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Surrogate Decision-Making Practices Regarding End-of-Life Care for People With Dementia in Long-Term Care Hospitals: A Qualitative Descriptive Study

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ABSTRACT

Aim: To explore surrogate decision-making practices regarding end-of-life care for people with dementia in Korean long-term care hospitals from the perspective of healthcare providers.

Design: A qualitative descriptive study.

Methods: The data were collected through individual semi-structured interviews with 24 healthcare providers (physicians, oriental medicine doctors, registered nurses and social workers) involved in dementia end-of-life care in their current long-term care hospitals in South Korea. The data were analysed using a conventional content analytic technique.

Results: The analysis yielded three categories and nine subcategories describing surrogate decision-making practices regarding end-of-life care for people with dementia: (a) typical circumstances of end-of-life care planning, (b) expected roles of key personnel and related challenges and (c) important considerations. Participants discussed available treatment options within long-term care hospitals and the potential transfers to acute care hospitals during admission and periods of health decline. Physicians typically led such end-of-life care planning, with nurses playing a supportive role and family members making the final decisions. However, they faced challenges in performing their roles. In end-of-life care discussions, participants weighed the patients' autonomy and best interests alongside family members' interests and other external concerns such as potential lawsuits and insufficient medical resources.

Conclusion: Surrogate decision-making regarding end-of-life care in the context of dementia within long-term care hospitals is considerably complex and challenging for healthcare providers, requiring multifaceted institution-sensitive support.

Implications for the Profession and/or Patient Care: The study findings suggest the need for targeted education and training to enhance healthcare providers' competencies in end-of-life care discussions, advance care planning and the development of policies and regulations supporting end-of-life care-related practices within long-term care hospitals.

Reporting Method: This study was reported in accordance with the COREQ checklist.

Patient or Public Contribution: No patient or public contribution.

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Summary

- Impact
 - Physicians, nurses and family members discuss limited treatment options and potential transfers during admission and periods of health decline in people with dementia, highlighting the need for effective end-of-life care discussions at these critical transitional points in Korean long-term care hospitals.
 - Healthcare providers face challenges in end-of-life care planning due to limited knowledge of end-of-life care and legal frameworks, whereas family conflicts and limited understanding of dementia and end-of-life care contribute to delays in decision-making. This study recommends strategies, such as palliative care training and timely advance care planning, to better support both groups.
 - Healthcare providers consider the individual's autonomy and best interests, family members' interests and external factors in end-of-life care planning, underscoring the need to carefully navigate these ethical and legal considerations with family members for people with dementia in Korean long-term care hospitals.
- What does this paper contribute to the wider global clinical community?
 - This study expands our understanding of surrogate decision-making practices related to end-of-life care for people with dementia, specifically within the context of Korean long-term care hospitals.
 - The insights derived from this study may assist healthcare providers and relevant stakeholders in developing effective strategies to improve surrogate decision-making practices in this care setting.

1 | Introduction

The global prevalence of dementia increases rapidly (Alzheimer's Disease International 2023), with the population comprising 10.4% of older adults aged 65 years and above in South Korea (National Institute of Dementia 2024). Globally, many people with dementia receive burdensome life-sustaining treatments at the end of life—defined as a life expectancy of months or less due to progressive life-limiting diseases (Hui et al. 2013)—despite limited benefit and are less likely to receive hospice care than those with other diagnoses (Broyles et al. 2023). As dementia progresses, individuals gradually lose the capacity to make informed medical decisions. In such cases, healthcare providers usually collaborate with family members to determine appropriate care pathways (Denning et al. 2019). From the perspective of healthcare providers, these discussions are often complex and emotionally challenging, as family members may struggle to make medical decisions in the absence of a clear understanding of the person's care preferences (Beck et al. 2017). Additionally, healthcare providers report ethical concerns when people with dementia receive aggressive treatments that may not align with their values or provide meaningful benefit (Beck et al. 2017; Chen et al. 2020).

While substantial research has explored the challenges faced by family members in end-of-life care planning for people with

dementia (Kim et al. 2024; Fetherstonhaugh et al. 2017, 2019), only a few studies have focused on healthcare providers' perceptions of surrogate decision-making practices concerning care in the context of dementia and long-term care hospitals (LTCHs).

2 | Background

The Organization for Economic Cooperation and Development (OECD 2023) defines 'long-term care beds' as hospital beds designated for patients requiring extended care. Long-term care beds are integrated within acute care hospitals in some countries (e.g., Iceland and Denmark), typically serving the palliative care needs. Countries such as the United States, Canada and South Korea maintain specialized hospitals exclusively dedicated to long-term care beds, referred to as LTCHs (Song 2012). In South Korea, LTCHs, accounting for approximately 33% of hospitals (HIRA Bigdata Open Portal 2024), function as subacute medical and long-term care institutions and constitute a key component of the national long-term care infrastructure alongside nursing homes (Ga 2017). These hospitals serve as the main end-of-life care setting for people with dementia (Lee et al. 2018).

