



Navigating end-of-life decision making: a thematic analysis of Uchinanchu American older adult's information behaviour

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Abstract

Introduction. End-of-life (EOL) involves complex decision-making, influenced by how individuals seek, share, and process information. This study examines the EOL decision-making information behavior of older Uchinanchu (Okinawan) Americans, an underrepresented ethnic minority.

Method. Qualitative, in-depth, semi-structured interviews were conducted with 18 Uchinanchu older adult participants to explore their information behavior in EOL decision-making.

Analysis. Reflexive thematic analysis, three key themes: (1) Prioritizing Family Well-being at EOL, where participants sought and shared information focused on minimizing burdens for adult children; (2) Keeping Cultural EOL Decision-making Customs, reflecting information exchange centred on filial responsibility; and (3) Navigating Fate when Making and Communication EOL Decisions, shaped by the concept of 'Shoganai' (acceptance of fate).

Results. Participants information behavior revealed a nuanced balance between actively seeking information for decision-making and deferring to cultural norms or family guidance. The interplay between cultural values and EOL decisions influenced how information was gathered, shared, and applied within families.

Conclusion. These findings show that EOL information behavior is deeply shaped by cultural values and family dynamics, particularly in balancing individual preferences with collective responsibilities. Future research should examine how underrepresented populations engage in health-related information practices related to promote inclusivity in end-of-life healthcare practices and policies.

Introduction

Decision-making at end-of-life (EOL) involves complex, nuanced information processing and often includes multiple stakeholders. Older adults may need to gather and consider various information when considering sensitive decisions such as surrogate decision-makers, desired medical interventions, and the appropriate timing for these choices. However, many adults lack both formal advance care planning (ACP) documents and informal plans (Biondo et al., 2017; Dennis & Washington, 2018; Sharma et al., 2012). Older adults (aged 65 and older), in particular, are often hesitant to communicate EOL decisions with family or medical professionals (Lum et al., 2015). Similarly, caretakers and healthcare providers may feel uncomfortable discussing EOL plans with patients, leaving room for deferred decision-making (Scholz et al., 2020). This poses challenges in the U.S. healthcare system, where patient autonomy and proactive decision making are increasingly emphasized (Gao et al., 2015; Lau, 2023).

While medical EOL decision making often emphasises clinical guidelines and individual autonomy, cultural EOL decision-making incorporates broader social and familial values, which can either complement or contrast with Western medical recommendations. Cultural influences play a significant role in how individuals' approach and communicate their EOL choices. Different cultures have varying beliefs and practices surrounding death and dying, which can shape preferences for medical interventions, surrogate decision-makers, and communication about EOL wishes. For example, some cultures emphasize collective decision-making and family involvement, while others may prioritize individual autonomy or religious considerations. These cultural factors can influence whether individuals are more inclined to discuss their EOL preferences openly or defer such discussions to family members. Understanding these cultural nuances is crucial for tailoring EOL care to meet the needs of diverse populations.

Cultural perspectives of EOL decision making

Careful examination of EOL decision-making from a cultural perspective is increasingly important as the U.S. population ages and becomes more diverse (Gott et al., 2017). The Asian American population, one of the fastest-growing racial and ethnic groups in the country (Budiman, 2020), presents a range of unique characteristics, including diverse ethnic backgrounds, histories, and cultural approaches to health information seeking (Islam et al., 2016; Jang et al., 2018). Despite this diversity, there is limited understanding of the EOL decision-making preferences and behaviors of Asian American older adults, and even less is known about specific ethnic groups within this broader category.

Outside of EOL decision making, a recent few information behavior studies have extended information behavior theories to include marginalized communities, such as Chinese ethnic minority groups (Zhu & Liao, 2020) and speakers of indigenous languages (Burke, 2020). Zhu and Liao (2020) applied information theories to explore the information behavior of small ethnic minority populations in China. They found that information behavior was deeply rooted in cultural contexts, with participants primarily seeking information within their small world and only consulting external sources for urgent matters. However, there is little research focused on EOL decision making of Asian ethnic minorities, let alone from an information science approach (Shiroma et al., 2019).

