



Navigating shared decision-making after the Life-Sustaining Treatment Decision Act: a qualitative study of in-depth interviews with terminal cancer patients, families, and healthcare professionals

Soo-Young Yu¹ · Yu-eun Lee^{2,3} · Sung Joon Shin^{3,4,5} · Go-un Woo^{2,3,5} · Dalyong Kim^{2,3,5} · Jung Hye Kwon^{6,7,8} · Do Yeun Kim^{2,3,5} · Eunyoung Eunice Suh⁹

Received: 22 April 2024 / Accepted: 29 October 2024 / Published online: 16 November 2024
© The Author(s) 2024

Abstract

Purpose End-of-life decision-making, particularly relating to withholding life-sustaining treatment (LST), is a complex and emotionally charged process involving healthcare professionals, patients, and caregivers.

Methods This qualitative study explored the decision-making process in South Korea, where cultural norms and ethical considerations influence the dynamics of shared decision-making (SDM). In-depth interviews were conducted with healthcare professionals, patients, and caregivers using a grounded theory approach to elucidate the themes and processes underlying SDM for LST. This study used the “6C” framework, which could reflect the intricacies of the SDM process.

Results The results suggest that healthcare professionals face emotional challenges and an ethical dilemma in disclosing prognoses and discussing LST withholding, often deferring such discussions until the condition of patients worsens. Cultural factors, such as collectivist values and societal taboos surrounding death, influence decision-making dynamics, highlighting the need for tailored interventions and cultural competence in healthcare settings.

Conclusion The proposed “6C” framework provides insights into addressing current challenges in SDM and emphasizes the importance of cultural norms and ethical obligations in end-of-life decision-making. Further research is warranted to examine the SDM process in diverse cultural contexts and develop interventions to enhance patient and family involvement in the decision-making process for LST.

Keywords End-of-life decision-making · Shared decision-making · Life-sustaining treatment

Introduction

Shared decision-making (SDM) is a Western concept rooted in the principles of mutual interaction through communication between healthcare providers and patients. This approach

has supplanted the older, paternalistic model, where doctors performed treatment decisions in isolation without patient engagement [1]. Subsequently, SDM enhances patient satisfaction and advances patient-centered healthcare [2].

South Korean society largely opposes discontinuing futile life-sustaining treatment (LST), emphasizing the need for SDM in guiding LST decisions. On February 3, 2016, South Korea enacted the “Act on Hospice and Palliative Care and LST Decision for Patients in Hospice and Palliative Care and at the End of Life,” covering hospice, palliative care, and LST decisions. This Act, implemented in 2018, is designed to respect a patient’s right to decide on their life-sustaining treatment, particularly for those in hospice or palliative care, thereby ensuring the dignity and value of individuals. Despite the strong link between SDM and achieving a “good death” resulting from LST decisions, the current Life-Sustaining Treatment Decision Act does not explicitly mention SDM.

Key message

To our knowledge, this is the first study to demonstrate the end-of-life care decision process reflecting the voices of patients, their caregivers, and health professionals (doctors and nurses) after the LST Act in Korea.

Soo-Young Yu and Yu-eun Lee are co-first authors.

This study was partially presented at Multinational Association of Supportive Care in Cancer and International Society of Oral Oncology (MASCC/ISOO) Annual Meeting 2021 (June 24–26, 2021, Virtual).

Extended author information available on the last page of the article

Studies conducted in South Korea have reported that most doctors and patients lack the time for decision-making, leading to an inability to share their opinions or contemplate decisions [3, 4]. These studies also highlight challenges, including patient anxiety regarding the information provided. Additionally, families often maintain hope for continuous and future treatment.

According to recent research [5], there has been an increase in patients providing advanced directives; this trend highlights the importance of policies that encourage patient-initiated discussions and the need to verify the procedures and quality of the decision-making process for LST [6]. Therefore, SDM processes that can enhance comprehension, reduce inappropriate treatments, improve healthcare quality, and potentially lead to cost savings are essential. SDM models have been introduced in other countries, allowing patients to exercise autonomy and caregivers and medical professionals to respect their choices [7–9]. However, there is currently no specific SDM model tailored to Korea, meaning it is essential to develop a model that fits the unique needs of the social environment. This study explored the decision-making process among medical professionals, patients, and caregivers. The findings would allow us to propose a suitable model for the SDM process for the Korean population.

Method

Study design

This qualitative research conducted in-depth interviews to explore the Korean decision-making process for LST. This qualitative study utilized a grounded theory approach with the expectation that rigor could be secured through repeated comparisons to elucidate the structure and context of the phenomenon [10, 11].

Recruitment of research participants

Theoretical sampling involved securing information-rich cases and good informants who had experience and could reflect on the research topic. The interviews were conducted for each of the three groups: healthcare professionals, patients, and family members as primary caregivers—the main individuals involved in the decision-making. We employed a “snowballing” chain recruitment method focused on internal medicine healthcare professionals and patients as they frequently encounter situations requiring decisions on LST. Participants were recruited and interviewed from April 2019 to October 2019. The inclusion criteria for healthcare professionals focused on experience in clinical fields and those who frequently encountered end-of-life situations, such as

respiratory medicine and hematology-oncology. Exclusion criteria included residents without experience in hematology–oncology wards. For non-healthcare participants, the inclusion criteria were individuals diagnosed with terminal cancer, those willing to forgo LST, and those capable of verbal communication without any respiratory assistance. Exclusion criteria were individuals unable to communicate effectively or those who had yet to make decisions regarding LST discontinuation. All face-to-face interviews were recorded using a mobile device with a recording application. Qualitative data collection through interviews was discontinued when data analysis revealed no new results; theoretical sampling was considered complete when the attributes and dimensions under each category were sufficiently developed, which means that theoretical sampling was considered to have been reached.

