BMJ Public Health

# Hearing, sharing and applying: a qualitative study of the experiences of family caregivers' end-of-life decision-making in Singapore

Min Li Ong,[1] Pin Sym Foong ,[2] See Mieng Tan ,[2] Xingyu Xia,[3] Gerald Choon Huat Koh[1]

**To cite:** Ong ML, Foong PS, Tan SM, *et al*. Hearing, sharing and applying: a qualitative study of the experiences of family caregivers' end-of-life decision-making in Singapore. *BMJ Public Health* 2024;**2**:e000646. doi:10.1136/bmjph-2023-000646

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/bmjph-2023-000646).

Received 10 October 2023
Accepted 3 May 2024

[1]Saw Swee Hock School of Public Heath, National University of Singapore, Singapore
[2]Telehealth Core, National University of Singapore, Singapore
[3]Department of Psychology, National University of Singapore, Singapore

**Correspondence to**
Dr Pin Sym Foong;
pinsym@nus.edu.sg

## ABSTRACT

**Objectives** This study aims to describe the caregivers' end-of-life (EOL) decision-making experience, what made family caregivers feel assured when they were making the right call, and when they felt uncertain or regretful about decisions made. The objective is to describe the decision-making journey and identify how interventions can be developed for these caregivers.

**Methods** Semi-structured interviews with 14 adult and spousal caregivers were conducted using an interview guide and transcripts were coded inductively via reflexive thematic analysis.

**Results** First, clarity in communication enhances satisfaction with their decisions. This involves transparency of communication channels within the family unit which is in charge of helping their patient make EOL decisions, and with the healthcare professional. Second, satisfaction was enhanced with clear prognostication of the patient's condition to the family who then used it to discuss their options. Finally, families often elect a lead facilitator within the family unit who manages the decision-making process, and collates multiple perspectives from all the stakeholders.

**Conclusions** Based on these findings, we recommend that interventions to support family-based decision-making in Singapore should be based on the three principles of hearing patient values, sharing these values with other loved ones and providers and applying these values in collaboration with the providers and family members.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Family caregivers often participate in end-of-life decision-making.

### WHAT THIS STUDY ADDS

⇒ Their experience of end-of-life decision-making is better when there is clear communication between stakeholders.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Singapore families are more satisfied with end-of-life decision-making when they receive a clear prognosis, understand the patient's values and a lead facilitator improves these collaborative efforts. Interventions for caregivers should focus on enhancing their ability to hear the patients values, share them among the stakeholders and apply them in end-of-life decision-making.

## INTRODUCTION

Advancements in medical interventions with the potential to prolong life have created challenging decisions for families of patients at the end-of-life (EOL). The benefits of these interventions at advanced stages of illness may be distinct but minimal life extension, or come at a great cost to quality of life.[1]

The behaviour of family caregivers in EOL decision-making in Singapore is influenced by Asian conceptualisations of filial piety,[2] where it is culturally acceptable to make EOL decisions with limited involvement from elderly parents to protect them from psychological distress[3] (which may, in turn, enhance the patient's quality of life). There also exists a persistent taboo in discussing 'inauspicious life events' such as illness, death and dying[4] and a prevalent 'worry about caregiver performance'—where caregivers fret about doing enough as caregivers.[5] These predisposed notions of filial piety may result in many caregivers consistently choosing to provide life-prolonging treatment to patients to avoid feelings of guilt or regret over not doing everything in their capacity to sustain an elderly parent's life.[6] To our knowledge, there have been no qualitative studies conducted to understand the EOL decision-making experience among family caregivers of terminally ill patients in an Asian context like Singapore's.

### EOL decision-making in Asia

Two recent studies in Asia describe the EOL decision-making practices in Singapore and Korea. When care preferences were not in initial agreement, about half of the patients were able to convince family caregivers to go along with their choices.[6] Here, EOL decisions were made bilaterally in consultation with both patients and family caregivers.

Among 990 patient-caregiver dyads in Korea,[7] it was found that most patients (82.9%) and caregivers (89.6%) preferred bilateral decision-making. While there was low agreement about who was leading the decision-making, both parties nevertheless preferred bilateral decision-making within the family unit, particularly where it was characterised by collaboration and communication among family members. In Singapore, activities of daily living such as bathing or feeding are commonly outsourced to community services or a foreign domestic worker to reduce caregiver burden. Nevertheless, decision-making is a distinct care burden that remains vested within the family caregiver's responsibility because it requires authorisation and personal knowledge, a responsibility that is not easily transferable.[8] However, to our knowledge, the literature has not previously addressed how to support such families in reaching a consensus, or what factors affect their satisfaction or dissatisfaction with the decisions they have made.