Healthcare providers in LTCHs play a pivotal role in supporting family members of people with dementia throughout the end-of-life care process. Beyond delivering clinical care, they serve as critical facilitators of communication, helping family members understand the person's clinical condition, prognosis and available treatment options (Caron et al. 2005; Denning et al. 2019). Their responsibilities also include guiding family members through ethically challenging decision-making processes, fostering shared decision-making and ensuring that choices align as closely as possible with the values and best interests of people with dementia (Denning et al. 2019; van der Steen et al. 2014).

However, healthcare providers in LTCHs may encounter significant challenges in fulfilling such roles. They face challenges in the surrogate decision-making process, including ambiguous legal frameworks (Erel et al. 2017; Sinclair et al. 2021), limited time and resources (Erel et al. 2017) and emotional distress experienced by family members (Cresp et al. 2020; Midtbust et al. 2018). These challenges may apply to long-term care settings with insufficient infrastructure and policy support.

Complex legal and ethical considerations further complicate decisions regarding life-sustaining treatment in such settings. In many countries, the lack of clear legal statutes governing advance care planning and surrogate decision-making for individuals with cognitive impairment complicates clinical decision-making (Davies et al. 2014; Midtbust et al. 2018). Although the national advance directive (AD) can be completed in various community centres in South Korea, only institutions with an established ethics committee are authorised to complete the national physician orders for life-sustaining treatment (POLST) document, register patient preferences, and access the AD and POLST registry (Life-Sustaining Treatment Decisions Act Articles 2, 10–18 2023). Consequently, LTCHs without such committees lack access to the registry, limiting their ability to honour the wishes of people with dementia. When a person's preferences cannot be inferred, decisions to withhold or withdraw life-sustaining treatment should be

based on family consensus and guided by the person's best interests (Life-Sustaining Treatment Decisions Act Articles 2, 10–18 2023), which may lead to delays. The Act also mandates that two physicians certify the imminence of death before life-sustaining treatments are forgone. Furthermore, hospice care remains unavailable for people with dementia (National Hospice Center 2019).

Ethical dilemmas frequently emerge as healthcare providers attempt to balance respect for patient autonomy with the principles of beneficence and non-maleficence. Divergent cultural beliefs about death, different expectations of family and institutional policies further complicate the standardisation of end-of-life care practices (van der Steen et al. 2014). In some cases, physicians may opt to continue aggressive treatment due to fears of legal repercussions, including potential accusations of negligence or abandonment of care (Erel et al. 2017). Such legal and ethical uncertainties can contribute to the overuse of life-sustaining treatments and delays in appropriate palliative care initiation.

Supporting family members is essential to ensuring that decisions made on behalf of people with dementia are well-informed, compassionate and ethically appropriate. Despite extensive evidence documenting family members' psychological and moral burdens, there remains a gap in understanding how healthcare providers perceive and navigate surrogate decision-making practices for people with dementia. Gaining such insight is critical for improving surrogate decision-making processes and ensuring that end-of-life care is truly person-centred.

3 | The Study

This study aimed to explore surrogate decision-making practices regarding end-of-life care for people with dementia in LTCHs from the perspective of healthcare providers. The research questions were as follows: (a) What end-of-life care decisions do healthcare providers discuss with family members of people with dementia in LTCHs? (b) When and how are these decisions made? (c) How do they contribute to surrogate decision-making for people with dementia? and (d) What challenges do they encounter during this process?

4 | Methods

4.1 | Design

This qualitative descriptive study employed individual semi-structured interviews and conventional content analysis. We selected qualitative descriptions to provide a comprehensive and straightforward summary of healthcare providers' perceptions of surrogate decision-making practices related to end-of-life care for people with dementia in LTCHs (Sandelowski 2000). This approach allows researchers to remain more closely aligned with the data and participants' literal words and events, rather than engaging in deep interpretation or transformation of the data (Sandelowski 2000). The study protocols and findings are reported according to

the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklists (Tong et al. 2007).

4.2 | Settings and Participants

We employed convenience sampling to recruit healthcare providers who were working in LTCHs. To be eligible, healthcare providers were required to be employed as physicians, oriental medicine doctors, registered nurses, or social workers who were involved in dementia end-of-life care and had at least 6 months of work experience at their current LTCHs. Due to limited understanding of which healthcare providers engage in surrogate decision-making about end-of-life care in Korean LTCHs, we aimed to explore this area by including healthcare providers involved in end-of-life care regardless of their direct experience with decision-making for people with dementia.

Participants were recruited from three LTCHs in Seoul and a nearby major province in South Korea and an online community of healthcare providers. We contacted the chief executive officers or directors of medicine and nursing at the LTCHs by telephone to request that they post an advertisement and facilitate the introduction of eligible healthcare providers. To facilitate recruitment, we contacted the representative of an online community and posted an advertisement. Interested individuals accessed the webpage that introduced the study and provided their names and contact information for participation. Subsequently, the first author contacted these individuals. Additionally, the participants were asked to introduce the study to other eligible individuals (snowball sampling, Polit and Beck 2021).

