

BMJ Open Exploring dementia family carers' self-initiated strategies in managing behavioural and psychological symptoms in dementia: a qualitative study

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ABSTRACT

Objectives Carer's self-initiated management strategies of behavioural and psychological symptoms of dementia (BPSD) can inform intervention development. These strategies are affected by cultural values. Little is known about non-Western dementia carers' BPSD management strategies. This study aimed to explore self-initiated strategies in managing BPSD adopted by Chinese carers.

Design Qualitative study using thematic framework method.

Setting Community setting in Hong Kong.

Participants 16 dementia carers with purposive sampling to include carers of different relationships to the people living with dementia (PLwD), education level and living arrangement.

Results Six overarching themes emerged from the data: (1) maintaining personhood in PLwD, (2) responding positively to BPSD, (3) explanation and bargaining, (4) responding negatively to BPSD, (5) controlling upsetting thoughts, and (6) getting respite care. Chinese carers treasured warm and supportive family relationships. They identified and minimised triggers to alleviate BPSD. Some carers struggled with care tasks and reacted with confrontation and avoidance. Changing attitudes and getting social and emotional support were described to manage carers' distress. Few self-care strategies including getting respite care were reported.

Conclusions Carers' self-initiated strategies largely aligned with existing theoretical frameworks in BPSD management, such as person-centred approach, and echoed Asian culture, which advocates filial piety and supportive family relationships. While these cultural values encourage the engagement of people living with dementia in the normal process of family life, they may also prevent carers from taking time away from care. Interventions could support carers by enhancing their knowledge and skills in managing BPSD, providing social and emotional support, and providing guidance in self-care. Future cross-cultural research could explore factors contributing to how carers manage BPSD and how interventions could be culturally adapted to facilitate carers to apply learnt skills in daily practice and hence benefit the people living with dementia and carer population.

Strengths and limitations of this study

- To our knowledge, this is the first study to qualitatively explore how Chinese dementia carers respond to behavioural and psychological symptoms of dementia.
- A purposive sampling strategy was used to identify carers with a range of characteristics to obtain diverse data.
- An integration of focus groups and individual interviews enhanced data richness.
- A combined inductive and deductive thematic analysis enabled exploration of carers' unique experience while making reference to existing theories and literature.
- Participating carers were all females and self-selective, therefore the findings reflect care experience from the perspective of female carers who might have higher functioning and were more socially connected.

INTRODUCTION

Over 80% of people living with dementia (PLwD) experience one or more behavioural and psychological symptoms of dementia (BPSD) during the course of dementia,¹ which affect quality of life in both PLwD and their carers.² Presence of BPSD is influenced by the interacting relationships between PLwD, carers and environmental factors,³ with a particularly complex relationship between the presence of BPSD and carer factors. Managing BPSD can increase carers' stress and depression,⁴ in turn, carers' negative emotions, together with non-adapting strategies and a lower sense of competence, may trigger or worsen the symptoms.⁵ A meta-analysis suggested that carer interventions, including education and skills training in BPSD management and better communication, have the potential to reduce BPSD and the associated carers' negative reactions,⁶ yet even though carers know how they should



handle BPSD in theory, they have difficulty putting these skills into practice.⁷

Knowledge of carers' self-initiated BPSD management strategies has implications for the development of practical interventions which build on approaches carers perceive as useful and address the practical constraints. To our knowledge, there are only five studies that have qualitatively explored carers' daily strategies in managing BPSD using focus groups,^{8,9} individual interviews^{5,10} and online discussion platform.⁷ Strategies identified from existing literature largely align with existing theoretical models of BPSD management and could be understood from three aspects of dementia care—managing disruptive behaviours, getting respite care and controlling upsetting thoughts related to care.¹¹ In terms of managing disruptive behaviours, carers modify interactions and environment to accommodate PLwD's changing needs and abilities,^{8,9} in accord with the need-driven dementia-compromised model¹² and the progressively lowered stress threshold model.¹³ Others took a person-centred approach¹⁴ by demonstrating love to PLwD^{9,10} and engaging PLwD in recreation, physical activities and household chores to promote the feelings of usefulness or reflect their interest and identities.^{8,10} Regarding obtaining respite care and regulating affective states, carers valued the importance of taking care of themselves,¹⁰ including taking time away from caregiving, discussing their feelings and experiences, and maintaining a sense of humour during the caregiving process.^{7,8}