Uchinanchu American older adults and their culture

Uchinanchu Americans are an ethnic minority group that are often aggregated under broader racial categories such as 'Asian', 'Asian/Pacific islander', 'Japanese', and 'other'. Uchinanchu and Uchinanchu Americans are descendants of the indigenous people of Uchina, more commonly known as Okinawa. The U.S Census American Community Survey (2022) estimates that between 2016 and 2020 the Okinawan American population was 3,526 people.

In Uchinanchu culture, EOL decision-making is deeply intertwined with both cultural traditions and medical considerations. Central to this is the Obon ritual, a three-day event that honors and celebrates ancestors, emphasizing the importance of family, community, and intergenerational connections. During Obon, the living engage in rituals such as preparing family altars, making food offerings, and lighting pathways to guide ancestral spirits back home, blending spiritual reverence with cultural practices. This ongoing relationship with the deceased, symbolized by the Eisa dance, reflects how Uchinanchu people view death not as an end but as a continuation of familial bonds (Johnson & Jaffe, 2008; Nelson, 2008). In this context, EOL decisions are not solely based on medical factors but are also shaped by cultural values—balancing respect for life with a deep sense of ancestral duty. Thus, medical decisions, while important, often coexist with cultural frameworks that guide how Uchinanchu individuals and families approach death and dying.

Beyond longevity studies (Buettner & Skemp, 2016), very little research focuses on Uchinanchu peoples' information preferences within the context of healthcare, decision making, and information science. This research gap, which promotes appropriation and commodification of a minoritized and/or indigenous culture's knowledge and behavior is problematic (Smith, 2012) and venerates an agenda of research being done to and on not with or for indigenous peoples (Smith, 2012).

To address this gap, this study aims to better understand the EOL decision-making information preferences and behaviours of Uchinanchu older adults by exploring three key research questions: (RQ1) What information do Uchinanchu older adults want to have when making EOL decisions? (RQ2) From what sources do Uchinanchu older adults draw on for the medical and/or cultural information they want when making EOL decisions? and (RQ3) What factors influence Uchinanchu older adults' information-seeking behavior in EOL decision-making? By focusing on Uchinanchu American perspectives, this study seeks to enhance understanding of diverse approaches to information behavior in EOL decision-making, contributing to more culturally sensitive healthcare practices and policies.

Method

Qualitative research methods are ideal for inductively examining information behaviours in EOL decision-making by allowing for participant's own words and experiences to drive the research and thus providing opportunities for ethically responsive and responsible research (K. L. Braun et al., 2014; V. Braun & Clarke, 2023; Smith, 2012). Therefore, to explore participants' in-depth perspectives, communication, and information behaviours in EOL decision-making, semi-structured, in-depth qualitative interviews were conducted.

Interview guide

The interview guide was developed with input from a literature review (Shiroma et al., 2019), results from a pilot study, and in consultation with community partners and health information behavior experts.

Participants

Eligibility criteria included: (1) self-identification as Uchinanchu (Okinawan) or Uchinanchu-American (Okinawan-American); (2) 65 years of age or older; and (3) proficiency in English or Hawaiian Creole English. A total of 18 older adults (aged 65 or older) participated in the study. Of these, 11 (61%) identified as female and 7 (39%) as male, with an average age of 74 years. Recruitment was facilitated by cultural community partners, supplemented by snowball sampling.

Interviews

Interviews were conducted in summer of 2023, with options for in-person or phone interviews based on participants' preferences. Interviews lasted 28-112 minutes, averaging 60-90 minutes. No participants discontinued the interview or refused to answer any question. Participants received

a \$20 gift card for their participation. Audio recordings and transcriptions were managed using Otter.ai and QuickTime, with transcriptions manually reviewed for accuracy and then uploaded into Atlas.ti for coding.

Data analysis

Data analysis employed reflexive thematic analysis (RTA) (V. Braun & Clarke, 2022, 2023). RTA is an iterative process where the researcher's expertise and personal experience guide theme identification. The analysis involved familiarizing with the data, coding based on a framework developed from EOL decision-making literature and cultural insights and generating themes through multiple iterations. The final themes were distinctly named and organized to reflect their contribution to the broader analysis, culminating in the report presented in this manuscript.

Ethical considerations

This study was approved by the Institutional Review Board at the University of Texas at Austin (#2019-09-0001). Approval and consultation from community partners ensured trust and accuracy in interview materials and final data. Informed consent was obtained from all participants prior to the interviews and recordings.

