

Tensions in support for family caregivers of people with dementia in Singapore: A qualitative study

Dementia

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journals.sagepub.com/home/dem**Ichha Basnyat** School of Communication Studies, James Madison University,
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Abstract

Background: Family members as informal caregivers are considered the first line of support for people with dementia across the world. In Singapore, caregiving expectations revolve around the cultural expectations of providing care in the home environment. However, studies in Singapore have identified a lack of family support for primary caregivers. Family support has been discussed in the literature as the provision of care for people with dementia, and rarely as a resource for family caregivers.

Method: To understand family support among primary caregivers in Singapore, 24 semi-structured interviews were conducted. Thematic analysis found four themes: excuses for lack of physical support for the caregiver, tensions between cultural expectations of caregiving and the provision of support, unmet emotional support, and lack of awareness of dementia and caregiving needs.

Findings: Caregivers rationalized and forgave the absence of physical support but were frustrated when the lack of support impacted people with dementia. This was seen as a lack of fulfilling cultural obligations of caring for elderly parents. The caregivers also felt frustrated with the lack of emotional support provided to them, but these were unspoken between the caregiver and the family members. Insufficient and unhelpful support giving was exacerbated with the perception of family members' limited understanding of the demands of caregiving.

Conclusion: The findings offer four practical suggestions to address unmet support needs. First, public education is needed to enhance general knowledge about the symptoms and progression of dementia. Second, help is needed to address miscommunication about support within the family.

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Third, the development of guidebooks is needed to help family caregivers communicate with family members about their various support needs. Fourth, the relationship between cultural expectation and caregiving must be understood within the context of modernity and urbanism.

Keywords

dementia, family caregiving, family carers, family support, interviews

[Alzheimer's Disease International \(2018\)](#) estimates that 50 million people worldwide live with dementia, and this number is expected to rise to 82 million by 2030 and 152 million by 2050. In Singapore, estimated 40,000 older adults above the age of 60 years (i.e., 10% of the older population) live with dementia, and this number is expected to increase to 80,000 by 2030 and 187,000 by 2050 ([Institute of Mental Health, 2015](#)). People living with dementia require high levels of care, most of which is provided by family caregivers often as home-based care ([Brodaty & Donkin, 2009](#); [Soilemezi et al., 2019](#); [Tay et al., 2016](#); [Tew et al., 2011](#); [Verbeek et al., 2012](#)). Home care places a heavy burden on family caregivers and is known to affect caregivers' health, and such carers are found to have significantly decreased quality of life ([Brodaty & Donkin, 2009](#); [Macleod et al., 2017](#); [Mason & Hodgkin, 2019](#); [Ornstein et al., 2013](#); [Soilemezi et al., 2019](#); [Tew et al., 2011](#)). Nevertheless, families often prefer to provide care at home for a variety of cultural, obligational, and practical reasons ([Erol et al., 2016](#)).

In many societies, people with dementia do not only receive home-based care but also often live in extended-family households ([Soilemezi et al., 2019](#)). In Chinese societies, filial piety, or Xiao in Chinese, is a concept frequently used to explain the impact of Confucianism on family values such as hierarchy, obedience, respect, and obligations that bound children to care for their aged parents ([Chan, 2011](#); [Jones et al., 2011](#); [Lai, 2009](#)). Filial responsibility is taught at a young age to care for aging parents, contribute financially, and provide emotional support as adult children ([Miyawaki, 2020](#); [Weng & Nguyen, 2011](#)). The family-centered cultural construct implies that adult children have a responsibility to sacrifice individual physical, financial, and social interests for the benefit of their parents or family ([Sun et al., 2012](#)). In Singapore, this translates to middle-aged women becoming the primary caregivers because of the hierarchy of expectations from caregivers: spouse (wife), daughter (unmarried), daughter-in-law, and other kin ([Seow & Yap, 2011](#)). Daughters or daughters-in-law usually handle day-to-day caregiving tasks such as feeding and bathing, while the eldest sons are usually expected to take the key financial responsibility ([Lai, 2009](#)). In fact, in both developed and developing countries, there is often a social expectation that women will provide informal care to people with dementia ([Erol et al., 2016](#)). Furthermore, Singapore's national policies promote family as the principal support system for older adults ([Yeoh & Huang, 2010](#)). Thus, despite the availability of a wide range of geriatric services in Singapore, family obligations informed by filial values contribute to the family caregiver's unwillingness to engage external services ([Tew et al., 2011](#)).