Despite heterogeneity in participants' demographics, including gender, relation to PLwD and duration of care, all studies were conducted in Western countries. Carers' experience of providing care, their choice of coping strategies and the strategies available to them, are influenced by cultural values.¹⁵ Using an emic meaning-centred lens, several coping strategies adopted by Latino carers were suggested to reflect some Christian values, such as love, patience and tolerance.⁹ Previous quantitative research has also demonstrated that dementia carers with a higher level of familism, a cultural value that emphasises warm, close and supportive family relationships and prioritises family over self,¹⁶ were more likely to adopt avoidant coping strategies than active coping style.¹⁷ Dementia is estimated to affect 9.5 million adults aged 60 years or above in mainland China, Hong Kong and Taiwan,¹⁸ yet little is known about how the Asian culture has implications on carers' self-initiated strategies in managing BPSD.

The cultural value system in Asian countries is influenced by Confucian tradition, which advocates respect and care for the elderly family members, filial piety and mutual support.¹⁵ Family is viewed as the basic and most important unit of human life, and the main source of support when encountering problems in life. Meanwhile, having a family member with dementia may cause 'face loss' or disgrace to the family¹⁹ and encourages carers to keep unfavourable things to themselves. Problems are often perceived as heaven's will and individuals accept

whatever happens as a normal course of life or fate.²⁰ These cultural values may facilitate carers to accept or endure the hardship in dementia care and show family support to the PLwD, yet preventing them from seeking help from external parties. Nonetheless, while the belief in filial obligation is upheld in most Asian countries, the nature of filial piety has evolved and shifted from an authoritarian nature, where children are obligated to fulfil parents' demands and expectations, to an egalitarian parent-child relationship due to modernisation and westernisation.²¹ Adult child carers may choose to express filial piety through mutual care that underscores utility, efficiency, personal choice and pragmatic compromises,²² such as financial support.²³ The extent to which Confucian tradition influences how carers manage BPSD, therefore, remains largely unknown.

Further understanding of self-initiated BPSD management strategies adopted by dementia carers with different sociodemographic background is necessary to facilitate the development of more effective and user-relevant interventions. We aim to describe how Chinese dementia carers in Hong Kong, where the cultural system is often influenced by the Confucian tradition, respond to BPSD.

METHODS

Carers were recruited from the researchers' professional and personal networks. Social workers at the community centres who have an existing research partnership with the researchers identified and invited eligible carers to participate in the study. Invitations were also sent to the researcher's (DKYL) personal network for further distribution to recruit eligible carers who might not be receiving community social service. Carers were eligible for inclusion if they were self-identified carers, with the exclusion of any employed domestic helper, and were 18 years of age or above. Care was taken to maximise sample heterogeneity where possible, including relation to PLwD, education level, housing conditions and whether or not they live with PLwD. Housing conditions might serve as a proxy of carers' socioeconomic status, which affected their access to dementia care support and service. Carers provided written consent and completed a brief survey on demographics before the interviews. An interview outline was developed to ask participants to share effective and ineffective BPSD management strategies they have tried while caring for someone with dementia (online supplemental appendix 1).

We conducted both focus groups and individual interviews due to pragmatic reasons. Participants who were unable to join the focus groups were invited to an individual interview. The combination of the two interviewing methods might also enhance data richness. Focus groups generated data through interactions between participants, where they can exchange experiences and comment on each other's points of view.²⁴ Individual interviews, on the other hand, allowed exploration of more in-depth information, including which they found

more personal and might not be willing to share in a group setting. DKYL conducted focus groups and interviews with carers between August and September 2019. Data collection occurred concurrently with analysis, in which focus groups and individual interviews were analysed together to generate themes. Recruitment continued until data saturation, where no new themes emerged from both focus groups and individual interviews. The interviews were conducted in a community centre or participants' homes and lasted approximately 40–75 min. All interviews were conducted in Cantonese, audiotaped and transcribed verbatim.