Ultimately, the final sample included 24 healthcare providers comprising 17 registered nurses, 3 oriental medicine doctors, 2 physicians and 2 social workers, with a mean age of 42.6 ± 11.6 (range, 24–64) years and mostly women ($n = 19$, 79.2%). More than half of the participants were married ($n = 14$, 58.3%), identified as religious ($n = 15$, 62.5%) and held a bachelor's degree ($n = 16$, 66.7%). Eleven (45.8%) participants held leadership positions, and the majority had ≥ 1 year of total professional experience in LTCHs ($n = 20$, 83.3%); as well as at the specific LTCHs included in the study ($n = 16$, 66.7%). Table 1 presents more information about the participants' general characteristics.

4.3 | Data Collection

The first author interviewed the participants using an investigator-developed interview guide based on the literature on end-of-life care planning for people with dementia (Denning et al. 2019; Lamahewa et al. 2018). Table 2 presents the interview guide. We discussed the interview questions within the research team and checked the appropriateness and clarity of the interview questions with a nurse involved in end-of-life care in an LTCH. Based on the consult, we prepared more probes for the main questions to facilitate interviews.

We collected data from 23 May to 19 October 2021. However, due to the coronavirus disease 2019 (COVID-19) pandemic, the first author interviewed the participants via telephone or videoconferencing. The participants completed an online survey

TABLE 1 | Participant characteristics ($N = 24$).

Characteristics	Mean $\pm$ SD, N (%)
Age, years	42.6 $\pm$ 11.6 (range: 24–64)
Sex	
Male	5 (20.8)
Female	19 (79.2)
Religion	
Yes	15 (62.5)
No	9 (37.5)
Marital status	
Single	10 (41.7)
Married	14 (58.3)
Education	
Associate degree	4 (16.7)
Bachelor's degree	16 (66.7)
$\geq$ Master's degree	4 (16.7)
Profession	
Physician	2 (8.3)
Oriental medicine doctor	3 (12.5)
Registered nurse	17 (70.8)
Social worker	2 (8.3)
Position	
Leadership	11 (45.8)
Staff	13 (54.2)
Total professional experience (years)	
< 1	1 (4.2)
≥ 1 and < 5	5 (20.8)
≥ 5 and < 10	3 (12.5)
≥ 10 and < 20	10 (41.7)
≥ 20	5 (20.8)
Total experience at long-term care hospitals (years)	
≥ 0.5 and < 1	4 (16.7)
≥ 1 and < 5	7 (29.2)
≥ 5 and < 10	4 (16.7)
≥ 10 and < 20	8 (33.3)
≥ 20	1 (4.2)
Experience at the current long-term care hospital (years)	
≥ 0.5 and < 1	8 (33.3)
≥ 1 and < 5	6 (25.0)
≥ 5 and < 10	6 (25.0)

(Continues)

TABLE 1 | (Continued)

Characteristics	Mean $\pm$ SD, N (%)
≥ 10 and < 20	3 (12.5)
≥ 20	1 (4.2)

Abbreviation: SD, standard deviation.

on their general characteristics (e.g., age, sex, education, religion, occupation and professional experience) before the interviews. Interviews were scheduled based on the participants' convenience and conducted in quiet settings to protect their privacy. The first author obtained the participants' permission to record the interviews, which lasted between 25 and 80 min, and contacted the participants if additional questions or clarifications were necessary. After each interview, the first author documented brief field notes capturing her impressions and key information; however, these notes were not included in the transcripts. A research assistant transcribed audio/video-recorded interviews verbatim, and the first author reviewed the transcripts against the original recordings for accuracy. The participants received a small token of appreciation for their participation.

4.4 | Data Analysis

Data were analyzed using conventional content analysis (Hsieh and Shannon 2005). All four authors, each with extensive experience in qualitative research, independently read the transcripts several times to understand healthcare providers' perceptions of surrogate decision-making practices related to end-of-life care for people with dementia in LTCHs. To ensure coding consistency, we independently coded the first three transcripts, reconciled discrepancies through team discussions, and collaboratively developed an initial codebook. We continued line-by-line coding of subsequent transcripts, cross-checked each other's work, and refined the codebook through iterative consensus meetings. Related codes were organized into subcategories and categories, which all authors reviewed and confirmed for data representativeness. The first author translated the representative quotations into English, which were reviewed by an external bilingual reviewer, who discussed any discrepancies with her. Qualitative data analysis and management were conducted using the NVivo 13 software (Lumivero, Colorado, USA). The participants' general characteristics were analyzed using descriptive statistics with IBM SPSS Statistics for Windows, version 26 (IBM Corp., Armonk, New York, USA).