In-depth interview process

Semi-structured interviews were conducted using a set of pre-interview guidelines (Table 1). This approach allowed for new insights and questions to be explored as they arose, making it suitable for a discovery-oriented process [12]. The main interview questions were structured into three categories: (1) the process of deciding LST, (2) the relationship with medical professionals during the LST decision process, and (3) the surrounding environment when deciding LST. A researcher with experience conducting qualitative research directly participated in all interviews. The data collection and analysis processes were discussed in at least five research meetings, and the authors who participated in the interviews were included.

Method of analysis

All interview recordings were transcribed into text to reflect the vividness of the verbal data while protecting personal information. A transcription protocol was followed to preserve the sense of the voice of participants. All personal information was anonymized. The grounded theory approach was utilized to systematically explore the formation context, structure, and process of a specific social phenomenon. In conducting grounded theory analysis, the six-component (6C) coding method was included alongside the axial coding methods, as follows [13]: causal conditions, context, central phenomenon, contingent conditions (intervening conditions), coordination strategies (action/interaction strategies), and consequences. Categories were identified and developed according to attributes and dimensions through processes that generate basic categories to describe data features, including continuous comparisons between cases and instances.

Table 1 Interview questions**A. Interview Questions for Participants: Patients and Caregivers**

Main research question: How is shared decision-making between patients and doctors regarding the withholding or withdrawing life-sustaining treatment (LST) conducted under recently revised regulations?

Q1. Process of deciding to withhold or withdraw life-sustaining treatment: motivation, triggers, support, and values

- *Q1-1: How did you learn about life-sustaining treatment?*
- *Q1-2: Can you describe the situation when you decided to withhold or withdraw life-sustaining treatment?*
- *Q1-3: What was the main motivation or reason for deciding to withhold or withdraw life-sustaining treatment?*
- *Q1-4: What most influenced your decision to withhold or withdraw life-sustaining treatment? What is your personal disposition, family support, medical staff, and religion?*
- *Q1-5: Did those around you agree with and support your decision? If not, please describe the situation*
- *Q1-6: If you found it difficult to decide on your own, please describe the situation. Did you experience personal conflict or fear regarding withholding or withdrawing life-sustaining treatment?*
- *Q1-7: Before becoming seriously ill, did you have any thoughts on withholding or withdrawing life-sustaining treatment? What do you consider the purpose of life? How did these thoughts influence your decision-making process regarding life-sustaining treatment?*
- *Q1-8: How interested were the medical staff in understanding your values? Have you ever discussed your thoughts on death with the medical staff?*

Q2. Relationship with medical staff during the decision-making process: explanations and familiarity

- *Q2-1: How was your relationship with the doctor during the decision-making process for withholding or withdrawing life-sustaining treatment? Were you provided with enough explanation? If not, what was the reason?*
- *Q2-2: Which medical staff member was most helpful? What aspect (attitude, explanation, empathy, being present) made you feel this way?*
- *Q2-3: How can you tell if the process was conducted through sufficient discussion and agreement with the medical staff?*

Q3. Surroundings and support systems in deciding to withhold or withdraw life-sustaining treatment: providing various options and support systems

- *Q3-1: What was the most difficult aspect or problem you encountered while deciding to withhold or withdraw life-sustaining treatment?*
- *Q3-2: How could the most difficult aspect have been made easier? What comes to mind if there is a way to solve it that does not involve individual effort?*
- *Q3-3: What were the difficulties or inconveniences encountered while preparing the advance directive for life-sustaining treatment or the life-sustaining treatment plan?*
- *Q3-4: Finally, if you were to compare the decision-making process for withholding or withdrawing life-sustaining treatment or your current state to a specific object (plant, animal, inanimate object, etc.), what would it be? Please also explain what influenced your decision*

B. Interview Questions for Doctors

Main research question: How is shared decision-making between patients and doctors regarding the withholding or withdrawing life-sustaining treatment (LST) conducted under recently revised regulations?

Interviews with participants were conducted in a semi-structured format. Additional questions could have been asked flexibly depending on the interaction space and situation with the participants within the scope of the following main questions

Q1. Process of deciding to withhold or withdraw life-sustaining treatment: motivation, triggers, support, and values

- *Open question: What is life-sustaining treatment? What is your opinion of life-sustaining treatments?*
- *Q1-1: If you have recently decided to withhold or withdraw life-sustaining treatment, please describe the situation*
- *Q1-2: How many consultations were needed to reach the decision on withholding or withdrawing life-sustaining treatment, and how long did they take? What stages did the consultation process go through?*
- *Q1-3: What was the situation like when deciding to withhold or withdraw life-sustaining treatment? Did the patient agree and support your decision? How did the caregivers react?*
- *Q1-4: What is the main motivation for bringing up the topic of withholding or withdrawing life-sustaining treatment when you feel there is a limit to continuing medical treatments? What do you think about directly discussing the patient's condition?*
- *Q1-5: Please describe if an event or memory made you develop your thoughts and values about withholding or withdrawing life-sustaining treatment*
- *Q1-6: If you have ever experienced personal conflict or fear about withholding or withdrawing life-sustaining treatment, please describe it*
- *Q1-7: When patients do not want to make decisions themselves, how much should 'the right not to decide' be respected?*

Table 1 (continued)**Q2. Relationship with patients during the decision-making process: explanations and familiarity**

- *Q2-1: How was your relationship with the patient during the decision-making process for withholding or withdrawing life-sustaining treatment? Were you able to provide sufficient explanation? If not, what was the reason?*
- *Q2-2: How was your relationship with the caregivers, not the patient, during the decision-making process for withholding or withdrawing life-sustaining treatment? How much do you think the caregivers' decision-making authority was reflected?*
- *Q2-3: How was your relationship with other medical staff (e.g., designated doctors, nurses) during the decision-making process for withholding or withdrawing life-sustaining treatment? Were there any conflicts or friction?*
- *Q2-4: Which aspect (attitude, explanation, empathy, being present) do you think would be most helpful for the patient? Please explain your answer in detail*
- *Q2-5: What do you think is the role of doctors in the decision-making process for withholding or withdrawing life-sustaining treatment?*
- *Q2-6: After discussing the decision to withhold or withdraw life-sustaining treatment with the patient, how did you feel when you met the patient again? What feelings or responses did you get from the patient?*
- *Q2-7: Have you ever found it difficult after a patient you were in charge of passed away following the decision to withhold or withdraw life-sustaining treatment? What made it difficult? How did you overcome it? What could help in overcoming it?*