Family caregivers often struggle to meet the demands of career, relationship, family, and caregiving ([Delgado et al., 2015](#)). Caregiving is usually added to household chores, childcare, and work demands, but at the same time, caregivers are facing declining support from their family members ([Huang et al., 2012](#)). Family caregivers of people with dementia are prone to burnout syndrome, which is characterized by emotional exhaustion, depersonalization (indifference), and reduced personal accomplishment ([Alves et al., 2019](#); [Jütten et al., 2019](#)), and are at greater risk of developing anxiety and depression ([Watson et al., 2019](#)). The consequences of burnout maybe mental, emotional, and physical such as low self-esteem, exhaustion, anxiety, frustration, lack of

concentration, reduced personal accomplishments, headaches, insomnia, pain, and gastrointestinal problems (Alves et al., 2019). In particular, Reed et al. (2020) found that the patient's decreased ability to perform activities of daily living, declined cognition, and increased behavioral problems were correlated with caregiver burnout. Similarly, Hiyoshi-Taniguchi et al. (2018) found that levels of distress and burnout reported by home caregivers were mostly correlated with dementia symptoms of aggression, irritability, abnormal motor behavior, and hallucinations. In general, caregivers for people with dementia have shown higher levels of burden and lower satisfaction with the caregiver role (Brites et al., 2020). Studies in Singapore have also reported increased burden and psychological stress among primary caregivers due to a lack of support from their family members (Jennings et al., 2015; Tew et al., 2011; Thompson & Roger, 2014; Vaingankar et al., 2013). This juxtaposition of cultural expectations of caregiving and the need for support resources provides a unique context to explore family support for caregivers in Singapore.

Family support refers to care beyond regular caring interactions in the family. The need arises when an individual requires constant caregiving attention due to chronic illness and disability (Singer et al., 2009). Family support has often been discussed as the provision of care for the people with dementia, but rarely as a resource for family caregivers (Leung et al., 2007; Singer et al., 2009). Recently, more research has linked family support to caregivers' improved adjustment to negative impacts of caregiving on their physical and mental health (Chan, 2011; Dam et al., 2016; Delgado et al., 2015). Support includes both tangible (e.g., physical and financial assistance) and intangible (e.g., emotional aid) resources available in a person's network (Queenan et al., 2010). Furthermore, there is a distinction between perceived support, a caregiver's subjective appraisals of others' actions, and received support, the objective evaluation of aids that a caregiver receives from the social network (Uchino, 2009).

Compared to received support, perceived support is more consistent with beneficial health outcomes and demonstrates better buffering effects on distress and depression (del-Pino-Casado et al., 2018; Haber et al., 2007). Quantitative studies conducted in similar Confucian societies such as Taiwan showed that perceived social support is a better predictor of mental wellness than received social support among family caregivers of frail seniors (Chiou et al., 2009; Lee et al., 2006). Concerns such as burdening others, the inability to reciprocate support, the desire to excuse others from providing support, the time and effort needed to coach others to provide effective support, the perceived disruption in relational boundaries, and possible negative interactions with family members are reasons that prevent caregivers from seeking and accepting support and explain their preference of perceived support over received support (Casale & Wild, 2013; Wittenberg-Lyles et al., 2014).

Currently, limited research exists on caregiver burden in societies where the availability and presence of family support are part of the cultural norms and societal expectations. This research article aimed to understand primary family caregivers' experiences with receiving support from family members, their perception and need for family support, and reasons underpinning unmet support needs, while paying attention to the context in which caregiving is an obligation and a duty. Specifically, the following research question was posed: How do primary caregivers of people living with dementia in Singapore experience family support?