4.5 | Trustworthiness

Trustworthiness was enhanced using the evaluation criteria proposed by Lincoln and Guba (1985). To establish credibility, we allowed participants sufficient time to express their thoughts and clarified ambiguous content during and after the interviews. Moreover, to address potential biases, we conducted a peer debriefing by sharing preliminary findings and selected transcripts with an external expert in long-term and palliative care, discussing the insights in a meeting, and re-examining

TABLE 2 | Questions from the interview guide.

- What do you think is the desirable goal of care for people with dementia at the end of life in LTCHs?
- What do you think about life-sustaining treatment for people with dementia?
- What decisions regarding end-of-life care were made for people with dementia in this LTCH?
- Have you engaged in the decision-making process about end-of-life care for people with dementia in this LTCH?
 - Could you tell me about the circumstances and processes?
 - What are your roles in the process?
 - What are the crucial things to consider when making decisions about end-of-life care for people with dementia?
- Have you witnessed end-of-life care decision-making between healthcare providers and family members for people with dementia?
 - Could you tell me about the circumstances and processes?
 - Who participates in the process?
 - What do you think are their roles in the process?
 - What do you think would be considered important in decision-making?
- What do you think are the difficulties and facilitators in this decision-making process?
- What would you like to suggest to families, LTCHs and policymakers to facilitate surrogate decision-making on end-of-life care for people with dementia in LTCHs?

Abbreviation: LTCH, long-term care hospital.

the data accordingly. For confirmability, we thoroughly documented the research process and activities and minimised biases through independent data analysis and regular team discussions.

4.6 | Ethical Consideration

The Institutional Review Board of the first author's institution approved the study and procedures (IRB No: 1041078-202103-HRSB-089-01; approval date: 20 May 2021). The first author explained the study objectives, responsibilities and duties, benefits and harms, voluntariness, confidentiality and withdrawal of participation to the participants and obtained written informed consent online. Additionally, the first author securely stored raw data (e.g., audio- and video-recordings and transcripts) on a password-protected institutional cloud and de-identified the transcripts and participant information. All research items will be securely retained for 3 years post-study completion before permanent deletion.

5 | Findings

The analysis yielded the following three categories supported by nine subcategories regarding surrogate decision-making practices related to end-of-life care for people with dementia in Korean LTCHs: (a) *typical circumstances of end-of-life care planning*, (b) *expected roles of key personnel and related challenges* and (c) *important considerations* (see Table 3).

5.1 | Typical Circumstances of End-of-Life Care Planning

Participants reported engaging family members in end-of-life medical decision-making at two pivotal transition points. Two interrelated subcategories—(a) *main transitional timepoints* and (b) *medical decisions to be made*—are described below.

5.1.1 | Main Transitional Timepoints

Participants identified two key moments for initiating end-of-life care discussions with family members of people with dementia: (a) upon admission to the LTCH and (b) during periods of health decline. Upon admission, participants commonly explored care preferences and sought family consent for do-not-resuscitate or no life-sustaining treatment orders. For instance, one nurse stated, 'We obtain consent on a do-not-resuscitate order form upon admission' (Participant 9, nurse). During health deteriorations—typically marked by significantly decreased oral intake, altered mental status, or recurrent aspiration—participants re-engaged family members to confirm the treatment plans or make urgent medical decisions. One participant reported, 'If the person keeps getting aspirated and cannot eat orally... we discuss L-tube insertion with family members' (Participant 4, nurse).

5.1.2 | Medical Decisions to Be Made

At the two transitional timepoints, participants discussed with family members primarily concerning (a) available treatment options within LTCHs and (b) potential transfers to acute care hospitals. Cardiopulmonary resuscitation emerged as the most routinely addressed treatment requiring family consent among the available end-of-life interventions in LTCHs (e.g., cardiopulmonary resuscitation, hemodialysis, transfusions, vasopressors, artificial nutrition and hydration and central venous catheterization). Although most family members consented to do not resuscitate orders, some declined. These decisions were influenced by the individual's previously expressed wishes, varying levels of family members' understanding of cardiopulmonary resuscitation outcomes in advanced dementia, or intra-family disagreements. Tube feeding, often recommended by physicians as essential care, was another contested treatment. Many family members declined it—along with transfers to acute care hospitals—citing the wishes and best interests of people with dementia and their circumstances. Discussions about transfers to acute care hospitals were generally aimed at

TABLE 3 | Analytic findings of surrogate decision-making practices related to end-of-life care for people with dementia in LTCHs from the perspective of healthcare providers.