Q3. Surroundings and support systems in deciding to withhold or withdraw life-sustaining treatment: providing various options and support systems

- *Q3-1: What was the most difficult aspect you observed in the process of deciding to withhold or withdraw life-sustaining treatment?*
- *Q3-2: How can the most difficult aspect be resolved? If there is a way to solve it, what comes to mind?*
- *Q3-3: Was there any organization or group that helped when there were difficulties in the process of withholding or withdrawing life-sustaining treatment?*
- *Q3-4: Have you ever received help from an ethics committee during the process of withholding or withdrawing life-sustaining treatment? How was the ethics committee involved? If there were the best and worst aspects, please describe them*
- *Q3-5: What are the difficulties or complications encountered in filling out forms related to withholding or withdrawing life-sustaining treatment?*
- *Q3-6: How do you feel when filling out forms related to life-sustaining treatment?*
- *Q3-7: Finally, if you were to compare the decision to withhold or withdraw life-sustaining treatment itself to a specific object (plant, animal, inanimate object, etc.), how would you express it? Please also explain what influenced your decision*

3. Interview Questions for Nurses

Main research question: How is shared decision-making between patients and nurses regarding the withholding or withdrawal of life-sustaining treatment (LST) conducted under recently revised regulations?

Interviews with participants were conducted in a semi-structured format. Additional questions could be asked flexibly depending on the interaction space and situation with the participants within the scope of the following main questions

Q1. Process of deciding to withhold or withdraw life-sustaining treatment: motivation, triggers, support, and values

- *Q1-1: If you have recently decided to withhold or withdraw life-sustaining treatment, please describe the situation*
- *Q1-2: What was the situation like when deciding to withhold or withdraw life-sustaining treatment? Did the patient agree and support your decision? How did the caregivers react?*
- *Q1-3: What is the main motivation for bringing up the topic of withholding or withdrawing life-sustaining treatment when you feel there is a limit to continuing treatment medically? What do you think about directly discussing the patient's condition?*
- *Q1-4: Please describe if an event or memory made you develop your thoughts and values about withholding or withdrawing life-sustaining treatment*
- *Q1-5: If you have ever experienced personal conflict or fear about withholding or withdrawing life-sustaining treatment, please describe it*
- *Q1-6: When patients do not want to make decisions themselves, how much should 'the right not to decide' be respected?*

Q2. Relationship with patients during the decision-making process: explanations and familiarity

- *Q2-1: How was your relationship with the patient during the decision-making process for withholding or withdrawing life-sustaining treatment? Were you able to provide sufficient explanation? If not, what was the reason?*
- *Q2-2: How was your relationship with the caregivers, not the patient, during the decision-making process for withholding or withdrawing life-sustaining treatment? How much do you think the caregivers' decision-making authority was reflected?*
- *Q2-3: How was your relationship with other medical staff (e.g., designated doctors, nurses) during the decision-making process for withholding or withdrawing life-sustaining treatment? Were there any conflicts or friction?*
- *Q2-4: Which aspect (attitude, explanation, empathy, being present) do you think would be most helpful for the patient? Please explain your answer in detail*
- *Q2-5: What do you think is the role of nurses in the decision-making process for withholding or withdrawing life-sustaining treatment?*
- *Q2-6: After discussing the decision to withhold or withdraw life-sustaining treatment with the patient, how did you feel when you met the patient again? What feelings or responses did you get from the patient?*
- *Q2-7: Have you ever found it difficult after a patient you were in charge of passed away following the decision to withhold or withdraw life-sustaining treatment? What made it difficult? How did you overcome it? What could help in overcoming it?*

Table 1 (continued)

Q3. Surroundings and support systems in deciding to withhold or withdraw life-sustaining treatment: providing various options and support systems
• Q3-1: What was the most difficult aspect you observed in the process of deciding to withhold or withdraw life-sustaining treatment?
• Q3-2: How can the most difficult aspect be resolved? If there is a way to solve it, what comes to mind?
• Q3-3: Was there any organization or group that helped when there were difficulties in the process of withholding or withdrawing life-sustaining treatment?
• Q3-4: Have you ever received help from an ethics committee during the process of withholding or withdrawing life-sustaining treatment? How was the ethics committee involved? If there were the best and worst aspects, please describe them
• Q3-5: What are the difficulties or complications encountered in filling out forms related to withholding or withdrawing life-sustaining treatment?
• Q3-6: How do you feel when filling out forms related to life-sustaining treatment?
• Q3-7: Finally, if you were to compare the decision to withhold or withdraw life-sustaining treatment itself to a specific object (plant, animal, inanimate object, etc.), how would you express it? Please also explain what influenced your decision

Ethical consideration

This study was approved by the Institutional Review Boards at the National Evidence-based Health Care Collaborating Agency (No.19–005-7) and Dongguk University Ilsan Hospital (IRB# DUIH 2019–03-004). Written consent was obtained for voluntary participation before each interview. The participants were informed that the verbal interview would be recorded, which they acknowledged. The recorded file was shared only by the interviewers. All personal information, such as name, region of residence, and hospital name, was anonymized when the voice file was converted into text. This research adhered to the fundamental principles of the Helsinki Declaration (revised in 2008, 59th World Medical Association General Assembly, Seoul), thus ensuring that it was conducted scientifically and ethically.

Results

Participant characteristics

A total of 22 participants took part in the in-depth interviews about the SDM process. The participants included healthcare professionals, patients, and caregivers. The healthcare professionals consisted of doctors and nurses. The doctors comprised senior and junior doctors specializing in hemato-oncology and pulmonology. Patients included those facing decisions on LST due to terminal illnesses. Caregivers were the primary support for these patients. This diverse group offered comprehensive insights into SDM processes for LSTs. Researchers conducted individual interviews with each participant using a set of predetermined questions. The characteristics of the participants are outlined in Table 2. The interviews were conducted with healthcare professionals, doctors (n = 4), and nurses (n = 4), as well as patients (n = 5) and their caregivers (n = 7).