Data analysis

A combined inductive and deductive thematic framework method²⁵ was used to analyse the transcripts. The combined approach allows researchers to explore issues based on previous literature and theories while leaving space to discover other novel aspects of the participants' experience.²⁶ The data from focus groups and interviews were analysed together so that findings from the two interviewing methods can complement each other. DKYL and KKYW independently coded the same two transcripts (one focus group and one interview), and then discussed the labels applied to generate a working analytical framework, which included a set of codes with a brief definition. DKYL continued with the coding of the remaining transcripts and charted the data into a framework matrix. Themes were generated by reviewing the connections between codes in the matrix and through discussion between DKYL and GHYW. The authors returned to the literature on BPSD non-pharmacological management strategies and dementia care domains deductively to aid the interpretation and generation of themes. We grouped the strategies according to known carer self-efficacy domains: managing disruptive behaviours, getting respite care and controlling upsetting thoughts related to care.¹¹ We further examined the extent to which the strategies in the domain 'managing disruptive behaviours' aligned to the principles of the existing BPSD management framework, including the person-centred approach,¹⁴ the need-driven dementia-compromised model¹² and the progressively lowered stress threshold model.¹³ The strategies that were conceptually related were grouped together. For instance, 'building trustful relationships with PLwD', 'engaging PLwD in family life' and 'respecting PLwD' each related to the underlying principles for person-centred care, thus, they were grouped to form an overarching theme which we named 'maintaining personhood in PLwD'. The final themes were reviewed and agreed on by all authors. Quotes relevant to the identified themes were translated to English and reported in the Results section. The translation was conducted by DKYL and an external researcher in the field of journalism and communication, who was blinded to the purpose of this study. They cross-checked each other's translation and discussed to resolve any discrepancy. The Standards for Reporting Qualitative

Research²⁷ checklist is presented in online supplemental appendix 2.

Reflexivity and integrity of the research process were maintained by all authors. All authors had a psychology training background and experience as researchers working with PLwD and their carers in Hong Kong (DKYL, KKYW and GHYW) and the UK (AS). DKYL, GHYW and AS received PhD-level education in the field of social work, psychiatry and psychology, respectively. AS is also a clinical psychologist. The authors conducted a literature review on the topic to inform the interview and analysis plan. The literature, however, mainly comes from the Western population. A combined inductive and deductive thematic analysis approach was chosen to compare participants' self-initiated strategies with previous literature while leaving space to explore how culture or personal values may influence their response to BPSD. The authors' cultural background aided reflection on the cultural influence. It is acknowledged that the authors' characteristics and their familiarity with Western literature may have influenced the coding and interpretation of data. Attempts made to reduce the impact of personal biases included having two researchers developing the analytic framework and generating themes.

Patient and public involvement

Carers were not involved in the development of research questions and interview schedule. Findings from the interviews and focus groups presented opinions from carers and could serve as a foundation for further discussion with PLwD and carers on intervention and service development.

RESULTS

Two focus groups and four interviews were conducted with 16 dementia carers. Demographic characteristics of participants are presented in [table 1](#). All participants were female with ages ranging from 48 to 75 years old. Two-thirds (n=12) of them were married. Half of them (n=8) had high school and university or above education. The majority lived in public housing (n=10). Nine of the participants were living with PLwD. The duration of disease ranged from 0.5 to 4 years. Half of the participants were children (n=7) or child-in-law (n=1) of PLwD, the rest were spouses (n=6), sibling (n=1) and niece (n=1).

Six overarching themes emerged from the data, which could be grouped in correspondence to the three domains of dementia care (see [box 1](#)). Themes under managing disruptive behaviours included: (1) maintaining personhood in PLwD, (2) responding positively to BPSD, (3) explanation and bargaining, and (4) responding negatively to BPSD. The other two themes were (5) controlling upsetting thoughts and (6) getting respite care.

Maintaining personhood in PLwD

Carers attempted to fulfil the psychological needs that constituted personhood in the PLwD to promote

Box 1 Overview of themes and subthemes

Theme 1: Maintaining personhood in people living with dementia (PLwD)

- ▶ Building trustful relationships with PLwD.
- ▶ Engaging PLwD in family life.
- ▶ Respecting PLwD.

Theme 2: Responding positively to behavioural and psychological symptoms of dementia (BPSD)

- ▶ Fulfilling unmet needs.
- ▶ Modifying care environment.
- ▶ Distraction.

Theme 3: Explanation and bargaining

Theme 4: Responding negatively to BPSD

- ▶ Confrontation.
- ▶ Avoidance.

Theme 5: Controlling upsetting thoughts

- ▶ Change of attitude.
- ▶ Acceptance and tolerance.
- ▶ Social and emotional support.