Categories	Subcategories	Codes
Typical circumstances of end-of-life care planning	Main transitional timepoints	Admission to LTCHs
		Deterioration of health status
	Medical decisions to be made	Treatment options available in LTCHs
		Potential transfers to acute care hospitals
Expected roles of key personnel and related challenges	Physicians serving as leaders	Primary information providers and counselors
		Decision-makers
	Nurses serving as supporters	Assessors
		Mediators
	Family members serving as final decision-makers	Secondary information providers and counselors
		Insufficient knowledge of end-of-life care and laws that challenges the roles
		Immediate medical decision-making
		Delayed medical decision-making
		Providers following the family members' decisions
		Decisional conflicts among family members that challenge medical decision-making
Important considerations	Individual's autonomy	Lack of understanding of dementia and end-of-life care that challenges the role
		Respecting the individual's care preferences/wishes
	Individual's best interests	Importance of advance care planning
		Current health and functional status
		Survivability with treatment at the end of life
	Family members' interests	Different views on life-sustaining treatment
		Family members' life values and beliefs
		Family members' financial status
	External factors	Potential legal issues/concerns
		Insufficient resources in LTCHs

Abbreviation: LTCH, long-term care hospital.

accessing diagnostic or therapeutic interventions beyond LTCH capability.

When the condition of a person with dementia changes, we report it to our physician and then talk to the person's family member about the situation and the worst scenario that could occur. Then, we ask the family member, "Would you want us to transfer the patient to an acute care hospital?"

(Participant 19, nurse)

5.2 | Expected Roles of Key Personnel and Related Challenges

Participants identified physicians, nurses and family members as central to end-of-life care planning, whereas noting the absence of formal interdisciplinary meetings that include family

members and people with dementia. Oriental medicine doctors and social workers played minimal roles in end-of-life decision-making. Participants' perceptions of key personnel roles and the challenges they face are described below.

5.2.1 | Physicians Serving as Leaders

Physicians were leaders responsible for end-of-life care decision-making, assuming the roles of (a) primary information providers and counselors and (b) decision-makers. They predominantly explained the conditions of people with dementia, potential clinical situations and available end-of-life care in the LTCH to family members. If requested, they conveyed their opinions about more beneficial care: 'I explain the patient's condition to the family members and attempt to receive consent on the do-not-resuscitate order form...' (Participant 3, physician). When family members were absent, physicians made treatment decisions by attempting to discuss

the situation with an acquaintance of the person with dementia (e.g., a public official or church pastor who had provided financial or social support to the person) if possible, despite their lack of decision-making authority.

5.2.2 | Nurses Serving as Supporters

Nurses served as supporters in end-of-life care planning with the following roles: (a) assessors, (b) mediators and (c) secondary information providers and counselors. When asked about their roles in decision-making about end-of-life care for people with dementia, most nurse participants initially answered that they had little contribution to medical decision-making. However, when asked to describe situations where treatment decisions were made for the person, their answers indicated they provided support during the process. These nurse participants closely assessed the health status of people with dementia and identified family members' concerns and thoughts regarding end-of-life care. Subsequently, they discussed the person's status and family members' concerns and thoughts with physicians and conveyed the physicians' opinions to the family members. Moreover, when family members inquired about the status of people with dementia, life-sustaining treatments and nurses' opinions before making decisions, they often explained these matters in understandable terms, shared their experiences with other people with dementia, and helped family members in decision-making.

Some family members do not understand [life-sustaining treatment] even after our physician provides an explanation. In that case, they call us or come to our nursing office [for a re-explanation]. Then, we explain [the treatment] in an easy, understandable way—when to apply cardiopulmonary resuscitation, what mechanical ventilation is...

(Participant 16, nurse)

However, nurses often reported limited knowledge of end-of-life care and misunderstandings about the Life-Sustaining Treatment Decisions Act, contributing to reluctance in engaging with related discussions. Some perceived completing ADs as an added administrative burden: 'When the advance directive was introduced initially, we felt like, "Here's another document added. We already had a do-not-resuscitate form. Why did [the government] create another one and make it difficult for us?"' (Participant 2, nurse). To address these challenges, participants emphasized the need for institutional education on dementia-specific end-of-life care and the designation of trained personnel to support decision-making and facilitate family counseling.

5.2.3 | Family Members Serving as Final Decision-Makers

Participants acknowledged family members as the final decision-makers in end-of-life care planning. Although most family members made decisions promptly after discussions

with healthcare providers, those facing sudden health declines in people with dementia usually needed additional time for family consultation. Despite personal disagreements, participants generally deferred to the family members' decisions, which at times caused emotional strain, particularly when they perceived care as suboptimal for people with dementia. One participant shared: 'I feel emotionally strained when family members decide not to do anything [any aggressive treatments], only maintaining minimal treatment and watching over the person with dementia. It is like just waiting for them to pass away' (Participant 4, nurse).

However, decisional conflicts among family members, which were identified as the primary challenge by participants, usually delayed end-of-life care decisions or caused some participants to default to aggressive treatments.

With no consensus among family members, the son refused tube feeding, whereas the daughter requested it. They insisted that we follow their decisions, not those of others. Thus, we did not know what must be accomplished. Therefore, we asked them to discuss and inform us about the [shared] decision.