Theme extraction

Themes were identified for the three participant groups (Table 3). The actual discussions with patients, caregivers, and healthcare professionals corresponding to each extracted theme are documented in Table 4.

Healthcare professionals’ perspective

Profound empathy for patients and regrets over unnecessary medical procedures Healthcare professionals believe that the final moments of patients can be inhumane and filled with suffering based on their previous experiences. As a result, when the condition of a patient deteriorates, the healthcare provider pondered whether aggressive LST, including admission to the intensive care unit (ICU), would be beneficial enough to justify the potential suffering the patient might endure.

Concerns and hesitations about initiating discussions on LST withholding In discussions on withholding LST, healthcare professionals noted that the attending physician usually only started the conversation with a patient or caregivers if the patient’s condition had deteriorated or the patient-initiated engagement. Even during discussions, the attending physician often preferred to talk to the caregivers first as they believed the patient could find the conversation distressing.

Start talking about LST carefully when a patient has the potential to deteriorate The attending physician often expedited decisions on withholding LST when they feared the patient’s condition had worsened. When the patient’s condition suddenly deteriorated without prior planning or discussion, it could be challenging for a different physician (on-call) to decide on the treatment approach. Therefore, the attending physician initiated these discussions with the patient or family at the earliest cancer stage. These discussions happened gradually, according to changes in the

Table 2 Characteristics of Interview Participants

ID	Position	Job/relationship with patient	Characteristics
D1	Doctors	Senior specialist	Hemato-oncology
D2		Junior resident	Internal medicine
D3			
D4		Senior fellowship	Pulmonology
D5			
N1	Nurses	Ward registered nurse	Nine years of experience
N2			Three years of experience
N3		Intensive care unit registered nurse	Fourteen years of experience
N4			Five years of experience
P1	Patients	Older adults	Gastric cancer, 5 years of illness
P2			Bone tumor, 3 years of illness
P3			Recurrent lung cancer, 1 year of illness
P4		Middle-age	Pancreatic cancer, 3 years of illness
P5			Bone tumor, 3 years of illness
P6			Salivary gland cancer, 10 years of illness
F1	Family member	Younger sister	Breast cancer with metastasis, cared for over 5 years
F2		Husband	Brain cancer, cared for over 8 months
F3		First son	Lung cancer, cared for over 6 months
F4		Husband	Bone tumor, cared for over 3 years
F5		Daughter	Pancreatic cancer, cared for over 3 years
F6		Wife	Brain cancer, cared for over 2 years
F7		Wife	Esophageal cancer, cared for over 1 year

Table 3 Themes of the decision-making process related to end-of-life care

(1) Healthcare professionals' perspective	Profound empathy for patients and regrets over unnecessary medical procedures Concerns and hesitations about initiating discussions on LST withholding Start talking about LST carefully when a patient has the potential to deteriorate Swift progression after family members established a consensus
(2) Family members' perspective	A strong belief that a close bond leads to mutual understanding Trust in healthcare professionals who genuinely care about patients Belief in medical professional judgments on LST decisions
(3) Patients' perspective	A belief in the correct chosen action for their loved ones A feeling of being gradually pushed aside in life A fear of the moment when death approaches

Table 4 The actual dialogues that correspond to each extracted theme**1. Healthcare professional's perspective**

1-1. Profound empathy for patients and regrets over unnecessary medical procedures

"Just keeping patients in the ICU can cause all sorts of problems, such as pressure sores and other health issues. As time passes, the family starts noticing these things, which is just heart-wrenching. I cannot even imagine how tough it must have been for the patients. I had no clue at that point, but seeing those treatments and what comes with them made me realize how careful we need to be in those situations" (D1)

1-2. Concerns and hesitations about initiating discussions on LST withholding

"I choose the hallway for discussions to ensure that families are provided with some space. I start by talking to the families about sensitive matters, and if needed, I will discuss the matters further with the patients in their ward. The CCTV in the hallway and its recording capability adds an extra layer of documentation and security" (D2)

1-3. Start talking about LST carefully when a patient has the potential to deteriorate

"Now, the patient has difficulty eating. When the patient was admitted previously, he had an infection, so I thought, 'If this infection is not controlled, it is going to be difficult.' I actually spoke directly to the patient about this possibility"(D3)

1-4. Swift progression after family members established a consensus

"The most difficult part might be for the patient's caregiver. Who thought that once the patient passed this critical illness state, maybe things could improve. Is it right to proceed with stopping LST? This is something that the family continues to discuss among themselves. Some say they will do LST, and others say they will not. There are many cases similar to this. Some family members say they will not administer LST, but later, they reappear and start crying again, asking what should be done... Then I thought they had already decided, but if I ask, 'Should we cancel this decision and make a new one?' they say no, that is not it. So now..." (D4)

2. Family member's perspective

2-1. A strong belief that a close bond leads to mutual understanding

Host 1: Then, in making that decision about LST, if she had expressed your wishes, then normally, in general, she would have—

F1: Of course, she would have made the first choice

Host 1: How do you speculate on that?