In Singapore, the Mental Capacity Act requires that healthcare providers make the final care decision when patients lack capacity.[9] However, providers are still encouraged to engage caregivers to elicit the patient's preferences. Since 2011, the Agency for Integrated Care, set-up by Singapore's Ministry of Health, has been promoting advance care planning to Singaporeans. The agency advocates early conversations and shared decision-making between individuals, caregivers and healthcare providers on one's care preferences in the event one becomes seriously ill and unable to speak for oneself. However, the programme has not gained sufficient traction in the country owing to low public awareness and difficulties experienced by healthcare workers in documenting the care plans among competing clinical priorities.[10] Even when presented with the space for these conversations in the care setting, challenges remain because doctors are unevenly skilled in conducting these conversations,[11] patients may change their mind regarding their preference,[12] simply defer to medical authority or their adult children and the previously mentioned Asian context that could enhance the pressure on family caregivers to choose life-extension by default.

The EOL decision-making process may have implications on caregivers' well-being, long after their loved ones have passed. A prospective multicentre study in the USA showed that unresolved decisional burden can lead to 'moderate or high levels of decisional conflict, which is associated with 'decision delay', 'feeling uncertain' and lower quality of life.[13] Studies like this have resulted in more attention on reducing decisional burden among caregivers through the development of decisional aids and care planning tools in the USA.[14] We understand that similar caregiver-focused interventions have yet to be developed in Singapore.

Developing these interventions for Singapore may be important, as they have been shown to result in less aggressive care at the EOL, better patient quality of life and caregiver bereavement adjustment. In addition, having an earlier discussion offered more timely referrals for EOL care, such as hospice placement.[14]

### Study objectives

The preceding literature suggests that in Singapore, the predominant model of EOL decision-making may be bilateral between patient and proxy decision-makers. For those who take on EOL decision-making duties, there may be significant burden but little is known about how these burdens are managed in Singapore, or what may be appropriate interventions for these Asian caregivers. While there is growing recognition of the diversity in EOL caregiving roles, few studies have provided an Asian viewpoint on the decision-making function of family caregivers, how they come to undertake this decision-making role, their decision-making journey and the ways in which they facilitate discussion with the patient, family members and the healthcare team to arrive at a satisfactory conclusion.

With the research focus in Singapore shifting towards supporting caregivers to feel better prepared for care decisions,[15] more needs to be understood about the unique relational dynamics of local family units and their norms and practices surrounding EOL decision-making. Hence, this study examines how family caregivers make EOL care decisions, by focusing on relevant moments in their caregiving journey such as information communication and preference elicitation from patients.

## METHODS

### Participants and recruitment

Participants were recruited via convenience sampling. The inclusion criteria were as follows: (1) English-literate; (2) no cognitive impairment; (3) was significantly involved as a family caregiver of someone who was seriously ill; (4) has been involved in EOL decision-making (eg, whether or not to resuscitate in the event of heart-stopping) OR had a patient pass way in Singapore, (5) the patient was 40 years old and above at the point of caregiving, AND (6) if participants were recently bereaved (patient passed away less than 3 months ago at point of recruitment), they must bring a 'trusted other' for the interview (this was encouraged but optional for other participants who were not recently bereaved). 'Trusted others' refer to individuals who would join the target research participants in the research study interview as emotional support. As the 'trusted other' could not be excluded from the audio recording if they contributed any verbal content, their consent as research participants was also taken for the research. Individuals who did not agree to audio recording were excluded from the study. The participant criteria were selected for patients who were 40 years old and above as it is the age at which chronic illness screening begins in Singapore, coinciding with the early onset of adult chronic disease. Hence, the sample should include caregivers caring for loved ones who are middle-aged or older. This is also congruent with the literature review that largely discusses the care of older persons.

Participants were recruited via (a) a recruitment channel hosted on the Telegram application; (b) a recruitment platform hosted on our university's online learning website; (c) personal contacts; and (d) invitations from participants recruited via (a), (b) or (c). In total, 23 individuals had registered their interest to participate (online supplemental appendix A). Of these, five did not meet the eligibility criteria, did not respond or later withdrew before consent-taking for the interview took place. 18 participants consented to be interviewed but only 16 participants were eventually interviewed. However, one participant's audio recording was too noisy for transcription and could not be analysed. Of the 15 remaining participants, 14 were caregivers and 1 was a 'trusted other'.