(Participant 2, nurse)

Many participants also noted that family members often lacked understanding of dementia, the concept of dignified death and dying, and life-sustaining treatments, which complicated end-of-life care decision-making. To address these gaps, they recommended public education initiatives and informational resources (e.g., pamphlets or videos explaining the prognosis of dementia) to better prepare family members for end-of-life care planning in the context of dementia.

5.3 | Important Considerations

Participants identified the following four key considerations in end-of-life care planning for people with dementia: the individual's autonomy, the individual's best interests, family members' interests and external concerns.

5.3.1 | Individual's Autonomy

Respect for previously expressed preferences of people with dementia regarding end-of-life care was viewed as essential: 'Family members tell us about the wishes regarding life-sustaining treatments the persons expressed before they lost cognitive function. We prioritize the persons' wishes' (Participant 6, nurse). In this context, most participants emphasized the importance of advance care planning to align decisions among people with dementia, their families and healthcare providers.

After the diagnosis of dementia, when cognitive decline is minimal, it would be beneficial [for family members] to have conversations with the person and decide on such treatments in advance.

This is because, if a decision is made contrary to the person's wish for no resuscitation, it would cause distress to the person.

(Participant 24, nurse)

difficulties tend to consent to the do-not-resuscitate document and often decide to place people with dementia in nursing homes.

(Participant 4, nurse)

5.3.2 | Individual's Best Interests

In assessing the best interests of people with dementia, participants emphasized the importance of evaluating current health and functional status and survivability with treatments. For instance, one participant stated, 'When performing cardiopulmonary resuscitation on people with dementia, the success rate is low, and in cases of pneumonia, intubation may be required... We have to consider these realistic issues' (Participant 3, physician). Clinical judgments were informed by the person's medical diagnoses, prognosis (including recent declines and hospitalizations) and capacity for daily activities. When faced with poor survivability, some participants recommended transfers to acute care hospitals for intensive or end-of-life care, whereas others supported providing conservative care within the LTCH. Family members often declined transfers, citing the person's old age, poor prognosis and perceived low quality of life. Participants expressed differing perspectives on life-sustaining treatments: some upheld the sanctity of life as justification for treatment, whereas others viewed such measures as prolonging suffering and impeding a dignified death.

Although many people say that life-sustaining treatment is meaningless, I still do not think there is anyone who thinks they just want to die without treatment. People with dementia had their lives, just like us, before dementia onset. Therefore, I am somewhat supportive of life-sustaining treatments.

(Participant 17, nurse)

Many people with dementia in the intensive care unit [of my institution] have L-tubes and are unconscious or unable to communicate. I often wonder whether living in such a state for a long time is meaningful... I believe that they experience immense suffering.

(Participant 18, nurse)

5.3.3 | Family Members' Interests

Family members' interests were often considered in end-of-life care decision-making for people with dementia. Most participants perceived family members' opinions/preferences—based on their life values, beliefs and financial situations—to be important. Particularly, they emphasised the importance of family members' financial status in end-of-life care decision-making.

I think the financial status of family members is important in decision-making. LTCH fees are not cheap, right? So, family members facing financial

5.3.4 | External Factors

Some participants reported that legal concerns and limited medical resources also shaped end-of-life care decisions in LTCHs. Fear of liability prompted some to administer treatments even when clinically questionable, due to ambiguities in the Life-Sustaining Treatment Decisions Act: 'In fact, according to the [Life-Sustaining Treatment Decisions] Act, not providing fluids and nutrients to patients who cannot eat is legally problematic. Therefore, we have to provide dextrose or TPN via IV' (Participant 3, physician). Resource constraints also prompted recommendations for transfers to acute care hospitals. To address these challenges, participants advocated clearer regulations tailored to end-of-life care for people with dementia in LTCHs.

The [Life-Sustaining Treatment Decisions] Act is not perfect, especially for LTCHs and people with dementia. It would be helpful to have a standardized form [about life-sustaining treatment] tailored to the realities of LTCH care. That way, people with dementia and their families could make decisions more clearly.

(Participant 11, physician)

6 | Discussion

This qualitative descriptive study aimed to describe healthcare providers' perceptions of surrogate decision-making practices related to end-of-life care for people with dementia in LTCHs. The conventional content analysis of the interviews with 24 healthcare providers yielded three categories and nine subcategories. First, in Korean LTCHs, participants discussed limited treatment options and potential transfers to acute care hospitals, especially at the time of admission and during periods of health decline. This finding highlights several important systemic and clinical issues, including limited resources in LTCHs, key transitional moments as critical decision-making points, and the need for continuity and quality of end-of-life care for people with dementia. Korean LTCHs are generally equipped to provide basic or maintenance-level medical care (National Health Insurance Service 2025). Additionally, 88% of Korean LTCHs lack established ethics committees (National Agency for Management of Life-Sustaining Treatment 2025), indicating that forgoing life-sustaining treatments is generally not permitted in these facilities under the Life-Sustaining Treatment Decisions Act Articles 2, 10–18 (2023). This structural limitation may prompt earlier discussions about potential transfers when a person's condition deteriorates and influence how end-of-life care is planned and delivered.