Theme 6: Getting respite care

psychological well-being. These include comfort, attachment, inclusion, occupation and identity, which ultimately contribute to the expression of love.¹⁴ Carers created a sense of attachment and security for the PLwD whenever needed. They also involved the PLwD in the lives of others and the processes of normal life in a way that is meaningful to them, as well as maintaining an identity that recognised their uniqueness.

Building trustful relationships with PLwD

Building trust and providing reassurance to the PLwD were often adopted by carers to alleviate BPSD. Carers described how the PLwD were less resistant to care if someone they can trust was around. Carers accompanied the PLwD to community centres for group activities and introduced familiar people or objects to them to increase their sense of security.

My mum likes hug and kiss, so I'd hug her from time to time... she trusts me more because I spend more time with her compared to my siblings. When there's someone trustable around, her mood and memory become better. (Participant 7)

Engaging PLwD in family life

Although the PLwD might not be able to fully comprehend the context, carers involved them in social gatherings and everyday activities to show them care from the family. They highlighted that the PLwD became more cheerful with family members around. Meanwhile, carers were aware that they needed to actively adapt the interactions among the involved parties, for example, explaining the situation of the PLwD or calming down family members or friends if they were irritated by the PLwD's behaviours. Moreover, carers also acknowledged that the PLwD's mood would fluctuate when the gathering ended.

She enjoys company although she may not be fully aware of the context. She'd say 'yes' when I ask if she'd like to go outside. We will go to the supermarket and get something nice for her breakfast. You can see the joy in her. As the Mid-Autumn Festival is approaching, our family send her mooncakes, and this makes her happy. She doesn't quite remember who we are, but she knows we're her family. It's about showing her care and I believe she knows the family care for her. (Participant 10)

Respecting PLwD

Carers described the need for respecting the PLwD in terms of how they identified themselves. Carers avoided using words (eg, dementia) that were not preferred by the PLwD or treating them like children.

He won't listen if you try to lecture him, and even worse if you make him feel he is being disciplined. You can tell his behaviours and thoughts are now

Table 1 Demographic characteristics of carers

	Mean/N	SD/%
Age	61.2	8.3
Gender (female)	16	100
Marital status		
Single	2	12.5
Married	12	75
Divorced	1	6.25
Preferred not to say	1	6.25
Education		
No formal education	2	12.5
Primary school	3	18.75
Secondary school	3	18.75
High school	6	37.5
University or above	2	12.5
Housing condition		
Public housing	10	62.5
Rental	1	6.25
HOS	1	6.25
Private housing	4	25
Relation to PwD		
Spouse	6	37.5
Child	7	43.75
Child-in-law	1	6.25
Sibling	1	6.25
Other relatives	1	6.25
Living with PwD	9	56.25
Duration of disease (year)	2.4	1.2

HOS, Home Ownership Scheme, a subsidised-sale programme of public housing; PwD, people with dementia.

different, but he still thinks he's an adult... he has strong self-esteem and needs respect from others. (Participant 9)

Responding positively to BPSD

Carers acknowledged the exhibition of BPSD could be due to unmet needs in the PLwD or external stimulation. On identification of the triggers, carers fulfilled the PLwD's needs or modified environmental cues, or distracted the PLwD from the stimuli, to prevent future BPSD.

Fulfilling unmet physical needs

Carers mentioned that BPSD in PLwD could be induced by their unmet needs, which included thirst, hunger and discomfort due to prolonged sitting in a daycare facility, and addressing these issues could reduce BPSD. One carer pointed out the necessity of spending more time to figure out what the PLwD needed due to his deteriorating communication ability.

His aphasia deteriorates day by day as his condition [dementia] develops. His expressions and word choices were increasingly chaotic. As a family member who interacts with him, you may understand most of it if you are willing to guess what he means. You would satisfy most of his demands. Many of the issues [BPSD] can be solved as long as you are willing to give a hand. (Participant 14)

Another carer illustrated the struggle of fulfilling an unhealthy desire of the PLwD in order to resolve the person's distress.

My mum has diabetes and needs to avoid certain food... She really wants to eat durian and I feel bad for not buying her, so I bought one and told her to eat one piece per day... I asked our domestic helper to monitor her, but the helper said if I was not around, my mum would get mad at her, saying she is bossy and telling her to leave. (Participant 8)

Modifying care environment

Carers described modifying environmental cues and interaction patterns with the PLwD to minimise stressors. Carers identified triggers for BPSD and modified environmental cues to prevent BPSD, such as putting up memos and keeping things out of the sight of the PLwD.