The demographic characteristics of the 14 caregivers who were interviewed and whose audio recordings were later transcribed for analysis are detailed in online supplemental appendix B. Of the 14 caregivers, 12 were adult children caring for their parents or grandparents, while 2 were spousal caregivers. Of the 14 caregivers, 11 were women and 3 men. All caregivers were Chinese, except for one who was Indian. The age range of caregivers was 20–29 years (29%), 40–49 years (29%), 50–59 years (21%) and 60–69 years (21%).

### Data collection

Semi-structured interviews were conducted with 14 participants in English, over 'Zoom', a teleconferencing application. An interview guide (online supplemental appendix C) was used for the interviews, which lasted approximately 60–90 min each. Participants were asked to share the barriers and enablers they had experienced as caregivers preparing for EOL decision-making for their loved ones. While there was concern the presence of trusted others might restrict how open the interviewees might be, ultimately only one participant brought a trusted other, who did not speak much. The bulk of the evidence comes from one to one interviews. Only the audio recording from each interview was retained for transcription and analysis. In accordance with Saunder's definition of data saturation,[16] data collection ceased when no new themes or subthemes were generated from additional interviews.

### Ethics

As part of consent-taking, participants were given a Qualtrics website link which contained the participant information sheet (online supplemental appendix D). All personally identifiable data was anonymised, and each participant was assigned a code (eg, P1). Mobile banking details (preferred mobile baking platform and mobile number) that were collected for the purpose of reimbursement (~US$7) were deleted after payments were effected.

### Patient and public involvement

It was not appropriate to involve patients in the study design, conduct, report or disseminate plans of our study, as the study's focus was on caregivers' experiences. Further, most of the patients had passed on at the time of the interview.

### Data analysis

De-identified audio recordings were machine transcribed by Otter.ai, then checked for accuracy. Participants were categorised based on[1] the care roles they reported involvement in: (1) emotional support (n=11), (2) financial support (n=7), (3) physical care (n=8) and (4) decision-making (n=13), as defined by the caregiver,[2] whether they described themselves in the interview as lead facilitators (n=8) or non-lead facilitators (n=6) in the decision-making process and[3] the illness trajectory of their patient.[17] A six-phase reflexive thematic analysis approach was applied to the transcripts, including (1) familiarisation; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes and (6) producing the report.[18] Given that the literature on caregiver EOL decision-making is not well-established, a largely inductive approach was taken in the coding process, with no specific conceptual framework or intent to theory-test in mind. The coding was done manually by MLO and relevant quotes were later transferred to a Microsoft Excel document. The first author coded five number of interviews first. The research team then met to discuss and refine the codes. The resulting codebook was applied to the remaining interviews in uncovering the central themes. Code suitability was assessed and amendments were made to the codebook when needed. The epistemological lens for this study runs closest to phenomenology, in its attempt to explore the unique experiences of caregivers.

## RESULTS

During the interviews, caregivers were asked to reflect on moments when they felt satisfied or unsatisfied about EOL decisions made and why.

Table 1 summarises the three themes uncovered.

### Theme 1: understanding and accepting patient's condition and options

Many caregivers expressed that the opportunity to embark on EOL discussions with family members and doctors was essential to arrive at a satisfactory decision. This observation was underscored by the experiences of several caregivers who faced limitations in visiting their

**Table 1** Three themes regarding communication, family support and facilitation in the family

| Theme | Elements | Enablers that led to certainty | Barriers that led to uncertainty |
|---|---|---|---|
| **Theme 1:** understanding and accepting patient's condition and options | Communication with healthcare team | A responsive healthcare team that one can talk through options with. | No time/space to explore care options with healthcare staff. |
| | Prognostication of patient's condition | Realistic prognostication (especially due to past experience/stories/occupation as healthcare worker). | Hope for miracle/lack of acceptance of impending death. |
| **Theme 2:** achieving family consensus alongside ongoing reflection of patient and/or family's wishes | Reflection on values and preferences | Ongoing reflection and discussion on care wishes. | Lack of understanding and reflection of disease trajectory, care options and outcomes etc. |
| | Family support/trust | A close-knit family to explore care options with. | Uninvolved family members who left most decision-making to primary caregiver. |
| **Theme 3:** families often have a lead facilitator whose role is to increase communication and collaborative decision-making | Presence of a lead facilitator in the family | The facilitator is present and capable of coordinating communication and decision-making. | The facilitator is proceeding with insufficient consultation and collaboration. |

family members due to COVID-19 restrictions in healthcare institutions just prior to the time of this study. This group of caregivers reported feeling that their loved ones were being de-prioritised by the healthcare team and had limited access to talk through care options with the doctor. Thus, an enabler of EOL decision-making would be communication access to the healthcare team, while limited or no access to the healthcare team constituted a barrier to EOL decision-making.