F1: My sister's personality and mine are quite similar. Now, it is like a definitive personality of either I am in or out, similar to hers. So now... I cannot speak directly to the monk, but after I sign, I do not cry much in front of the patient (F1)

2-2. Trust in healthcare professionals who genuinely care about patients

"The Professor communicates well with the patient. I trust Professor KDY and the patient trusts Professor KDY, which is why this dynamic works. We have conditions for mutual communication, so, of course, we have to do what Professor KDY says" (F2)

2-3. Belief in medical professional judgments on LST decisions

"I trust Professor K and the patient trusts them, meaning this situation works. Therefore, we can communicate with each other, well, if Professor KDY asks, they have no choice but to do it"(F2)

3. Patient's perspective

3-1. A belief in the correct chosen action for their loved ones

"I wish I could go quickly, you know, with that kind of feeling. Why do I have to do this treatment? I think like that, and then I think about my family, and these two feelings keep going back and forth. But, well, I really do not want to cause harm to my kids or my family. That is why I made the decision because the harm is just too severe" (P4)

3-2. A feeling of being gradually pushed aside in life

"I used to be really strong, you know? I was very healthy and strong. I can overcome this. Then suddenly, when I heard it from my husband, it felt like he was pushing me towards death, like pushing me away from life" (P2)

3-3. A fear of the moment when death approaches

"I mean, I have already made a decision and mentally prepared myself, but it is still scary. Anyway, once I fall asleep, I will not know anything. Really scary. I just hope it goes painlessly; that is all I think about now" (P1)

patient's condition, to ensure that decisions on withholding LST were made progressively.

Swift progression after family members established a consensus Gathering opinions from family members was identified as the most time-consuming activity. Therefore, when a consensus was reached, subsequent steps, such as completing forms and planning, could proceed swiftly.

Family members' perspective

A strong belief that a close bond leads to mutual understanding Family members believed their close bond allowed them to understand the patient's intentions. Family members discussed death and their thoughts casually when someone they knew had passed away. Moreover, family members who had lived together for a long time felt that they could infer the meaning behind the words and actions of the patient.

Trust in healthcare professionals who genuinely care about patients Family members expressed great satisfaction when they encountered healthcare professionals with whom they could communicate well and establish rapport. Families trusted doctors who showed their human side, understood their feelings, and engaged in meaningful conversations.

Belief in medical professional judgments on LST decisions Caregivers acknowledged the challenges of obtaining medical information online due to complex terminology and nuances in cancer types. Therefore, families seeking precise guidance turned to healthcare professionals for comprehensive advice on patient-specific treatments, which involved understanding prognoses and the remaining survival time-frame. Thus, a patient-centric assessment and clear explanations could foster a shared understanding. This process could facilitate end-of-life decisions, especially in cases where viable treatment options are exhausted.

Patients' perspective

A belief in the correct chosen action for their loved ones The patients believed that withholding LST may be appropriate as caregivers could already be under financial, psychological, and physiological stresses. Consequently, most patients did not wish to place this additional burden on family members.

A feeling of being gradually pushed aside in life The phrase "a feeling of being terribly pushed aside in life" might sound awkward, but it accurately reflects the patient's words during the interview. This phrase can be further interpreted as a "feeling of alienation" or an "emotion of being distanced from others and life." This feeling is similar to the

experience described in a study that explored the end-of-life narrative of older people, where patients noted that their well-being was acknowledged even as they lost their sense of self and connection to the world. When the patients were interviewed in this study, they expressed having thoughts that they could fight and conquer cancer. However, when they discovered that no more treatment options remained and that it was time to decide whether to withhold LST, they became overwhelmed and experienced the sensation of someone pushing them out of life and into death.

A fear of the moment when death approaches Despite deciding not to undergo LST, when patients tried to complete the related paperwork, they expressed feeling like they were entering a deep pit from which they could never emerge, and there was still a fear of the moment of facing death. Therefore, they expressed hope for a natural death without being aware of the precise moment, wanting to peacefully pass away in their sleep without experiencing pain.

Emergence of the SDM process for LST

In the SDM process for deciding LST, we applied the 6C framework (Table 5). As outlined previously by Strauss [10], this study used a thematic analysis to categorize interview data into higher-level concepts (Fig. 1). This framework was referenced to enhance our understanding and intuition regarding human actions and interactions, and we ensured inter-coder reliability through a triangulation process involving two to three researchers.

Causal condition: an advanced-stage cancer diagnosis

Causal conditions refer to events that trigger or lead to the occurrence or development of a phenomenon. In the process of end-of-life medical decisions, the initial condition that precedes everything is the clinical and laboratory diagnosis, indicating a state where further cure is medically impossible with modern medicine. Subsequently, various treatment options are explored, often involving repeated failures and disappointments, leading to a realization that a return to a healthy state is no longer attainable.

Context: opting out of life-sustaining treatment (LST) amidst the conflict between perceptions of futility and the instinct for survival

A contextual phenomenon is a specific set of attributes that define a situation. During this phase, patients grapple with a balance between the perceived futility of LST and their innate desire to live. Patients employ their personal beliefs and past

Table 5 The actual dialogues correspond to the “6C” framework

Component	Verbatims
Causal condition	“For example, last year, it recurred, and now, after the surgery, it has again been removed; however, it kept coming out in different places, and now it is colon cancer, so it is getting worse. Unfortunately, it seems I will not live for a long time anymore” (P1) “I used to be really strong, you know? I am very healthy and strong. I can overcome this. However, suddenly, when I heard that from my husband, it felt like he was pushing it away, like pushing it away. I am really strong. I am not in pain; I can endure anything, but when he said that I could live only until next summer, I did not know how to deal with it; like, it feels like people around me are pushing me away, that kind of feeling” (P2)
Context	“As the colon cancer got worse, I felt like I could not stay like this for a long time. So, I thought it would be better to do it when I have a clear mind” (P1) “Previously, our mother had a fall, and unfortunately, she hit her head hard on the ground. At that time, we took her to Hospital B, and the doctor there said that if she did not undergo surgery immediately, she would pass away soon. From the family’s perspective, we could not accept the idea that our mother would pass away right then and there. So, we decided to go through with the surgery. However, after just about two or three weeks, it became clear that there was nothing more they could do for her in terms of treatment. They advised us to take her to a hospital closer to home for care. It was incredibly disheartening. We spent a significant amount of money on her treatment, and her condition deteriorated to the point where she could not even recognize us...(omission). Now, I have made up my mind. I am grappling with thoughts like, ‘Do I really need to continue life-sustaining treatment?’ and ‘Do I want to keep living?’ It is a constant back-and-forth. So, I have decided to complete the paperwork as soon as possible while mentally capable” (P2)
Central phenomenon	“My family and I have not really gotten into discussions about death, especially with each other. It is kind of tough. They are like, ‘Why think about death? Focus on staying alive’. But as we chat, every now and then, it feels like my family is also considering the idea of me not being around. It looks like they have pondered about my death, too” (P2)
Coordination strategy	“Because I sense that, I am gradually thinking, ‘Oh, it is getting worse,’ but my wife still believes she can overcome it by herself. In the midst of this, I have been saying, “Do whatever you want,” thinking it is best to let her decide, given that she is still alive. It is important to allow her to do what she feels is right. However, I have been keeping my thoughts to myself, not revealing them to her” (F4)
Contingent condition	“I hoped to hear more detailed discussions from the Professor’s perspective. However, these opportunities for such conversations are not always readily available, and it is nearly impossible with my mom and brother. If there is a chance, I would be the one to listen, but since I am constantly with my dad, there is no chance to ask separately. Additionally, as mentioned earlier, my family and I were curious whether my dad knows how much time he has left” (F5)
Consequence	“For my sake and the people around me, it is a choice I made. So, I keep thinking I am right” (P1) “My children have to pay for everything once a month, such as medical expenses. How can they not do that, being children and all, being their mother? They have their own things to do, too, right? So, it is not possible, so... I think I made a good decision. (Laughs) It seems like I made a good decision, even thinking about it” (P2)