Method

Recruitment and ethical approval

The study received approval from the Institutional Review Board as well as from the Alzheimer's Disease Association, Singapore (ADA). Upon approval, the ADA helped send a recruitment email

drafted by the researchers to its members. The email invited interested English-speaking primary caregivers of people with dementia to contact the researchers through email or phone to participate in the research. There were no restrictions based on age or gender. When a potential participant reached out, a member of the research team briefed the participants about the interview process, the questions, and their right to withdraw at any time before setting up the interview at the participants' convenience.

Data collection

This study took a qualitative approach to reveal nuances in supportive communication among family members. In-depth interviews were selected over focus groups to accommodate participants' sporadic free time between caregiving tasks. Semi-structured interviews were arranged according to a time, date, and location (e.g., at the ADA, a home, or a neighborhood community center) convenient to the participants while privacy was ensured. The interview process consisted of an introduction to the research, a briefing on ethical procedures, and a short demographic survey. Prior to the interview, participants gave their written consent and confirmation to be audio-recorded and received 10 Singapore dollars as reimbursement regardless of whether they completed the interview. All the 24 participants completed the interview. The interviews lasted between one and 2 h. The main questions centered on participants' experiences as primary caregivers, the perceived availability or lack of support, and their appraisals of caregiving support from family members. For example, participants were asked the following: "Please tell me how important family support is to you when you take care of your [insert relation]?", "What kinds of [financial/information/emotional/physical—asked as separate questions] support do you receive from your family members to help you take care of your [insert relation]?", and "How does your family show appreciation of your role as the primary care taker of your [insert relation]?" The questions were developed based on existing literature on social support and previous work on culture and health management (Chang & Basnyat, 2017) that were directly related to the research question. These questions were shared with the ADA for expert feedback and were pilot-tested with the first two interviewees to examine their relevance and comprehensiveness. The revised main questions were then asked in all interviews, while the follow-up questions were adjusted and phrased depending on the participants. One trained research assistant conducted all interviews and transcribed them verbatim, and the authors double checked them all. After 24 interviews, the research team concluded that no new information emerged from the data, and data saturation was attained (Fusch & Ness, 2015).

Data analysis

Six steps of thematic data analysis discussed by Braun and Clarke (2006)—namely, familiarizing, generating initial codes, searching for themes, reviewing the themes, naming the themes, and writing—were employed. First, both authors began familiarizing themselves with the data through open coding. A line-by-line analysis of the transcripts was performed individually. Second, initial codes were generated by taking notes about patterns that emerged from the data. At this stage, the authors discussed the relevance of the emergent concepts to the study. Third, through further discussions, initial codes were narrowed down to potential themes. Fourth, the authors refined the potential themes to address the research question. Fifth, four themes were defined and named. Sixth, vivid and representative quotes were selected from the research to relate to the research question and the literature. Throughout the coding process, to ensure reliability, the authors coded the data separately and discussed the emerging patterns at each step to eventually derive the same themes. To ensure validity, member checking occurred during the interviews (i.e., sharing previous interview

findings with later participants). Moreover, findings were compared to existing literature, the authors' previous interview data (author), and alternative explanations to triangulate multiple observations and conclusions (Carter et al., 2014) and establish descriptive and interpretive validity (Whittemore et al., 2001).

Findings

Participants' characteristics

Thirty-seven caregivers initially responded to the email recruitment asking for more information. Out of them, 13 participants dropped out primarily due to personal circumstances and others due to the limitations of the interviews being conducted in English. Finally, 24 primary caregivers completed the interviews. No two participants from the same family were interviewed to meet the research criterion of only interviewing the primary caregiver in a household. Pseudonyms are used in the quotations for confidentiality. Most participants were women ($N = 21$), taking care of their mothers ($N = 17$). Their ages ranged from 38 to 75 years ($M = 53.38$; $SD = 11.29$). Table 1 presents the demographic characteristics of the participants.

Four themes emerged from the data. The first theme addressed the family members' forgivable absence of physical support for caregivers. The second theme described the unforgivable absence of family support for people with dementia as violating filial expectations. The third theme revealed the absence of emotional support needed by caregivers. The fourth theme presented barriers to receiving useful support due to family members' limited understanding of dementia and caregivers' needs.