The family's shared decision-making processes were aided by recommendations from the attending doctor or medical team, which helped to inform the eventual EOL decision. This was experienced by P6:

> P6: …either to keep her on ventilator but the doctor said unlikely she will wake up ever again… The other option, which the doctor recommends. is more practical to let her go peacefully.
>
> (P6_Male_20–29 years old_Chinese)

Having a clear prognosis from the medical team aided the consensus-building in EOL decision-making among the family members. For example, at each hospitalisation, the doctor for P3's mother conveyed his mother's diagnosis clearly and made recommendations, with the final decision being made by P3 after consultation with his mother and family members.

Conversely, not being told of the prognosis by the doctor was disempowering for the caregiver as this absence of communication meant an inefficient information conveyance. Further, the lack of a clear prognosis, delayed prognosis or unexpected prognosis impeded consensus-building in EOL decision-making among family members. Caregivers who were affected by this expressed their wish to have sufficient time and thinking space to make consensual decisions for their patients, and experienced regret and guilt when they could not. According to P4, she was not allowed to talk to her patient's attending doctor over the phone but was allowed to speak with a nurse. This information asymmetry led P4 to bring her patient to a private doctor for a second opinion.

> P4: Yeah, the first time the first time like when this (referring to COVID-19 pandemic) escalated right, I couldn't go up (to the ward) at all. They (the healthcare team) didn't think it was very critical. So I did not have the chance to go and talk to the doctor and everything …
>
> …I felt that maybe if I if I was able to go and talk to the doctor, it might have been slightly better like we could have changed to another drug quicker.
>
> (P4_Female_20–29 years old _Chinese)

Aside from clinical expertise, another source of prognostication was referencing past EOL experiences. Whether with people they had cared for directly, or observations of others who have passed, these experiences were used as reference points in the current EOL decision-making process. Caregivers who were healthcare workers had a particular advantage in this aspect of previous experience. They possessed prior knowledge and/or experiences relating to EOL treatment options and had higher acceptance of the patient's terminal prognosis. Such is the case of this caregiver who worked as a healthcare worker in the operating theatre:

> P1: So we all agree, but before that because I'm a healthcare worker, so the family members turn to me. "How, how, what do you think?". So I said just listen to what the doctor says, it's logical. Just let her feel comfortable. So then

> all agreed, so no dispute no dispute. So really thank God so then so towards the end then they give a morphine to relieve pain and let her drift off no CPR so that's how she passed on. Because layman still think that there is hope. But because we have seen it in operating theatre. And the surgeon agree with those cases of operation it's because the family members think that there is still hope so they let them have that hope whereas I've seen it, seen enough of it, I know what is it. In the end, its just extending. That life also will not be … quality life… the extension of that you know, … so no point.
>
> (P1_Female_60–69_Chinese)

In contrast, the absence of past experiences meant caregivers may find it hard to accept a terminal prognosis. For instance, there were two caregivers who were especially pained by EOL decisions to not prolong life as they had hoped for a miracle, had no reference point from patients on their EOL decisions nor had they ever reflected on EOL options as caregivers. Further, these caregivers witnessed their loved ones undergo a sudden death, where the latter were still relatively well prior, but deteriorated suddenly and passed away within a week or so of being hospitalised. The interview excerpt below details the pain experienced by one caregiver:

> P2: To be very frank, I've ever heard about death but I've never thought my own parents, my family, there'd be death. But I've never once ever thought that my own parents one day will leave us or anybody in my family would have left us. I've never thought of that. To me it's always we are together. So when my mother left us, it was a big blow for me. It was a big blow for me.
>
> Interviewer: So you're the last person right that she saw. So when the decision-making was happening to not proceed for surgery, do you feel uncertain?
>
> P2: Yeah I was.
>
> Interviewer: Okay. What was your uncertainty at the time?
>
> P2: To me, it's like, I had this feeling she will survive, you see? But my family didn't want her to go through the pain that's all. So until now I still carry the guilt that if only I could have been firm about it, maybe she could be alive until today.
>
> (P2_Female_50–59 years old_Chinese)

### Theme 2: achieving family consensus alongside ongoing reflection of patient and/or family's wishes

Caregivers seemed to experience particular satisfaction with the decisions they made when there is a sense of consensus or harmony among family members. Among our participants, there was an overwhelming inclination for multilateral, shared decision-making in EOL treatment and care options within the family unit. Such shared decision-making was instrumental towards consensus-building for the EOL treatment and care decisions made by the caregivers in consultation with or on behalf of their patients.