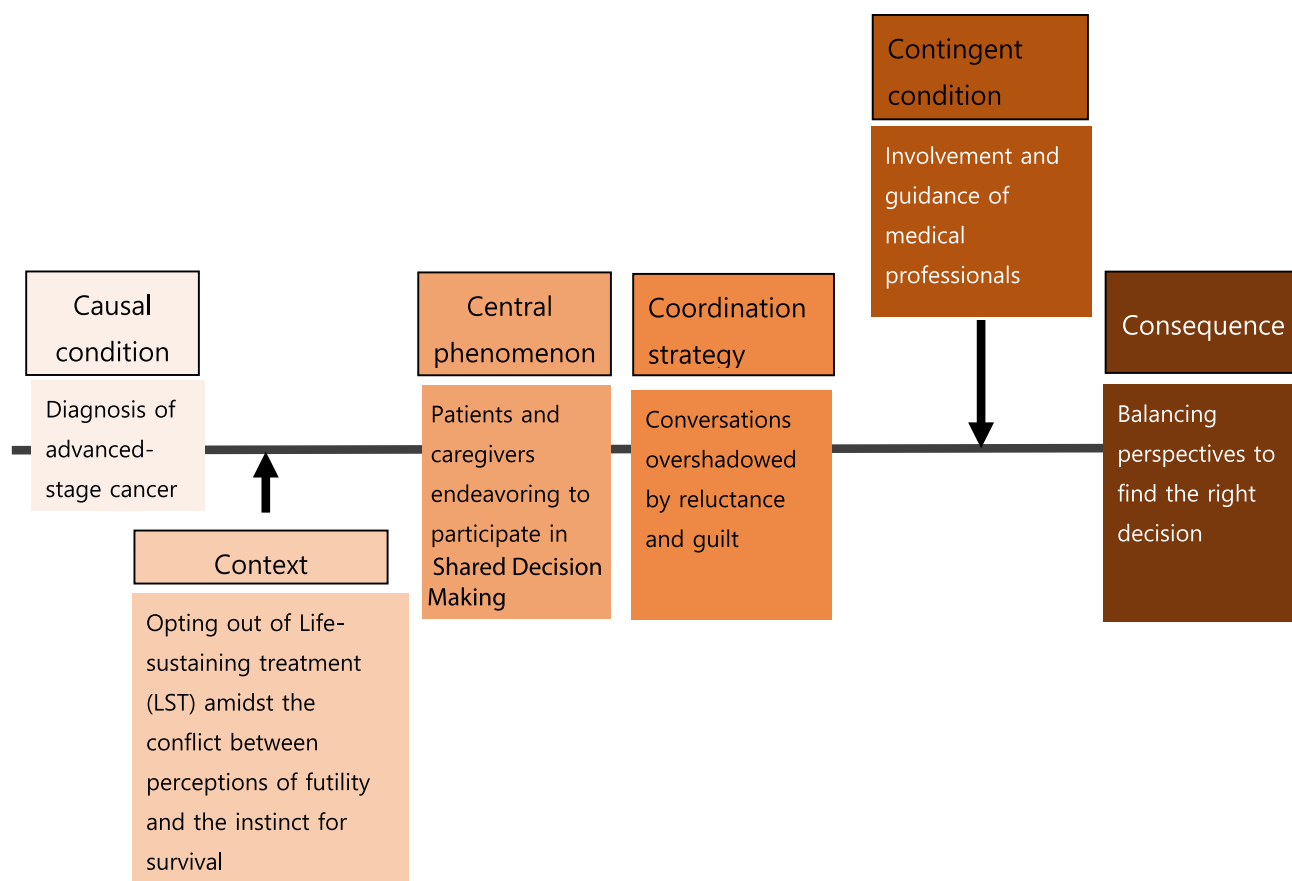


Fig. 1 The SDM process for LST based on interviews using “6C”

experiences to consider the worthlessness of LST. Additionally, this process triggers various emotions, including financial worries from LST, caregiver distress, and frustration from physical impairments. Ultimately, the patients decide to withhold LST.

Central phenomenon: patients and caregivers endeavoring to participate in SDM

Patients and caregivers often try to engage in careful discussions on LST since they believe that directly asking each other about death can cause emotional distress. Instead of openly stating their intentions, they subtly explore each other's thoughts, describing a situation as if it were someone else's business and gradually working to understand each other.

However, as the health of the patient deteriorates or the medical professionals intervene, these groups begin to inquire about each other's preferences and how the patient wishes to confront death. If their preferences align, an advanced care plan is created, and hospice care is considered. If preferences do not align, it leads to significant challenges among the patients, caregivers, and medical professionals. Nevertheless, a dialogue can be held regarding each party's preferences and approach to navigating the end of life.