Theme 1: Excusing lack of physical support

Caregivers described that family members were unable to provide physical support such as feeding, bathing, dressing, and attending doctor's appointments that would help alleviate the day-to-day caregiving burden. Work demands, family obligations, and poor health were reasons for the absence of family support. Caregivers were considerate about the conflicting obligations that their family members, particularly siblings, had to fulfill and tended to excuse the lack of their assistance in caregiving. For instance, participants described their empathy with siblings' prioritization of other obligations over assisting them in caring for their parent with dementia:

My younger sister is married, and she has her in-laws. She has her family and her children to take care of. She just went to America to look after her daughter, who got married. She looks after her grandson. So, she seldom helps me. She is working as a nurse. (Lin)

Caregivers rationalized that family members just did not have the time to provide support with day-to-day caregiving. For example, participants often noted that family members were willing to offer support but were overwhelmed by their own caregiver roles:

Not that she [sister] does not feel like taking care of mother, she does because my parents love her the most. She is the youngest, and they love her the most. It is just that she has too much on her plate as she is taking care of her husband, her two sons, and her mother-in-law. (Pang).

Participants like Lin and Pang were unmarried daughters who retired or quit their jobs to provide full-time care for their parents. In comparison, their married and working siblings were primary

Table 1. Demographic data of the participants.

Demographic	<i>n</i>	%
Age (years)		
Below 40	4	16.7
40–49	6	25.0
50–59	8	33.3
60–69	3	12.5
70 and above	3	12.5
<i>M</i> = 53.38; <i>SD</i> = 11.29	—	—
Gender		
Male	3	12.5
Female	21	87.5
Years of caregiving		
1–5	14	58.3
6–10	6	25.0
11 and above	4	16.7
<i>M</i> = 5.75; <i>SD</i> = 3.11	—	—
Highest educational level		
Middle school	4	16.7
High school	6	25.0
Vocational school	3	12.5
Undergraduate degree	11	45.8
Providing care for		
Mother	17	70.8
Father	2	8.3
Spouse	3	12.5
Parent-in-law	2	8.3
Place of care		
Caregiver's home	20	83.3
Patient's home with full-time domestic helpers	4	16.7

caregivers of their own families, taking care of their children, husband, and in-laws, and juggling their work–life balance. Knowing the difficulties of being a primary caregiver, participants accepted the lack of support from their family members.

Additionally, work-related obligations were perceived to create barriers for family members to offer timely support: long working hours, fixed work schedules, financial stress, requirements for advance notice for leaves, and undermined family members' ability to quickly respond to primary caregivers' emergency call for help even if they wanted to.

She [sister] is willing to [help], but at the bank, she cannot just take a leave of absence 1 day in advance. If I have a last-minute appointment and if I ask her, she would say, "How can I take a leave? You did not tell me in advance. I cannot just walk in and tell my manager. I cannot take leave like that." (Dong).

Participants could relate to the time constraints that family members had, as it was a similar experience that they experienced in day-to-day caregiving. Understanding siblings' difficulties in giving support often resulted in refraining from seeking support and communicating their needs:

His [brother] work is quite busy so most of the time I do not want to disturb him. I have told him to take care of himself and that I do not expect him to take care of our mother. And if he wants to visit, I will welcome him. (Teo)

Although caregivers recognized the importance of family support, they empathized with the various roles that family members juggled. Accordingly, they avoided asking family members to share more caregiving activities as a thoughtful effort aimed at not increasing their burden. As a result, the absence of assistance in daily care was excused.

Theme 2: Tensions in cultural expectations

Although caregivers excused the lack of physical support from family members, they were unable to accept family members' emotional detachment from people with dementia. Caregivers felt angry, disappointed, and frustrated when family members avoided spending time and being around the person with dementia. The lack of interactions with people with dementia and ignorance of their emotional needs were seen as violating culturally bound filial norms. Tensions were intensified when children failed to show care for their parent with dementia:

My eldest son is not involved at all. Once in a while, he comes and gives a little bit of pocket money to me and that's it. Even when my husband was in the hospital, he came just once and hardly stayed for about 15–20 min. He has not been a son that he should be, he has forgotten all the good things I have done for him. (Kah).