Among our study participants, there was no case of a unilateral decision made by a single family member. Having a tight-knit, larger immediate and/or extended family base encouraged shared decision-making that led to mutually agreeable EOL decisions for patients.

For example, during family discussions details such as financial considerations and the degree of caregiving burden associated with the care option were tabled. This open discussion was instrumental to helping P3 and P5 reach EOL decisions for their patient that they were personally comfortable with and also mutually agreeable within the family unit. This point can be aptly summed up with P1's description: '…there was no dispute, no regret…we are all on the same page'.

Caregivers also took reference from their mutual experience of past family events in forming and norming the values and preferences of patients and family members. The quotes from P5 and P10 illustrate how witnessing the prolonged terminal condition of an elderly loved one had led to the evolution of values and preferences. In the case of P10, this came to bear when her own father turned ill, and expressed a desire not to prolong life. This wish was aligned with the family's, and ultimately came to pass.

> P5: I can tell like from my mom's side, it's more like, like the ethos is okay, let's keep the person like alive for as long as possible. You know, just like her whole family also decided as a as a unit to keep my grandfather alive for like the past to keep resuscitating and like, you know, treating him for the past like four years of his life. Maybe a month or two ago, we were talking about my late grandfather, who was vegetative for maybe the last like, four years of his life. He had a hospital bed in his house, then they had 2 maids taking care of him. Oh, okay. So, then my dad kind of expressed, like, like, he just kind of said that. It's quite a sad state to be like that for your last four years. Especially when you're just like waiting to die. It just it feels quite… yeah, it's quite like, difficult. You know, seeing someone you love like that.
>
> (P5_Female_20–29 years old _Chinese)
>
> P10: Decision like NG (*nasogastric*) tube and where he wants to pass on right? My mum didn't bring this out. But really, because we have seen our grandfather bedridden and on NG tube. So it's very clear. My dad was when he was diagnosed at stage two cancer, he already say very clear. He doesn't want any tube inside his nose.
>
> (P10_Female_40–49 years old _Chinese)

Overall, the analysis of the data indicates that having ongoing reflection and discussion of the values and preferences within a tight-knit family unit positively affected the eventual EOL decision-making process for the terminally ill patient.

### Theme 3: families often have a lead facilitator whose role is to increase communication and collaborative decision-making

This theme arose when caregivers described a distinctive function in the decision-making process, where an

**Table 2** Reported characteristics of the lead facilitator role

| Category | Reported characteristics | Illustrative example |
|---|---|---|
| Seniority | Oldest | We just give that due respect to her that she is the eldest. The hierarchy la. She was the one corresponding with the medical team. Yes, Yea she will gather all our opinion.<br>P1_F_60–69_Chinese |
| Availability | Being single with no other family commitments | Yeah, but my brothers had family I was single. So is this is your typical story? single girl staying with mummy? So in a way caregiving fell on me, but I was very lucky because my brothers are very, very supportive. And they help out as much as they could.<br>P12_F_40–49_Chinese |
| Closeness to patient | This person is trusted most by patient, has best understanding of him/her, that is, ‘favourite person’. | I will say he trust me most.<br>Yeah, I will say because most the time I’m at home.<br>P9_F_40–49_Chinese<br>. |
| Gender | Male | Interviewer: even as the youngest the family, is there a reason why generally the decision will go to you?<br>P6: I think its because I’m a guy. Yeah, its better to bear this responsibility.<br>P6_M_20–29_Chinese |
| Personality | Assertive, organised, logical | I’m more direct person. So I asked question direct. And, you know, I’m not the so called guess. I will just ask, do you want this or don’t want that? And see, this is what we need to do. We sit down and discuss and we proceed. And if we need to have a roster, let’s sit down and work out who come which day, you know, breakfast, lunch or dinner.<br>P11_F_60–69_Chinese |
| Persuasiveness | ‘The one patient listens to’ | It’s always my sister, she’s a stronger person than I am. Okay, so even now also, she’s the one who my father shower all that he won’t listen to us. My sister ask him to shower, he will listen.<br>P2_F_50–59_Chinese |
| Language | English-speaking/educated | Yeah, because my parents are not educated. So then, he makes sure that all of us are educated, go to education. So because I believe it’s because of that. So he he had that trust in us that as compared with them doesn’t have that knowledge or info to make decisions.<br>P1_F_60–69_Chinese |

individual in the family consistently facilitates discussion between the patient and the wider caregiving structure. This individual was responsible for coordinating information sharing and decision-making within the family unit to arrive at a satisfactory EOL decision for their loved one. Table 2 details the characteristics that suggest why a particular caregiver leads. We chose the term ‘lead facilitator’, as opposed to ‘main decision maker’, because the person operates with the context of multilateral decision-making.