Analysis

Uchinanchu older adults' information preferences and behaviours in EOL decision making reflect a nuanced interplay between individual and familial considerations, shaped by cultural values and practices. Three themes were identified from the data: (1) prioritizing family well-being at EOL: burden minimization; (2) keeping cultural EOL decision-making customs: filial responsibility; and (3) navigating fate in EOL decision making: the concept of Shoganai.

Theme 1: Prioritizing Family Well-Being at EOL: Burden Minimization

The first theme, '*prioritising family well-being at EOL: burden minimization*' describes how Uchinanchu American older adults' approach EOL decision making with a strong emphasis on mitigating potential challenges that their EOL decisions might impose on their families, specifically their adult children. This focus on reducing burden encompassed financial, emotional, and physical aspects of EOL caregiving, reflecting a strategic approach to EOL planning that prioritizes family welfare. This motivation influenced their information seeking behaviours and decision-making processes, as they aimed to provide clarity and ease for their family members. For example, Participant 15 articulated the desire to pre-emptively address EOL decision to simplify the process for her children:

I want my children to have..... I don't want them to have to make difficult decisions and guessing this and that what I wanted or what? They will just follow my wishes. And to make it easy for them (P15).

This proactive stance is indicative of a deliberate effort to minimize the decision-making burden on family members by providing clear instructions and EOL decision-making information in advance. Participant 15 shared that by having EOL decisions made in advance, she believed her adult children would be able to easily make EOL decisions on her behalf.

Participant 9's approach to information seeking further illustrates this theme. Her EOL information behaviour included organizing a comprehensive EOL decision-making portfolio, including documentation on property, finances, and medical preferences, to aid her adult children: '*What else do I have in that binder? So, property, finance, medical...I don't want to be a burden.*' This information behaviour reflects the complex and multifaceted nature of EOL decision-making and underscores the participants' efforts to centralize and simplify access to critical information.

Similarly, Participant 6 discussed the importance of making financial EOL decision to avoid familial conflicts: 'It's [financial plans] so that they won't fight.' The need to manage financial information in EOL decision making to prevent disputes underscores the broader objective of reducing emotional stress and friction within the family.

Participant 8's decision to include a Do Not Resuscitate (DNR) order highlights how the loss of independence can drive individuals to make EOL decisions that prioritize their autonomy and reduce the caregiving burden on others: 'I already made it. I said no resuscitation. If I can't take care of myself, aloha. And that's it'. This communication of EOL preferences illustrates a strategic approach to information behaviour, where individuals proactively manage their EOL choices, formally or informally, to minimize the emotional and logistical burden on their families and caregivers.

Prior experience with EOL decision making for others has also influenced participant's information behaviours. Participant 11, reflecting on her past experiences with her husband's EOL, expressed the importance of making EOL decision to ease the burden on her family:

I don't want whoever's left to have to struggle. I want to make it as easy as possible for them. So, because I did for my husband before my husband died, I put together all the information I would need. On the occasion of his death, had all the phone numbers of people I would have to commute communicate with the organization I would have to communicate with that made it easy, because you don't want to have to think about this when somebody dies (P11).

This quote underscores how past experiences with EOL decision-making for family members influence current information behaviour. Such prior experiences can motivate proactive information strategies in deliberate effort to streamline access to essential information, thereby mitigating emotional and logistical challenges faced by loved ones during a difficult time.

The theme of 'prioritizing family well-being at EOL: burden minimization' reveals a critical aspect of Uchinanchu American older adults' EOL decision-making information behaviour. Participants' proactive strategies in organizing and communicating their EOL preferences reflect a concerted effort to minimize the impact on their family members, emphasizing the importance of clarity and preparation in the EOL decision-making process.

Theme 2: keeping cultural EOL decision-making customs: filial responsibility

The second theme of 'keeping cultural EOL decision-making customs: filial responsibility' illustrates how cultural expectations and familiar roles shape information behaviour in EOL decision-making among Uchinanchu American older adults. This theme emphasizes that while participants might view EOL decision-making as a burden on their adult children, they themselves approach it with a strong sense of filial duty, particularly when it involves their parents.