Kah indicated the lack of support from her son. The emphasis on "he should be" revealed the underlying cultural expectations regarding the role obligation of a son, which was to provide support and care for his parents when they needed it. Caregivers' narratives strongly expressed that filial piety must be realized and adult children must care and love their frail parents. As Wang expressed, "*It is our parent. We all must provide this love. Do not neglect your duty.*" With this filial belief, they became the primary caregiver:

When mother was discharged from the hospital after the stroke. The doctor asked who was going to be her main caregiver. Whom will she stay with? Nobody raised their hands so I raised mine and that how it has been ever since. (Yip)

Using the same filial standards, caregivers criticized those who were aloof toward their parents. The principle of reciprocity was emphasized, that is, paying for what the adult children have received earlier in life from the parents. For both spouse caregivers like Kah and offspring caregivers like Yip, they emphasized the importance of adult children meeting the filial expectations. Failing to do so showed irresponsibility and created tensions:

I told my siblings: "How long can she live? She loves you. She cooked for you all when you were young. She took care of all of you. Where is all your love now? Do not cry when she is in the coffin, it will be of no use then. Now is the time to give her the love she gave you." (Lau)

From the caregivers' perspective, filial piety entailed both physical and emotional obligations. While one's physical filial duties such as providing physical care for aged parents may be carried out by

someone else, emotional duties such as affection and attachment must be fulfilled by their family members. Moral judgments occurred when emotional support for the parent was missing:

I used to interact with [my sister], but now I am a bit fed up with her. I do not want to talk to her. I was angry, I scolded her, I said, "She is your mother, you know! You just think about yourself. She took care of you when you were young." Even after I told her that, there was no change in her. (Goh).

Another principle raised by caregivers was the fair sharing of filial responsibilities. Filial norms should be obeyed by all family members, not just by the caregivers. There was a distinction between "cannot" and "do not want to" provide support. Family members should attempt to show their filial sincerity. Their aversion to filial obligations and deliberate ignorance of the parent's emotional needs were condemned as culturally inappropriate:

Once my mother-in-law said, "I want to go to my daughter's house." My husband called his sister but she had gone to the market. He talked to the son and said, "I am bringing Ah Ma [grandma] to your place." My husband traveled all the way to Yishun. But the daughter came back from the market and immediately called my husband: "Can you please take mother back?" They feel that by default, we have to take care. They never think that they are also her children. (Chin)

This theme highlights caregivers' expectations of interactions between family members and the person with dementia. Filial piety required both physical and emotional engagement with them. The expectations for emotional support were bound to cultural beliefs that adult children should care for their parents with genuine affection. While caregivers took on the physical duties of caregiving, they expected their family members to at least provide support to the person with dementia through emotional attachment, spending time, and showing empathy and patience. Emotional support for the person with dementia was seen as the minimum fulfillment of filial piety.

Theme 3: Unmet emotional support needs

Caregivers noted a challenge in understanding the lack of physical support and being frustrated with the absence of emotional support. They felt that they contributed a lot in day-to-day caregiving but were not appreciated, acknowledged, and supported by family members:

Everybody is busy earning a living. I do not ask them to help with the physical work because you do not want to force people. If they can understand that I am already quite worn out, then they can volunteer. Support is important in a way that you feel love. You feel that you are being cared for. (Beng)

The support caregivers looked for was beyond physical help and financial aid; it was for an understanding of the sacrifice they made for the family and the mental stress they carried. Lack of empathy from family members created frustration among the caregivers:

They don't understand. That is the basic thing. They thought it [caregiving] is easy. Then they should come to take care. Why don't I work instead? The mental stress that I carry is from the others [referring to siblings]. So do not tell me what to do. (Tan)

To understand what kind of support to provide required being sensitive, empathetic, considerate, and perceptive of the needs of the caregivers. The lack of emotional availability fueled negative feelings toward family members:

I really wanted to discuss with them [siblings], but they do not want to know. What can I do? I cannot force them, right? They even say that I am very demanding. They want me to send my mother to a nursing home. I said, "When she was okay, she told me not to send her to a nursing home. She already told me beforehand." (Ong)

Participants like Ong were torn between the heavy caregiving load and their parent's will. Family members' lack of empathy and appreciation added to the frustration they experienced with dementia care. However, caregivers also pointed out that while emotional support was desired, it was not always helpful when the family members were not attuned to their needs:

If one wants to help, the person must know what kind of help I require. Help is crucial, but your help must accommodate my needs. You must feel, listen, and try to understand what others need. If you do not try to understand and you do things in your ways, according to what you think, then you trouble others more than you help. (Min)

Caregiving is a tiring and enduring task. Some caregivers reported that because of the lack of emotional support, they felt burnout or developed clinical depression. Caregivers expected others to understand their sacrifices and struggles. The feeling of being understood, valued, and supported was critical to their coping with caregiver burden.

Theme 4: Lack of awareness of dementia and caregiving needs

Caregivers related the challenge of insufficient support for them and for the parent with dementia to the family members' lack of awareness about dementia and dementia care requirements. Poor knowledge about dementia symptoms and progression largely explained family members' misunderstanding of the health condition of the person with dementia, the intensity of dementia caregiving, and the psychological stress of the primary caregiver:

Nobody understands. Even my sister. I tell her, but she does not understand. In my own family nobody knows what dementia is. They think it is just how the elderly act when they get old. Just take care of them. They do not feel anything at all. (Ng)

Caregivers wanted to talk to someone about their observations of the person with dementia and the caregiving adjustments as dementia progressed. However, they were unable to discuss their emotions and decisions even with those closest to them if the latter did not attain similar knowledge levels:

Sometimes I told him [husband] about my mother's funny behavior, then after listening, he would say, "That cannot be. She can remember this, then how come she cannot remember that. I think she is pretending to be like that." Because people don't understand dementia, you can't convince them that my mother is not lying. (Jing).

In extreme cases, family members' lack of understanding of dementia could spark harsh criticisms and delay in treatment for the person with dementia:

In the initial stage when she [wife] was having this problem, I roped in a family member to help, to talk to her. I thought that she needed some avenue, someone to talk to her. Instead of helping, they accused me of causing her dementia. They took her away and did not want to bring her back. Four months, they kept her away—she missed all her appointments with the doctor. (Seow)

A common experience shared by caregivers was that asking for support from family members sometimes meant more work for caregivers. Lack of awareness of dementia and caregiving needs became a major source of distress:

When they visit, they would buy food for mother, but the thing about my mother is that she wants to eat whatever she sees. I control her food intake but I do not like to take that joy away from her. When I try to control her food intake, the others are displeased and question my actions, thinking that I deliberately stop my mother from eating. People at home, like me, have to pick up her vomit when she cannot control, and when she has diarrhea I have to wash her and the floor. They will not know these things. (Min)

Caregivers noted that it took time for family members to understand the status of the person with dementia. However, because family members were not the primary caregivers, they were not proactive in increasing their knowledge and awareness. As a result, caregivers often found themselves providing emotional and informational support to family members by lightening the atmosphere and teaching them things about dementia, while at the same time coping with caregiving demands and associated emotions by themselves:

When father-in-law keeps repeating the same questions, of course, the siblings will get angry and say: "Since I step into the house, you have been asking me the same question so many times. I have been telling 'ta-da-da-da-da.'" The mood in the family becomes very tense. You need some tactic, or to say, "He is a sick man, you need to joke it off" to lighten the mood. You need such reminders. (Qian)

Caregivers developed knowledge about dementia and dementia care through their interactions with the person with dementia, medical professionals, and organizations such as the ADA and self-learning. In comparison, many of their family members did not seek to develop similar levels of understanding about dementia. This knowledge gap juxtaposed with family members' lack of motivation to understand and empathize increased difficulties in communicating with the person with dementia and caregiver's support needs. The lack of understanding curbed the provision of emotional support and physical assistance in a way that could be useful. The additional work of educating family members and dealing with the aftermath they created escalated the overwhelming caregiving demands rather than mitigating them.