Table 3 summarises the types of activities that were expected of the person taking on this role.

Typically, the spouse would be the default person who took on this role (such as P13, whose spouse eventually passed on due to breast cancer), especially if their children were still young. However, when the children were adults, or in the absence of a spouse (ie, the patient is single, widowed or divorced) the adult children or sibling tended to step in to facilitate the discussion.

The interviewees gave various reasons for a person to take on the role of the lead facilitator (table 2). For example, some came to assume the role due to traditional reasons such as seniority or gender.

On the other hand, lead facilitators perceived that they were thrust into this role because they were trusted by the patient who felt that the former understood them best or were meticulous in handling matters. Such qualities allowed these caregivers to navigate conversations between patient, family members and the healthcare team. This point is exemplified by the two quotes below:

P3: I wanted to avoid such thing (referring to family disputes). That’s why I get involved. I inform my brothers. Nowadays with WhatsApp, you know nephew, nieces, everybody in the group chat. So inform everybody just

**Table 3** Reported duties of the lead facilitator

| Category | Description | Illustrative example |
|---|---|---|
| Patient-related | ► Translate and synthesise information to patient.<br>► Persuade/ convince patient of what they think is best.<br>► Elicit/ guess patient's preferences.<br>► Reconfirm patient's past decisions.<br>► Apply patient's values to treatment decisions. | So when the heart attack happened, the doctor wanted to discuss privately with me but I told him it's okay. You can talk in front of my mum. My mom is very strong. Because I want her to know. So I was a primary caregiver. Although my mum don't speak English, but she can understand when people talk to her. So she was a little conscious and she can know so of course I interpreted in my language my mother tongue was Hindi.<br>P3_M_50–59_Indian |
| Family-related | ► Comfort or prepare other kin.<br>► Discuss care options with other family members, especially the primary caregiver (if not self) who is most involved in physical care.<br>► Circulate information to wider family unit. | So one of the factors is also my dad's partner so we keep counselling her, you have to come to terms, very unlikely he'll go home ah so if he go home you know this is going to happen you're going to do this this this. So we try to paint the picture to her. And I guess giving her closure also giving ourselves opportunity for the closure, right and the usual lo, whoever wants to come see him make sure they come.<br>P12_F_40–49_Chinese |
| Other | ► Anticipate care decisions.<br>► Conduct research.<br>► Weigh up options.<br>► Decide what is 'best'.<br>► Liaise with the healthcare team. | Yes, we are lucky, there's no financial issue. There's no medical disagreement. And, you know, it's like, my dad asked me to do it. and whatever I say after I research, I will tell them what I have researched. And this is the decision. And there's no question that we proceed accordingly.<br>P11_F_60–69_Chinese |

put the message there so whoever have anything to say will say, but normally my brothers are the first ones to say.

> P3: …it is not that I am guided by her (referring to patient) vision…I roughly know she don't want to suffer. I will listen to the professionals…So I will just make it more clear to her as simple as possible for her to understand. And then I'll tell her this is what we're going to do. Are you okay with it? Like getting her to agree with what the professional is saying.
>
> (P3_Male_50–59 years old _Indian)

Lead facilitators often put in effort to elicit, reconfirm and interpret patient's EOL values and preferences. An excerpt from P11's interview below demonstrates this point:

> P11: My mum is one person that she always said, when it's time to go, go. No need to prolong. And she also told us she would want to be sea burial…This was even prior to being sick. She had expressed this when she was sick with a red and green card… without fail, she goes to the green card because I say mum you told me you want to scatter your ash in the sea after cremation. Is that still there? She pointed to the green card.
>
> (P11_Female_60–69 years old _Chinese)

Some data also suggested the lead facilitator sometimes needed to 'take over' and do what they thought was 'best' or to fill a gap in the decision-making in cases where they judged the patient to be lacking in capacity or disinterested (eg, P3 and P8). However, this was not the norm and most of the data implies that caregivers preferred to build consensus even as they led the decision-making.