Admission and periods of health decline represent key moments to initiate or revisit care goals. Health declines—such as poor oral intake, changes in mental status and other emergencies—are often signs of approaching end-of-life (Mitchell et al. 2009) and represent

a common but stressful moment when healthcare providers and family members must make medical decisions under tremendous pressure (Erel et al. 2022). Erel et al. (2022) suggested initiating end-of-life care discussions as early as possible, even when the person appears stable at hospital admission. Therefore, healthcare providers in Korean LTCHs should use admission as an opportunity for a structured end-of-life care discussion for people with dementia. Furthermore, transfers to acute care hospitals may disrupt continuity of care and expose people with dementia to potentially burdensome interventions (Gozalo et al. 2011). Therefore, improving resources, using admission for structured care planning, and minimising unnecessary transfers are key to enhancing end-of-life care for people with dementia in Korean LTCHs.

Second, physicians led the process of end-of-life care planning, with nurses in supportive roles and family members as the ultimate decision-makers. However, despite performing functions—such as assessors, mediators and counselors—nurses usually underrecognized their involvement in decision-making. This suggests a lack of awareness of their contributions or ambiguity regarding their formal responsibilities in end-of-life care planning. Such unawareness and role ambiguity are noted in the literature. For instance, Lee et al. (2025) reported that nurses in Korean care settings (e.g., hospitals and nursing homes) had low awareness of and participation in advance care planning, citing their limited time and competence. Punia et al. (2024) also found that nurses in Canadian long-term care homes were unclear about their role in advance care planning and deferred to physicians. The reported difficulties nurses faced in our study, especially due to limited knowledge of end-of-life care and relevant legal frameworks, underscore the need for targeted education and training and role clarification. Therefore, addressing these gaps is critical to enhancing interdisciplinary collaboration and ensuring that all healthcare providers, particularly nurses, are empowered to participate effectively in surrogate decision-making processes.

Most participants noted that family members serve as the final decision-makers for people with dementia in LTCHs but faced challenges due to family conflicts and limited understanding of dementia and end-of-life care. Family conflicts—particularly in emotionally charged contexts—can delay decision-making or result in choices that may not fully align with the person's needs or best interests (Su et al. 2014). This highlights a need for structured communication strategies within the care setting. Additionally, family members' lack of understanding of dementia progression and the realities of end-of-life care may lead to unrealistic expectations or decisions driven by fear or misinformation. This underscores the critical role of healthcare providers, especially nurses and physicians, in offering clear, compassionate education and guidance throughout the decision-making process.

Numerous researchers have developed educational interventions that target healthcare providers and/or family members to facilitate shared decision-making between healthcare providers and family members of persons with advanced dementia by increasing their knowledge and skills related to end-of-life care (Geddis-Regan et al. 2021). For instance, Hanson et al. (2017) developed a goals-of-care intervention consisting of training for staff (i.e., watching a video decision aid, learning communication

principles and observing the role-play of a goals-of-care discussion) and education for family members (i.e., a video decision aid about dementia and goals of care). The concordance between healthcare providers and family members regarding the goals of care and family members' satisfaction with end-of-life communication was higher in the intervention group than in the control group (Hanson et al. 2017). Therefore, culturally sensitive educational and training programs related to palliative and end-of-life care and related communications should be developed for healthcare providers and family members in Korean LTCHs.

Lastly, participants weighed not only the ethical principles of patient autonomy and best interests but also the practical realities faced by family members and healthcare providers in our study. This finding indicates the complex interplay between ethical, emotional and systemic factors in care planning and underscores the need for advance care planning, clear guidelines for assessing the person's best interests, and legal protections to facilitate ethically sound and practically feasible decisions.

In dementia, advance care planning is recommended as early as possible or before the person loses their decision-making capacity (Denning et al. 2019). Several factors make timely care planning challenging. Challenges faced by people with dementia and their family members include limited awareness of advance care planning, reluctance to engage in discussions about death and dying, dependence on healthcare professionals to initiate such conversations, and fear about the future (Denning et al. 2019). Challenges faced by healthcare providers include resistance, discomfort and insufficient knowledge (Kim and Flieger 2023). In South Korea, approximately 70% of older adults aged ≥ 60 years who complete ADs are those with cancer, indicating a low proportion of AD completion in people with dementia (Lee et al. 2022). Several advance-care-planning interventions have targeted persons with early dementia and their family members, such as the Support, Health, Activities, Resources and Education (Whitlatch et al. 2019) and Sharing Patient's Illness Representation to Increase Trust (Song et al. 2019) programs. Both programs highlight the dyads of people with dementia and their family members in structured discussions focused on future care planning and the articulation of the persons' end-of-life values and preferences. Although the impact of such early advance care planning on patient outcomes is unknown (Geddis-Regan et al. 2021), family members have positively evaluated their experiences with advance care planning (Song et al. 2019; Whitlatch et al. 2019). Practical strategies, such as education and campaigns via various media and clinical guidelines, are necessary to promote early advance care planning for people with dementia and their family members.