While the eldest male adult child is often examined within the context of filial responsibility, Uchinanchu participants more frequently highlighted Uchinanchu women as central to EOL caretaking and decision making. These experiences of fulfilling filial responsibilities for their parents helped to shape participants' understanding of EOL decision-making practices and policies. Such responsibilities influenced participants' information behaviour by increasing their familiarity with medical EOL decision-making processes. For instance, Participant 11's role as a caretaker and EOL decision-maker for her parents exemplifies this dynamic:

They already had like a health directive. So, we knew we knew what to do. We didn't really have to make decisions because they had already like they had already had their funeral plan. They had their urns picked out. They had already what was to go on the urn, the inscription

on the urn, and the Rinzai Zen emblem. So, we really didn't have to make decisions. Yeah, because they took care of everything (P11).

Her experience with her parents' medical directives and funeral plans not only informed her understanding but also streamlined her own EOL decision-making process. This demonstrates how past EOL responsibilities shape the way individuals manage and navigate information related to EOL decisions.

Participant 5's positive experience with EOL decision-making was enhanced by the formalized information available through advance EOL decision-making forms, reflecting their commitment to filial responsibility. They noted, *'I helped with my mother-in-law's (EOL decision making). But it was simple, I just follow the instructions on the forms.'* This underscores how effective information management practices in EOL decision-making support the fulfillment of filial responsibilities, streamlining the process and reducing the burden on family members.

For Participant 2, the approach to his own EOL decision-making and caregiving was deeply influenced by the principle of filial responsibility, reflecting how he has internalized family obligations across generations. He described how he has adopted a family plan that mirrors his parents' approach to EOL care, explaining:

My dad, he's the oldest in family told me that it'd be my responsibility to take care of him when he gets older. And so, I accepted that. And when my brothers had his daughters, in case he passed away, we're in agreement that I would raise his kids. And when, if I were to pass away, my kids would be raised by my two sisters, with the financial backing of my brother (P2).

This structured plan exemplifies the way filial duty shapes EOL information behavior by ensuring that family members are prepared to manage and support each other's EOL needs.

Currently, Participant 2 is engaged in caregiving for both his elderly spouse's mother and his grandchildren. He sees this responsibility as a manifestation of filial duty and anticipates reciprocal support from his children in the future, stating: *'Two generations, one up and two down. But, you know, that's what family do, take care of each other. We do our best and hopefully [adult children] will take some lessons.'* This ongoing caregiving role highlights how filial responsibility influences EOL decision-making and information behavior, demonstrating how cultural expectations inform the management of both current and future EOL responsibilities within the family.

Participants' experiences with their parents' EOL decision-making influenced their own information behaviours, reflecting a deep cultural commitment and sense of family obligation. This information behaviour illustrates the role of information in how participants manage EOL decision-making to align with cultural norms, including fulfilling their filial responsibilities and adhering to established familial roles.

Theme 3: navigating fate in EOL decision making: the concept of Shoganai

The third theme, *'navigating fate in EOL decision making: the concept of Shoganai,'* examines how participants approach EOL decision-making through the lens of Shoganai, a Japanese concept reflecting acceptance of one's fate. This theme reveals how the belief in accepting the inevitability of death influences participants' information behaviours regarding EOL decisions.

Participant 7 introduced the term Shoganai, explaining its meaning as *'the Japanese have a saying: Shoganai, [it] cannot be helped.'* He elaborated on how this mindset helps individuals cope with unpredictable events and death:

and some things, they're accidents. Some people's life is so much shorter, and this is unpredictable, I'll use that word, Shoganai. That's life, things happen, and we have no control over them.

The concept of Shoganai influenced some participant's information behaviour by leading to a reluctance to engage in advance EOL planning. Participant 8 expressed a passive attitude toward death: *'I really don't think about it. Time comes, time comes.'* This mindset, which aligns with a cultural aversion to discussing death, often resulted in a lack of proactive EOL decision-making. Participant 8 further explained how having fewer responsibilities allowed them to avoid worrying about death: *'To me, life is just life. I'm not married, I don't have many responsibilities. If I die, I die. It's like live for today and don't worry about tomorrow.'* This mindset reveals how Shoganai can lead to minimal engagement with information related to EOL decisions, as it prioritizes acceptance of fate over planning.

In combination with a Shoganai mindset, the notion of having fewer responsibilities can diminish the urgency to consider EOL decisions, particularly if there is a pre-existing aversion to discussing or planning for death. Participant 6, who was adamant about not preparing for death, articulated the spontaneity of death and the perceived futility of planning for it:

Death is so spontaneous unless you're very sick. And you have a little bit more time with an individual. But when death comes quickly, you know, like you don't anticipate an accident in the car. And you die. There's no time to plan anything out (P6).