Discussion

In Singapore, with the national policies of family as the first line of support and a cultural emphasis on filial obligations, family caregivers are expected to take on the caregiving responsibility and often as home-based care (Tew et al., 2011; Yeoh & Huang, 2010). Thus, it was not a surprise to find that in this study; all of the people with dementia were cared in home environments by their family. Aligned with the existing literature (Brodaty & Donkin, 2009; Mason & Hodgkin, 2019; Ornstein et al.,

2013; Soilemezi et al., 2019; Tew et al., 2011), caregivers interviewed in this study reported their experience with physical and emotional fatigue and a heavy burden placed by home care. Moreover, most of the primary caregivers and the persons they cared for were women. This resonates with the existing literature which highlights that dementia disproportionately affects women, either through developing the condition themselves or as a carer for someone with dementia (Erol et al., 2016). Although home-based care and the impact on women maybe more global, our findings highlight the strong cultural expectations and obligations on adult children's fulfillment of their filial responsibility.

Caregivers in this study described their fulfillment of filial norms and their expectations that all siblings should share their filial responsibilities. Even for the few spouse caregivers, who took on the primary caregiver role, they held fulfilling filial expectations from their adult children. Family members who refused to fulfill filial expectations are perceived as selfish by the caregivers because filial values indicate a need for self-sacrifice to fulfill one's duty. Thus, the caregivers tended to link the absence of tangible support (e.g., assisting in the patient's daily activities for living) and intangible support (e.g., caring for the patient and giving emotional support to the caregivers) with the family members' failure in fulfilling their filial obligations.

Compared to known studies on family support for older adults in the cultural context of filial piety (Chen & Silverstein, 2000; Peng et al., 2019), our study reveals the nuances in caregivers' dependence on family members for physical and emotional support. Support is needed for family caregivers to continue this role in the longer term (Erol et al., 2016). Physical support such as sharing the tasks of assisting people with dementia with daily activities is welcomed but not required. Caregivers take into consideration family members' availability, sincerity, knowledge, and ability to provide physical support to the person with dementia. Moreover, the importance of physical support is conditional, depending on its usefulness to the caregiver and the person with dementia. In contrast, emotional support is generally desired. Being understood and appreciated plays a critical role in caregivers' coping with caregiving burden. While many extant quantitative studies treated social support as a composite variable to evaluate its effect on caregiver health (del-Pino-Casado et al., 2018; Haber et al., 2007; Silverstein et al., 2006), our qualitative findings offer important nuances of primary caregivers' varying needs for different kinds of support and the underlying process in which physical and emotional support functions in different ways to meet or not to meet their needs.

This study reveals how filial piety shapes caregivers' expectations and judgment of support presence and provision within the family. Although previous research consistently found that perceived support is more helpful than received support in enhancing caregivers' adjustment to stressors and burden of care (del-Pino-Casado et al., 2018; Haber et al., 2007), we identified that variations in their importance linked to filial norms. On the one hand, caregivers do not consider the actual reception of family support (i.e., received support) to be more important than the general impression of family members' willingness to be supportive (i.e., perceived support). This is reflected in their tolerance of absence of physical support when good reasons, such as conflicting role obligations, are presented. The concerns of not wanting to be a burden to others, feeling for others' multiple role duties, avoiding negative interactions, and declining unhelpful assistance are also seen in other studies (Casale & Wild, 2013; Wittenberg-Lyles et al., 2014). On the other hand, caregivers hold an opposite view on the importance of perceived support and received support when the recipients are people with dementia. The actual provision of support to people with dementia is emphasized, and the ambiguous availability of support is not sufficient. This emphasis on received support for people with dementia is intertwined with the cultural significance of filial piety and the government's integration of family networks into the dementia care system (Jones et al., 2011; Yeoh & Huang, 2010). Primary caregivers distinguish between the support provided to them and that to the person with dementia. As caregivers themselves appreciate perceived support from family

members and can develop strength to tackle psychological stress based on the latter's attempt to help and empathize, they weighed received support more important than perceived support for people with dementia based on filial concerns. In particular, high expectations are set on the received emotional support for people with dementia, as the relational bond and intimacy cannot be substituted by others, including the primary caregivers. Our study illustrates the importance of perceived support and received support according to cultural expectations and the familial hierarchy between support providers and recipients.

