296044

Yu, H., Wu, L., Chen, S., Wu, Q., Yang, Y., & Edwards, H. (2016). Caregiving burden and gain among adult-child caregivers caring for parents with dementia in China: The partial mediating role of reciprocal filial piety. *International Psychogeriatrics*, *28*(11), 1845–1855. https://doi.org/10.1017/S1041610216000685

Zhang, W., Ding, H., Su, P., Duan, G., Chen, R., Long, J., Du, L., Xie, C., Jin, C., Hu, C., Sun, Z., Gong, L., & Tian, W. (2016). Does disability predict attempted suicide in the elderly? A community-based study of elderly residents in Shanghai, China. *Aging & Mental Health*, *20*(1), 81–87. https://doi.org/10.1080/13607863.2015.1031641

Zhang, X., Clarke, C. L., & Ding, R. (2021). The experience of bereavement on family caregivers of people with dementia in China. *Dementia*, *20*(7), 2235–2247. https://doi.org/10.1177/1471301220988237

Zhang, X., Clarke, C. L., & Rhynas, S. J. (2019). What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis. *Dementia*, *18*(7–8), 2620–2634. https://doi.org/10.1177/1471301217753775

Zhang, X., Clarke, C. L., & Rhynas, S. J. (2020a). Tensions in dementia care in China: An interpretative phenomenological study from Shandong province. *International Journal of Older People Nursing*, *15*(1), Article e12291. https://doi.org/10.1111/opn.12291

Zhang, X., Clarke, C. L., & Rhynas, S. J. (2020b). A thematic analysis of Chinese people with dementia and family caregivers' experiences of home care in China. *Dementia*, *19*(8), 2821–2835. https://doi.org/10.1177/1471301219861466

Zucca, M., Rubino, E., Vacca, A., Govone, F., Gai, A., De Martino, P., Boschi, S., Gentile, S., Giordana, M. T., & Rainero, I. (2019). High risk of suicide in behavioral variant frontotemporal dementia. *American Journal of Alzheimer's Disease and Other Dementias*, *34*(4), 265–271. https://doi.org/10.1177/1533317518817609

Xiubin Zhang, PhD, MPH, RN, Research Associate at the Imperial College London, National Heart and Lung Institute. Her research interests are care for older people and improving life for people with dementia; chronic diseases in cardiovascular and respiratory field.

Charlotte Clarke, MSc, PGCE, PhD, R. she is the Executive Dean (Social Sciences & Health) at Durham University. Through her research, Charlotte has worked to address health inequalities and stigma and has influenced international health and social care policy and practice in relation to dementia.

Rong Ding, BSC, MSc. In January 2022, she started her PhD studying in psychology at School of Heath in Social Science, the University of Edinburgh, the UK. Her research interests include caring for children's wellbeing and health. People with learning disability and dementia.