Thus, the concept of Shoganai can overshadow the perceived value of EOL decision-making, as it promotes a 'live for the day' attitude.

However, for some participants, the inevitability and unpredictability of death prompted them to consider advance EOL plans. Participant 7 noted:

Sometimes life don't happen that way. You might have a stroke. You might have dementia, or you don't know what's going on. So, somebody still have to. You have to designate somebody to make the decisions for you (P7).

Here, the Shoganai mindset helped them recognize the importance of making advance EOL decisions to manage uncontrollable health circumstances.

Maintaining a Shoganai mindset was also tied to reflections on what participants had learned from those who had already passed away. Participant 13, when reflecting on their experiences, invoked Shoganai by saying: *'Have your plans set out. I think mostly is to be grateful. And when the time comes, you know [it is] time to go move on.'* This view framed EOL information behaviour as a final act of gratitude, allowing for a transition with minimal worry, and emphasized the proactive approach in preparing for the future.

Conversely, Participant 12 discussed how dwelling on average lifespan statistics could lead to mental health challenges, particularly when not maintaining a Shoganai mindset:

You know, there are many people with psychological issues, mental issues. I mean, those that can be manipulated by saying, like I just said average lifespan is 78, I'm 60. And if they dwell on something like that, and you know, ticking bomb, oh I'm 77, I'm gonna die next year? I think some people think like that (P12).

This highlights how mental health considerations can influence the Shoganai mindset, with some participants using it to alleviate worries and justify either avoiding or embracing EOL planning as a means of managing life's uncertainties.

Results

The results of this study provide a nuanced understanding of Uchinanchu older adults' information behaviour in navigating EOL decision-making through a small-world lens, revealing the intricate interplay between familial responsibilities, cultural values, and personal attitudes. The themes of mitigation of burden, filial responsibility, and the Shoganai mindset emerge as central to understanding this dynamic. These themes reflect how information behaviour in EOL decision-making is influenced not only by immediate family needs but also by broader cultural and generational contexts.

Mitigation of burden in EOL decision making

In Uchinanchu older adults' EOL decision-making, a key information behaviour observed is the strategic effort to mitigate the burden on their adult children. Participants actively sought and utilized information to develop plans that address potential emotional, financial, and logistical challenges their families might face. This forward-looking approach highlights how their information preferences are guided by a focus on the generational impact of their decisions. This finding aligns with previous research on the burdens encountered by family members during EOL planning (Gao et al., 2015; Lau, 2023). However, this study reveals a unique emphasis on practical concerns, such as family conflicts over property and wealth, that older adults proactively address.

Mitigation of burden for adult children is a significant theme in this context, reflecting a broader strategy to ease the potential impacts of their death on their descendants. Uchinanchu older adults are motivated to minimize practical, emotional, and financial burdens by providing clear and organized instructions for their family members. By anticipating and addressing potential challenges in advance, they aim to reduce stress and prevent familial discord. This proactive approach ensures their wishes are communicated and executed without placing unnecessary strain on their loved ones, highlighting the essential role of interconnected dynamics in fostering thoughtful and effective EOL planning.

This factor underscores how Uchinanchu older adults' information behaviour is shaped by the close-knit nature of their familial and cultural settings. The focus on burden mitigation reveals how familial ties and cultural expectations influence individuals to engage in meticulous planning, demonstrating a commitment to family cohesion and support. By considering the generational impact of their decisions, these adults navigate EOL planning with a deep awareness of their role within their family structure, thereby highlighting the interplay between practical concerns and cultural values in shaping their approach to EOL decision-making.

Filial responsibility in EOL decision making

Within these intimate, familial settings, the cultural expectation to care for one's parents drives individuals to approach EOL decisions with a strong sense of duty. This filial responsibility is often passed down through generations, shaping how older adults plan for their own EOL while considering the needs and expectations of their descendants. Filial responsibility in this context means that decisions are made not only to reflect personal preferences but also to honour familial obligations and streamline the caregiving process for family members, ensuring that all necessary arrangements are in place to uphold cultural and familial norms.