Another contribution of this study is to reveal the critical role of knowledge in providing support. Family members' knowledge about dementia symptoms, progression, and care requirements has direct impacts on how they interact with the people with dementia and how they assist caregivers in providing care. While primary caregivers are compelled to learn everything about dementia bound by their role, other family members can bypass the learning process as they have not taken on the responsibility. As a result, poor understanding of dementia and care may further hindrance to the provision and availability of physical and emotional support and result in inappropriate treatment of the person with dementia and underestimating the intensity of caregiving demands. However, the magnitude of disparities in caring and tensions derived from unspoken and unmet expectations may vary from one household to another (Willyard et al., 2008). Nonetheless, our study contributes to demonstrating that knowledge can play a role in shaping family members' responses to dementia, to people with dementia, and to the primary caregiver within the complex and idiosyncratic family dynamics. To some extent, knowledge has the potential to enhance understanding, empathy, and interaction patterns. The practical value of knowledge suggests that public education programs may help tackle the issues of dementia care and caregiver burden by enhancing public awareness at the societal level.

Limitations

First, the participants were recruited through the ADA, indicating that they were experienced support seekers who had access to external support to some extent. More socially isolated caregivers, however, might be excluded from the sampling pool. Future research should consider adopting a different sampling scheme to reach the isolated and resource-impooverished to explore their barriers to family and social support. Second, only English-speaking participants were recruited in this study. By doing so, participants who only spoke any of the other three official languages in Singapore, namely, Malay, Mandarin, and Tamil, were unable to participate. Future research should attend to language-related selection biases. Third, the caregiving experience may vary with dementia progression. Future study should pay attention to the dementia progression and the impact on caregivers' health. Fourth, as this research focused on exploring caregivers' experiences with family support, only primary caregivers were interviewed. To gain a more complete understanding of support provision, sharing, and communication among family members, future research should consider dyadic interviews with primary and secondary caregivers to reveal more nuances in family dynamics embedded in the context of dementia caregiving. For instance, there are competing familial obligations to spouses, children, parents, and in-laws. The ways in which primary and secondary caregivers balance multiple role obligations to meet the cultural expectations of home-based care for people with dementia are worth further investigation.

Implications and conclusions

Negative sentiments that lead to repressed feelings of burden and isolation can adversely impact caregivers' health and well-being. Our findings point to multiple implications for health promotion

strategies that promote better family support for caregivers who are expected to fulfill cultural obligations. First, in line with Varik et al. (2020) suggestion, it is important to raise public awareness of dementia and dementia care to develop awareness and friendly community. Public education can help enhance knowledge about dementia caregiving tasks, burden, and responsibilities, and reduce misunderstanding. This provides a bedrock for family communication about support for people with dementia and caregivers. Second, Asian caregivers and their families might benefit from family-centered intervention approaches designed to provide support to caregivers in home-care settings (Chow et al., 2010). This requires further collaboration between the formal healthcare system and support organizations at the community level. Third, the minimum supportive communication among family members informs the design of interventions tailored to facilitate dialog between caregivers and suggests that external support providers can take into account the miscommunication of support within the family and move toward meeting caregivers' unspoken but expected support from family members. Communication tool kits could help caregivers to better communicate with other family members about their needs at various levels. Fourth, the relationship between filial piety and caregiving must be understood within the context of modernity and urbanism, such as higher cost of living and more demands at work, which perhaps influences the ability to provide family support for caregivers. In conclusion, the present study reports barriers to family support for caregiving dementia and also points out areas where more supportive communication can be made with help from culture-sensitive health promotion strategies.

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