> P3: Not just to avoid that (referring to keeping all family members informed to avoid family disputes), but I always feel I don't know. I'm still I think maybe I'm still Asian la, even though I study more, but I think for me as an Asian Asian value still is there because it must be done as a family because the parents are only one you see.
>
> (P3_Male_50–59 years old _Indian)

## DISCUSSION

Overall, the findings agree with previous literature that favours bilateral or multilateral decision-making as the dominant EOL decision-making model in Asian caregivers. As with previous literature[5 17] we observed a distribution of roles, such as a spouse overseeing physical care while an adult child facilitates medical decision-making (eg, P10, P11, P12) with the extended family and the healthcare team. Furthermore, even if a lead facilitator is present, they were not expected to make independent decisions without familial support.

In more positive EOL decision-making experiences, there was a family member who stepped up to facilitate the collaborative decision-making effort, whom we have labelled the ‘lead facilitator’ in our study. With this role, they take on the responsibility of being a go-between who facilitates discussion with the patient, family members and the healthcare team to arrive at a consensus on EOL treatment and/or care options.

However, it may be that not every family has such a person, or if there is, they may not be fully skilled to take on this role. In this study, we could not assess if the lead facilitators were accurate in their assessment of what the patient would want. Other studies suggest that caregivers may have conflicting preferences where patients may wish to hide information from caregivers[19] or caregivers have other competing care concerns such as household maintenance or sustainability of care.[20] Hence, if an intervention is to support caregivers who take on facilitation duties, it should help them elicit the values of the patient and subsequently prioritise the values of the patient when making EOL decisions in the moment.

The presence of the lead facilitator role in our study presents a critique of the terms ‘proxy decision-maker’ or ‘surrogate decision-maker’ that is commonly used in literature on advance care planning. These terms imply that there is just one other party involved, which is not reflective of a context where multilateral decision-making in the family is preferred. Future work, particularly in the area of item and survey development, should remain critical of the terminology used and consider if the language is reflective of collaboration.

Based on these findings, we conclude that caregivers’ experience of EOL decision-making is degraded when there is (1) the lack of previous experience or domain knowledge about the experience of EOL care in caregivers (especially for caregivers without previous EOL decision-making experience), (2) the lack of clarity in communication in EOL prognosis, treatment and care options and (3) the lack of reflection and communication within the family towards consensus building.

Consequently, the findings suggest that interventions for family caregivers who participate in making EOL decisions could focus on three key facilitation tasks to improve their experience of family-based decision-making. These are to (1) hear: caregivers should be supported in eliciting patients values where possible, and in centring them in their process of EOL decision-making (2) share: caregivers should be supported in sharing these values and subsequent patent choices with other caregivers and providers (3) apply: caregivers need adequate domain knowledge of the implications of various care choices so that they can appropriately apply the values in making EOL decisions.

## STRENGTHS AND LIMITATIONS

To the best knowledge of the authors, this paper is the first study of how caregivers in Singapore come to assume decision-making roles at their loved ones’ EOL, the factors that led to the materialisation of this role and the functions these caregivers play in facilitating discussion between patient, family members and the healthcare team. The pool of participants was of different ages, had varying lengths of caregiving duration and cared for patients who underwent different types of EOL trajectories. A major limitation in our study is that the profile of the target sample cannot be generalised to the Singaporean population because of the convenience sampling recruitment method used. Although there was a good balance of male and female participants at the point of recruitment, several male participants were lost to follow-up (ie, they did not respond afterwards or did not turn up for the interview). In addition, all but one caregiver was a non-Chinese. Hence, most perspectives from this study comes from female Chinese caregivers. Future studies would benefit from a more purposive inclusion of ethnic and gender groups.

This study may have suffered from selection and social desirability bias, given that caregivers with more positive experiences may be more forthcoming to be interviewed, or may paint their experiences more positively to the interviewer, rather than discuss regretful, painful or embarrassing moments of family dispute. Further, given that the data came exclusively from caregivers, the study was not able to triangulate the data from patients or other stakeholders (eg, healthcare workers) to assess if caregivers were accurate in their assessment of patients’ preferences.

## CONCLUSION

The results offer new insights into the lead facilitator role played by caregivers in EOL decision-making, and the enablers and barriers experienced in the decision-making journey. While several previous studies recognised the diversity in EOL caregiving roles, few have examined how families make decisions. Based on the findings, we recommend a ‘hear, share and apply’ approach for interventions for family caregivers to reduce decisional burden through a combination of learning and training to improve communication with providers and among family members.