While filial duty is frequently emphasized in research on Asian American families (Gao et al., 2015; Lau, 2023), the findings of this study highlight that Uchinanchu older adults view this responsibility within a broader, multigenerational framework. Their EOL decision-making is influenced not only by the needs of their parents but also by a commitment to future generations, including children and grandchildren. This extended view of filial responsibility reflects a deep cultural value that prioritizes family cohesion and interdependence. Participants expressed a sense of duty that spans multiple generations, demonstrating that their information behaviours are intricately tied to maintaining family harmony and meeting cultural expectations across the familial lineage.

This multi-generational perspective is evident in how participants prepare for their own EOL, ensuring their decisions address both their immediate family's needs and their obligations to descendants. The concept of filial responsibility thus shapes their approach to EOL planning, integrating both the practical aspects of caregiving and the cultural imperatives of family support. This comprehensive view underscores the significance of family roles in shaping EOL decision-making processes, reflecting a broader cultural ethos that values both personal preparation and collective familial care.

Shoganai mindset in EOL decision making

The concept of Shoganai, or acceptance of fate, introduces a nuanced perspective on EOL decision-making within this population. Shoganai, which embraces the inevitability of death, influences how Uchinanchu older adults engage with planning processes. For some, this mindset leads to a more passive approach, reflecting a belief that certain aspects of life are beyond control and should not be overly planned or worried about. This contrasts with the fear-based avoidance often associated with death taboos in other Asian cultures (Biondo et al., 2017; Sharma et al., 2012), where discussions about death are frequently shrouded in anxiety.

Conversely, Shoganai also fosters a proactive approach to EOL planning, highlighting a duality where acceptance of fate coexists with the practical need to prepare for potential life events. Some participants embraced Shoganai by adopting a carefree attitude towards EOL planning, focusing on living in the present rather than worrying about the future. Others, however, used Shoganai to acknowledge life's unpredictability, prompting them to make provisions for unforeseen circumstances, such as designating decision-makers in case of incapacitation. This balance between cultural acceptance and practical readiness illustrates how Shoganai can shape both passive and active approaches to EOL planning, depending on individual interpretations.

Overall, while Shoganai might reflect a broader cultural hesitation around detailed EOL planning, all participants engaged with the process in some capacity. This suggests that Uchinanchu older adults navigate EOL decision-making with a balanced view, integrating their cultural values with practical considerations to manage what can and cannot be controlled.

Conclusion

This study explores how the end-of-life (EOL) decision-making of Uchinanchu older adults is profoundly shaped by the dynamics of their unique perspectives and cultural approaches, focusing specifically on the factors of burden mitigation, filial responsibility, and the Shoganai mindset. The proactive efforts to mitigate burdens reveal a strategic approach where individuals actively seek information to ease potential challenges for their descendants. Filial responsibility underscores the generational and cultural imperatives that shape how EOL decisions are made, demonstrating how familial obligations and cultural values guide information-seeking behaviors in a context of close-knit familial relationships. The Shoganai mindset introduces a nuanced perspective, balancing acceptance of fate with practical readiness, thus illustrating how cultural attitudes towards control and destiny influence both passive and active approaches to EOL planning.

These findings have significant implications for understanding how cultural and familial contexts shape information behaviors related to EOL decision-making. The emphasis on burden mitigation highlights the need for support systems that address the practical aspects of EOL planning, such as resources for managing financial and logistical challenges. The theme of filial responsibility suggests the importance of integrating cultural values into EOL planning tools and services, recognizing the role of multi-generational obligations. The dual nature of the Shoganai mindset points to the need for flexible approaches that accommodate varying attitudes towards fate and control.

This qualitative research is one approach by one researcher within one community at one specific point in time. As such, there are opportunities to extend our understanding of information behavior in EOL decision making. Future qualitative research could explore how these themes manifest in different cultural contexts and examine how those dynamics influence information behaviors in other settings. Additionally, further investigation into how the Shoganai mindset interacts with contemporary EOL planning practices for could provide deeper insights into the balance between cultural acceptance and practical preparedness for Uchinanchu American and other Asian American older adults. Future quantitative research may add empirical support and work towards generalizability. A longitudinal approach may help to develop insights on how EOL decision making changes over time. By expanding our understanding of these dynamics, future studies can enhance the development of culturally sensitive and practical EOL planning resources that better support individuals and families in navigating these critical decisions.

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