Take my mother [who shows symptoms of sundown syndrome] as an example, we avoid taking her out in the evening. If we have to dine out at 6 pm, we choose the corners when sitting in a restaurant, where she can't see the streets. Therefore, she won't notice when night falls since the indoor lighting remains the same after dark. She would be fine with that. (Participant 3)

He keeps putting the ingredients or dishes to the fridge while I'm preparing a meal... He doesn't mean to hide your things, but to keep things tidy and in the

fridge. I have to write a memo saying 'do not put in the fridge'. Otherwise, he will put everything in the fridge. (Participant 12)

Distraction

A number of carers mentioned confronting the PLwD would only induce further argument and agitation, and distress in carers. Distraction was a frequently described strategy to avoid further argument between the PLwD and carers.

When she lost her temper, distract her by saying other things, she won't remember what she was mad at later (Participant 7)

Explanation and bargaining

Attending activity groups in community centres and moving to respite care facilities were commonly identified by carers as means to maintain the PLwD's social life, cognitive abilities and care quality. Nonetheless, the PLwD often refused these arrangements because they were not interested in the activities.

Carers would explain to the PLwD the rationale behind the activities. For instance, cognitive training could train their brain and slow down their cognitive decline, otherwise, they may risk not being able to remember family members or living independently. Some carers told PLwD that it was an appointment with the staff at the community centres that the PLwD must attend.

I told him it was the doctor who asked him to go [to the community centre]... I told him the nurse wanted to chat with me and it would be nice if he accompanied me... I also told him, I'm not sure if it's correct, that 'you have some illnesses here [in your brain] and there's no medication for it. Social workers are there to chat with you in the community, so you won't sleep all day. If you sleep all day, you won't know anything. You don't know how to go home nor take a shower and that's really bad.' (Participant 11)

Carers might use incentives to encourage cooperation, such as food or things that the PLwD valued.

He likes money, so I told him he'd get HKD100 allowance every time he comes to the [cognitive training] class... He found it suspicious because it was impossible to get money just by sitting there... He said he won't come again even with money after attending one or two sessions. (Participant 9)

Responding negatively to BPSD

Confrontation

A lack of understanding of dementia caused frustration to some carers, leading them to take a confrontational attitude towards the PLwD's behaviours. These strategies might have had a negative impact on the PLwD's symptoms and the relationship between the care dyad.

My sister is harsh to my mother. She is rude, forcing her to do stuff, and getting angry sometimes. My mother couldn't take it. She would lie flat or crouch on the floor. Many times, she kneels on the ground, trying to beg. (Participant 1)

Avoidance

One carer mentioned that her sister refused to visit the PLwD where possible to avoid arguments. Another carer hinted at suicidal thoughts and giving up due to the tremendous stress in taking care of PLwD.

Sometimes he becomes so ill, messing up my thoughts. I would want to push open the window and not struggle anymore. (Participant 14)

Controlling upsetting thoughts

Change of attitude

Carers mentioned having upsetting thoughts and being easily irritated at the beginning of the caregiving journey. Some carers took accusations from the PLwD personally. Gradually, they adopted a more flexible attitude or simply cared less. 'Let it be' is a common expression among carers. Several carers mentioned that considering taking care of the PLwD as caring for a child allowed them to be more patient with the PLwD. However, one carer illustrated the challenge in adopting a reversed parent-child role when she convinced her mum to go to the hospital for an examination after a fall.

If she was your kid, you could beat her, make her scared of you, or just take her there. But she's my mum, I can't carry her on my back nor scold her. (Participant 8)

One carer suggested that the PLwD's reaction can be rewarding and make her care experience worthy.

It can be frustrating to convince him to join the activities and sometimes I'd rather give up, but then you can tell he's happy when he's in the group chatting and laughing with others. (Participant 11)

Acceptance and tolerance

Carers reflected that taking care of the PLwD is a challenge of patience. Medication was generally described as an effective solution for mood and disruptive behaviours, but a few carers were concerned about the sustainability and side effects of taking medicine. Accepting and avoiding challenging unhelpful behaviours were often described in dealing with difficult behaviours after carers tried various ways to reduce symptoms but in vain.