Coordination strategy: conversations overshadowed by reluctance and guilt

While understanding each other's intentions, patients and caregivers may experience internal and external conflicts. Deciding to discontinue LST is regarded as an act of “giving up on life,” which can induce feelings of guilt and hesitation. This fear and sense of burden can cause delays in the decision-making process, especially when patients are unable to express their wishes due to conditions such as coma, cognitive impairment, or mental health issues.

Contingent condition: involvement and guidance of medical professionals

Contingent conditions involve regulating or managing a phenomenon or problem. Healthcare professionals often grapple with feelings of despair and helplessness when they come to terms with the absence of further treatment options for patients. In such a situation, healthcare professionals strive to provide a comprehensive overview of the remaining treatment options, highlighting their drawbacks and benefits. Following internal conflicts and exploration of alternatives, the

healthcare professionals gradually explain the futility of LST to the patients and caregivers. Here, healthcare professionals would draw on their experience of witnessing end-stage cancer patients undergo unnecessary suffering from LST. Ultimately, the aim is to facilitate a deeper understanding for patients and caregivers regarding the importance of a peaceful and dignified dying process.

Consequence: balancing perspectives to make the right decision

A consensus is reached after multiple conversations about each other's thoughts and values. As the illness progresses, the intensified pain of patients leads to more frequent thoughts of wanting to end their suffering. However, these contemplations increase their guilt in leaving behind young children or dependents, who often require care. Amidst these internal conflicts, patients gradually solidify their commitment to discontinuing LST, while caregivers acknowledge that they have done their best. Ultimately, the patients and caregivers mutually decide to discontinue LST, in alignment with their shared objective of prioritizing comfort or minimal pain during the remaining time.

Discussion

Exploring the end-of-life decision-making process, particularly withholding LST, could provide insights into the intricate dynamics among healthcare professionals, caregivers, and patients. Healthcare professionals experience various emotions. For example, there are feelings of empathy and remorse regarding unnecessary and inhumane medical procedures and emotional challenges of disclosing a prognosis, as observed in prior research [14]. In addition, they hesitate to initiate discussions on withholding LST until the condition of patients worsens, reflecting an ethical dilemma and emotional burden inherent in end-of-life conversations [15]. In this situation, healthcare professionals usually discuss withholding LST with the caregivers, not the patients. According to South Korean law, the "Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life," discussing LST discontinuation with caregivers first, not patients, can violate patient autonomy and their right to be fully informed. This law mandates that patients be fully informed about their medical conditions and treatment options to ensure autonomous decisions. Despite these legal requirements, many healthcare professionals first talk to family members due to fears of causing patients significant emotional shock or loss of hope.

This reversal in priority in favor of caregivers differs notably from the approach in Western countries. In certain Asian countries, such as Thailand, family members have more decision-making authority and options [16]. Recognizing the

influence of caregivers in clinical settings may lead to a tendency to provide them with information about the condition of patients. In Korea, similar cultural factors significantly influence SDM in end-of-life care. Most decisions are often made by caregivers, especially the sons or daughters of patients. However, due to the cultural notion that discontinuing LST is considered an unfilial act, caregivers may hesitate to make appropriate decisions. Moreover, in cases where caregivers do not want to discontinue LST, there is a tendency to prioritize the caregivers' opinions over the patients' wishes. This dynamic can lead to situations where treatment is administered based on a caregiver's preference, disregarding the explicit wishes of the patient. In a typical healthcare setting in Korea, where such an atmosphere prevails, there is a greater need for a SDM process that respects the patients' opinions. Therefore, a unique SDM model tailored to the specific characteristics of the Korean community is required.

Additionally, a reluctance to discuss death directly exists due to the taboo surrounding death [17]. However, deferring decisions until patients reach a terminal illness stage poses a significant risk of failing to fulfill their wishes [18], thus highlighting the need for nuanced approaches and cultural competence in healthcare settings [17]. Introducing communication courses, such as open conversation workshops, for families in hospital education centers could enhance communication and facilitate SDM. Open conversation workshops could also aid in addressing the psychological issues faced by patients.

In our study, we developed the "6C" framework to guide the complex and challenging SDM process for Koreans. This model covers the overall process of deciding whether to withhold LST following a terminal cancer diagnosis, which reflects the emotional states and perspectives of patients and caregivers, as well as the interactions among healthcare professionals, caregivers, and patients. The findings of this study are consistent with the literature [19], emphasizing the need for tailored interventions that acknowledge and navigate the complexities of cultural norms and moral obligations in SDM.

This study utilized a qualitative approach, which helped illustrate several themes, particularly concerning cultural factors, perceived barriers to the decision-making process, and opinions that have yet to be well-documented in prior quantitative studies.

This study is valuable because it proposed a SDM model based on the Korean sentiment and social context following the introduction of the Life-Sustaining Treatment Decision Act and using a grounded theory research methodology. These findings could serve as a basis for constructing a SDM model for the discontinuation of LST in various clinical settings in accordance with the cultural and social context of a community. Future studies should be conducted to apply the SDM model with guidance in routine clinical practice for patients and medical professionals.

Conclusion

End-of-life decision-making involves intricate dynamics among healthcare professionals, patients, and families, particularly when withholding LST. Healthcare providers face emotional challenges in disclosing prognoses and an ethical dilemma in performing unnecessary medical procedures. Furthermore, in the SDM process, cultural differences (e.g., Korean collectivist culture vs. Western individual autonomy) could significantly influence the decision-making process. Therefore, there is a need for systems that allow more flexible and open communication when making decisions on withholding LST. In line with these challenges, the current “6C” framework also emphasizes the significance of cultural norms and ethical obligations in the SDM process. Thus, this study highlights the necessity for tailored interventions to enhance patient and family involvement and calls for further research in diverse cultural contexts.

Acknowledgements The authors would like to acknowledge professor Anita Ho, who introduced us shared decision model (SEED) and instrumental in shaping this work.