**Contributors** MLO is the main author, interviewer and guarantor. As the lead researcher, she had a personal interest in End-of-Life work, and previously worked as an Advance Care Planning programme coordinator at a public hospital, though she had moved onto another role at the time of the study. She held a BA(Hons) in Public Policy and Global Health, and initiated this study as part of fulfilling the requirements of her Masters in Public Health. PSF, SMT and XX contributed to the analysis of the data, writing and paper conceptualisation. GCHK contributed to the writing and paper conceptualisation.

**Funding** This work was supported by the Singapore Ministry of Heath’s National Medical Research Council Grants, grant number NMRC/CG1/009/2022-NUH and CareEco21-0030, and Saw Swee Hock School of Public Health’s practicum funding.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by NUS-IRB-2021-773 Preparing for the End-of-Life (EoL): Perspectives from Caregivers in Singapore. Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data sharing not applicable as no data sets generated and/or analysed for this study.

**ORCID iDs**
Pin Sym Foong http://orcid.org/0000-0002-4437-8326
See Mieng Tan http://orcid.org/0000-0003-2750-6995

## REFERENCES

1. Lo JJ, Yoon S, Neo SHS, *et al*. Factors influencing potentially futile treatments at the end of life in a multiethnic Asian cardiology setting: a qualitative study. *Am J Hosp Palliat Care* 2022;39:1005–13.
2. Lee G. Navigating complex end-of-life decisions in a family-centric society. *Nurs Ethics* 2020;27:1003–11.
3. Chong JA, Quah YL, Yang GM, *et al*. Patient and family involvement in decision making for management of cancer patients at a centre in Singapore. *BMJ Support Palliat Care* 2015;5:420–6.
4. Cheng S-Y, Lin C-P, Chan HY-L, *et al*. Advance care planning in Asian culture. *Jpn J Clin Oncol* 2020;50:976–89.
5. Lim WS, Cheah WK, Ali N, *et al*. Worry about performance: a unique dimension of caregiver burden. *Int Psychogeriatr* 2014;26:677–86.
6. Ozdemir S, Jafar TH, Choong LHL, *et al*. Family dynamics in a multi-ethnic Asian society: comparison of elderly CKD patients and their family caregivers experience with medical decision making for managing end stage kidney disease. *BMC Nephrol* 2019;20:73.
7. Shin DW, Cho J, Roter DL, *et al*. Preferences for and experiences of family involvement in cancer treatment decision-making: patient-caregiver dyads study. *Psychooncology* 2013;22:2624–31.
8. Østbye T, Malhotra R, Malhotra C, *et al*. Does support from foreign domestic workers decrease the negative impact of informal Caregiving? Results from Singapore survey on informal caregiving. *J Gerontol B Psychol Sci Soc Sci* 2013;68:609–21.
9. The Statutes of the Republic of Singapore. Mental capacity act. Sect. 2. 2008. Available: https://sso.agc.gov.sg/Act/MCA2008?ProvIds=P12-#pr5
10. Malhotra C, Chaudhry I. Barriers to advance care planning among patients with advanced serious illnesses: a national survey of health-care professionals in Singapore. *Palliat Support Care* 2023;1–8.
11. Malhotra C, Chan N, Zhou J, *et al*. Variation in physician recommendations, knowledge and perceived roles regarding provision of end-of-life care. *BMC Palliat Care* 2015;14:52.
12. Gupta I, Finkelstein E, Ozdemir S, *et al*. Changes in prognostic beliefs of patients with metastatic cancer and their association with changing health status. *BMJ Support Palliative Care* 2023;A34–A35.
13. Chiarchiaro J, Buddadhumaruk P, Arnold RM, *et al*. Prior advance care planning is associated with less decisional conflict among Surrogates for critically ill patients. *Ann Am Thorac Soc* 2015;12:1528–33.
14. Wright AA, Zhang B, Ray A, *et al*. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300:1665–73.
15. Malhotra C, Huynh VA, Shafiq M, *et al*. Advance care planning and caregiver outcomes: intervention efficacy – systematic review. *BMJ Support Palliat Care* 2023;13:e537–46.
16. Saunders B, Sim J, Kingstone T, *et al*. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 2018;52:1893–907.
17. Lunney JR. Patterns of functional decline at the end of life. *JAMA* 2003;289:2387.
18. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health 2019;11:589–97.
19. Ancker JS, Witteman HO, Hafeez B, *et al*. ‘You get reminded you’re a sick person’: personal data tracking and patients with multiple chronic conditions. *J Med Internet Res* 2015;17:e202.
20. Foong PS, Lim CA, Wong J, *et al*. You cannot offer such a suggestion”: designing for family Caregiver input in home care systems. Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (CHI ’20); NewYork, NY, USA, 2020:13.