Arguing is not an option (he shuts the windows because of the illusion that something entered the room through the windows). He would say 'believe it or not,' but forgets what he just said soon after. He shuts the windows whenever I open them. I decided

to stay quiet, simply open the windows a while after he shuts them. (Participant 12)

Some carers allowed lone time for the PLwD to calm themselves, thinking that they might forget the incident later.

There is no solution, you just stay silent. It is pointless to argue with him when you know it is because of the illness. Let it be if he can keep quiet, it is much better when he slowly calms down. (Participant 15)

Social and emotional support

Sharing caregiving experiences with others helped settle carers' emotions. They resonated with other carers' experiences and realised that they were not alone in the care journey. They could also exchange ideas for handling difficult behaviours and thus saving them from taking the unnecessary long way to figuring out effective management strategies.

By sharing how we handle these issues, we learn to save redundant efforts through exchanging experiences. Otherwise, it is quite disconcerting when everything happens all of a sudden. Moreover, there is a resonance between us in the discussions. We know the people sitting next to you have been through the same stage. Gradually, you would perceive everything objectively. I find it helpful. (Participant 10)

Getting respite care

Carers with domestic helpers appreciated their help in sharing the caregiving tasks and supporting each other around challenging issues. Carers who lived with the PLwD demonstrated frustration and distress of monitoring the PLwD around the clock. They believed taking time away from caregiving tasks would reduce their stress.

My husband wouldn't go out, unless with my company. All in all, he would stick close to you, even for groceries, when only buying a pack of flour you forgot previously. I have no freedom at all as a result. (Participant 16)

It's not that I don't want to take care of her, yet spending too much time with her builds pressure upon me. Yes, living together is difficult, really difficult. I really want to hire a domestic helper or so. Then I will have some time to relax, to stretch, and my emotions wouldn't be the same. (Participant 2)

However, some carers expressed the concern that staff at day-care centres or care homes might not provide as much attention and stimulating activities to the PLwD due to the overwhelming workload.

We sent our mum to respite care home for three weeks and visited her every day... she was happier when family members were around... usually she got nothing to do and looked dull in the care home. (Participant 3)

DISCUSSION

To our knowledge, this is the first qualitative study to explore how Chinese carers respond to BPSD. Carers' self-initiated strategies were similar to those identified in Western literature.^{5 7-10} The strategies employed in handling disruptive behaviours largely aligned with existing theoretical frameworks in BPSD management. Carers modified care interaction and environment to address the PLwD's personhood and unmet needs. Particularly, carers created a warm and supportive family relationship with the PLwD. Similar to previous studies, carers expressed frustration at the beginning of the care journey but gradually adjusted their attitude towards BPSD. Social support, such as sharing care experiences with others, played an important role in resolving carers' distress and allowed them to continue with dementia care. However, relatively less were mentioned regarding self-care or getting respite care by the carers, except for seeking help from domestic helpers. The adoption and challenges in adopting these strategies could be understood from a cultural perspective.

In line with the Asian cultural value that family is the most important unit in life,²⁰ carers valued their relationship with the PLwD and involved them in the normal process of life with the company from family members, such as attending a family gathering. Love and support from family members were described as the most important by Chinese PLwD.²⁰ Support from family gives them a sense of security whereas a lack of support leaves feelings of socially isolation, loneliness and helplessness. Therefore, showing love and reducing insecurity through, for example, company and hugging, appeared to help elevate PLwD's mood. Carers also attempted to maintain harmony with other family members and friends by comforting them when they were irritated by the PLwD's behaviours. Apart from psychological needs, carers learnt to identify and fulfil the PLwD's needs and modify environmental cues to reduce triggers of BPSD. These echo the emphasis of harmonious, interdependent, interpersonal relationships and family relationships in Chinese society,²⁰ as well as Kitwood's research in maintaining personhood in PLwD,¹⁴ and the need-driven dementia-compromised model.¹²

Filial piety was not mentioned by adult child carers as a motivation or demand to care for their parents. The evolution of filial piety could be observed through the interactions between the PLwD and carers. Apart from behaviours that were difficult to modify, carers did not necessarily tolerate PLwD's behaviours or demands as authoritarian filial piety may suggest. Instead, they could have open communication while taking care of the changing identity in PLwD, reflecting the egalitarian manifestation of filial piety. However, they might have trouble fulfilling PLwD's need for autonomy and control. Convincing the PLwD to attend activity groups in community centres was a frequently described strategy, replicating the findings from highly distressed carers.¹⁰ While engaging PLwD in activities provides purposeful

occupation and improving mood may attenuate BPSD,²⁸ some carers in this study attempted to engage PLwD in activities without considering the interest of the PLwD, which might in turn trigger resistance.