Assessing the best interests of people with dementia involves ethical reasoning, clear communication, and respect for the person's values and dignity (Griffith 2024). Combining legal frameworks, clinical judgment, family input and institutional support (e.g., interdisciplinary team discussions and ethics consultation) helps ensure that decisions align with the person's best interests (Worthington et al. 2022). In practice, healthcare providers may benefit from using a standardized tool to guide best-interest assessment such as the Best Interests Checklist from the United Kingdom (Mental Capacity Toolkit 2025). Therefore, healthcare providers, researchers, and other stakeholders should

collaborate to develop a standardized, culture-sensitive, best-interest assessment tool for end-of-life care in dementia.

Furthermore, surrogate decision-making regarding end-of-life care (especially life-sustaining treatment and hospice care) for people with dementia in LTCHs should be supported by legal frameworks. In our study, healthcare providers expressed concerns about potential legal issues associated with forgoing life-sustaining treatment, largely due to the absence of legal protections supporting such decisions in their practices. The current Life-Sustaining Treatment Decisions Act focuses on practices in acute care hospitals rather than all types of healthcare settings (Lee 2024). As LTCHs are the primary venue for end-of-life care for people with dementia, decision-making and implementation of forgoing life-sustaining treatments for people in the advanced or end stages should be legally supported in LTCHs, regardless of the availability of institutional ethics committees. More public institutional ethics committees should be made available to LTCHs. Furthermore, the scope of the population that can benefit from inpatient hospice care should be expanded to include people with dementia at the end of life.

6.1 | Limitations and Strengths

This study had some limitations. First, as the research period coincided with the peak of the COVID-19 pandemic, LTCHs strongly prohibited outsiders (e.g., researchers) from visiting; thus, the recruitment of participants was extremely limited. Consequently, the small, predominantly female nurse sample recruited through convenience and snowball sampling likely limited a balanced view of surrogate decision-making practices among healthcare providers in LTCHs in South Korea. Second, institutional characteristics, particularly the presence of protocols for end-of-life care decision-making, were not identified. Third, the study's focus on healthcare providers excluded family members' perspectives on end-of-life decision-making for people with dementia. Fourth, conducting interviews online may restrict the participants' full engagement in the interview and the researchers' ability to observe important nonverbal behaviours. Fifth, data saturation by profession was not achieved due to the significantly small number of physicians, oriental medicine doctors and social workers. Lastly, member checking was omitted to avoid participants feeling judged about their practices.

However, this study is among the few that explore surrogate decision-making practices in the context of dementia, end-of-life care and Korean LTCHs, thereby contributing to the current body of knowledge on this complex phenomenon. These findings may also inform the development of practical strategies aimed at improving the practices and alleviating the emotional and moral burdens experienced by healthcare providers in this care setting.

6.2 | Recommendations for Further Research

Future research should include large-scale surveys that assess family members' knowledge, levels of uncertainty, decisional conflicts and emotional distress regarding end-of-life

care decision-making for people with dementia in LTCHs. Interventional studies are also necessary to develop testable programs (e.g., audiovisual educational materials and artificial intelligence-based mobile applications) that support family members and healthcare providers in value-laden surrogate decision-making.

6.3 | Implications for Policy and Practice

This study highlights the urgent need for clear policies and structured protocols within Korean LTCHs to support collaborative and ethically sound end-of-life care decision-making for people with dementia. Such policies should define and strengthen the roles of physicians and nurses in end-of-life care planning, ensuring that nurses are adequately equipped with the knowledge and skills necessary to actively participate. Additionally, expanding LTCH resources or establishing guidelines for surrogate decision-making may help reduce provider uncertainty and protect the best interests of people with dementia. Efforts to support family members, such as providing clear information about dementia, care options and legal frameworks, are also essential to enhance informed, person-centered decisions.

7 | Conclusion

This study indicates that decision-making regarding end-of-life care for people with dementia is complex and challenging for healthcare providers, suggesting multifaceted strategies that include education and training to enhance healthcare providers' competency in this area, advance care planning and the development of policies and regulations supporting end-of-life care-related practices in LTCHs. Implementing these strategies may enable healthcare providers to deliver more informed, compassionate and effective end-of-life care that upholds the dignity of people with dementia in this care setting.

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Ethics Statement

The study procedures were approved by the institutional review board of Chung-Ang University on May 20, 2021 (IRB No: 1041078-202103-HRSB-089-01).

Consent

The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Research data are not shared because the participants were not informed of data sharing.

Peer Review

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.70136>.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** jan70136-sup-0001-DataS1.pdf.