Taking time away from caregiving seems to be a challenge for the carers, especially for those who lived with the PLwD. Being constrained in care tasks could be devastating and the desperation might even lead to suicidal thoughts. Even though some carers were aware of respite care services and the potential benefits of having a domestic helper to share some of the care tasks, they were concerned about the quality of care their family members received due to the overwhelming workload of the care staff. They may accompany the PLwD even when they were sent to respite care facilities. It is possible that familism held in Asian culture and their belief in enduring the unchangeable reinforce carers in taking up the responsibility of providing care and prevent them from taking time away.²⁹ Considering the poorer mental and physical health in carers associated with care-related activity restriction,^{30 31} the challenges in taking care of oneself and obtaining respite from caregiving is of particular importance to address.

Although Chinese tend to keep unfavourable things to themselves, including having a family member with dementia, carers in this study expressed the importance of social and emotional support in continuing the care provision. In particular, discussing care experiences and building relationships with other carers seemed to be a valuable asset to the carers.^{7 8} The discrepancy may lie in the anticipated response from different audiences. Disclosing the diagnosis of dementia to the general public may trigger stigmatisation associated with a 'mental illness' label. On the contrary, sharing experience with carers who have similar experiences allows them to resonate with and validate each other's feelings, as well as exchanging ideas for managing difficult behaviours.

Clinical implications

Findings from this study highlight the potential of enriching carers' knowledge of BPSD, social support and self-care in facilitating BPSD management. Interventions could aim at increasing carers' knowledge of the potential mechanisms underlying BPSD and providing guidance in applying effective management strategies. Developing support groups or networks for carers would be beneficial. This may allow carers to discuss feelings and experiences, and share practice wisdom with each other. Advocating the importance of self-care in promoting quality care and well-being in PLwD and carers is essential. Particularly, self-care could be presented as aligning with the belief of filial piety or providing quality care to family members, in which taking time for oneself is not equivalent to leaving PLwD behind, but instead maintaining own physical and psychological well-being to continue the care tasks. In view of the challenges in taking time away from caregiving tasks, intervention could target developing self-care

techniques that could be adopted amid caregiving tasks and providing guidance in applying these skills.

Future research

This study demonstrates the influence of cultural value in coping with BPSD on top of some common themes across cultures. Further cross-cultural research could explore the factors that determined how carers manage BPSD and how interventions could be culturally adapted to facilitate carers to apply learnt skills in daily practice and hence benefit the PLwD and carer population. Furthermore, while the current study included carers with diverse education levels, there seems to be a higher proportion of highly educated carers participating in existing studies. More studies on carers with lower education levels may be needed since they may have different management strategies⁵ so that adequate interventions could be designed for this group of carers.

Limitations

The generalisation of the current findings is limited. First, all carers were female, who may show a tendency to use more nurturing strategies, treating PLwD in a 'parent-child approach', or non-adapting strategies, approaching PLwD with impatience, anger and irritation.⁵ Despite that almost 80% of the carers are women globally and they predict a higher level of burden, future study should consider the experience of male carers, who may encounter different challenges, such as role reversal, during the caregiving process.³² Second, the sample size was small and self-selective. Although all carers had the opportunity to contribute to the focus groups and data were collected till data saturation, they could have higher functioning and be more socially connected, compared with other carers. Third, there may be bias in the recall of coping strategies due to the retrospective nature. Moreover, although some carers were willing to share personal struggles and negative coping strategies during the interviews, some might report positive management approaches only due to social desirability.

Conclusion

The present study reveals that self-initiated BPSD management strategies adopted by Chinese carers largely align with existing theoretical frameworks in managing BPSD as identified in Western literature. Echoing Asian cultural values, carers took up the responsibility to take care of their family members and attempted to maintain supportive family relationships with the PLwD. Despite the difficulty in taking time away from caregiving to care for themselves, carers expressed the importance of social and emotional support in managing their distress. A greater understanding of how Chinese carers manage BPSD will facilitate the development of interventions tailored to the growing population of PLwD and carers in the Chinese community.

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