Author contribution S-Y. Y, D. K SJ. S, JH. K, E.E.S and DY. K conceived the study. S-Y. Y, D.K, SJ. S, G. U and DY. K collected data. DY. K, Y. E, E.E. S and S-Y. Y performed qualitative analyses for the study. Y. E, DY. K and S-Y. Y wrote a draft of the manuscript. All authors contributed to data interpretation and the writing of the manuscript. DY. K is the guarantors.

Funding This work was supported by the National Evidence-based Healthcare Collaborating Agency (NECA) grant, a sub-organized research center under the Ministry of Health, South Korean government (No.NECA-NA-19-008). This research was supported by a grant from the Patient-Centered Clinical Research Coordinating Center (PACEN), funded by the Ministry of Health & Welfare, Republic of Korea (grant number HC21C0115).

Data availability No datasets were generated or analysed during the current study.

Declarations

Institutional review board statement This qualitative study’s ethical approval was obtained from Institutional Review Boards: National Evidence-based Health Care Collaborating Agency (No.19-005-7) and Dongguk University Ilsan Hospital (IRB# DUIH 2019-03-004).

Competing interests The authors declare no competing interests.

Open Access This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material

derived from this article or parts of it. The images or other third party material in this article are included in the article’s Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article’s Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Elwyn G et al (2005) The OPTION scale: measuring the extent that clinicians involve patients in decision-making tasks. *Heal Expect* 8:34–42
2. Edwards A, Elwyn G (2006) Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Heal Expect* 9:307–320
3. Kim DY et al (2007) Do-not-resuscitate orders for terminal patients with cancer in teaching hospitals of Korea. *J Palliat Med* 10:1153–1158
4. Oh DY et al (2006) CPR or DNR? End-of-life decision in Korean cancer patients: a single center’s experience. *Support Care Cancer* 14:103–108
5. Yoo SH et al (2023) Ethical issues referred to clinical ethics support at a university hospital in Korea: three-year experience after enforcement of Life-Sustaining Treatment Decisions Act. *J Korean Med Sci* 38:e182
6. Wi E (2019) “I want to finish it according to the law.” The number of patients receiving life-sustaining treatment has increased 29-fold in one year. Dong-a ilbo. <https://www.donga.com/news/list/article/all/20190709/96399590/1>
7. AHRQ. The SHARE Approach: A Model for Shared Decision-making. <https://www.ahrq.gov/health-literacy/professional-training/shared-decision/tools/factsheet.html>. Accessed 26 Jan 2023
8. Elwyn G et al (2012) Shared decision making: a model for clinical practice. *J Gen Intern Med* 27:1361–1367
9. Ho A, Jameson K, Eiser A (2017) Sowing the SEED for patient empowerment. *Am J Bioeth* 17:42–45
10. Strauss AL, Corbin J (1990) Basics of qualitative research: grounded theory procedures and techniques. Sage, Newbury Park, CA
11. Glaser BG (1978) Theoretical sensitivity: advances in the methodology of grounded theory. Sociology Press, Mill Valley, CA
12. Kallio H, Pietilä AM, Johnson M, Kangasniemi M (2016) Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *J Adv Nurs* 72:2954–2965. <https://doi.org/10.1111/jan.13031>
13. Mohajan D, Mohajan H (2022) Exploration of coding in qualitative data analysis: grounded theory perspective. *Res Adv Educ* 1:50–60
14. Yoo SH et al (2021) Difficulties doctors experience during life-sustaining treatment discussion after enactment of the Life-Sustaining Treatment Decisions Act: a cross-sectional study. *Cancer Res Treat* 53:584–592
15. Gordon EJ, Daugherty CK (2003) Hitting you over the head: oncologists’ disclosure of prognosis to advanced cancer patients. *Bioethics* 17:142–168
16. Tanaka M, Kodama S, Lee I, Huxtable R, Chung Y (2020) Forgoing life-sustaining treatment – a comparative analysis of regulations in Japan, Korea, Taiwan, and England. *BMC Med Ethics* 21:99
17. Van Keer RL, Deschepper R, Huyghens L, Bilsen J (2021) Withholding/withdrawing life-sustaining treatment in a

- multiethnic critical care setting: an ethnographic study. *J Palliat Med* 24:338–346
18. McPherson K, Carlos WG, Emmett TW, Slaven JE, Torke AM (2019) Limitation of life-sustaining care in the critically ill: a systematic review of the literature. *J Hosp Med* 14:303–310. <https://doi.org/10.12788/jhm.3137>
 19. Holloway RG et al (2014) Palliative and end-of-life care in stroke: a statement for healthcare professionals from the american heart association/american stroke association. *Stroke* 45:1887–1916
 20. Lee HR, Lim C, Yun HG, Kang SH, Kim DY (2018) Making an informed decision of Korean cancer patients: the discrepancy between a patient's recall of information and the information needed for acquisition of radiotherapy informed consent. *Support Care Cancer* 26:297–303

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Authors and Affiliations

Soo-Young Yu¹  · Yu-eun Lee^{2,3}  · Sung Joon Shin^{3,4,5}  · Go-un Woo^{2,3,5}  · Dalyong Kim^{2,3,5}  · Jung Hye Kwon^{6,7,8}  · Do Yeun Kim^{2,3,5}  · Eunyoung Eunice Suh⁹ 

✉ Do Yeun Kim
smdkdy@hanmail.net

✉ Eunyoung Eunice Suh
esuh@snu.ac.kr

Soo-Young Yu
sooyoung0809@gmail.com

Yu-eun Lee
dlbmdms2@gmail.com

Sung Joon Shin
shine@med.dongguk.ac.kr

Go-un Woo
palimpseste@naver.com

Dalyong Kim
moondragon81@naver.com

Jung Hye Kwon
kwonjhye.onco@gmail.com

¹ College of Nursing, Chonnam National University, 160 Baekseo-Ro, Dong-Gu, Gwangju 61469, Republic of Korea

² Division of Hematology and Medical Oncology, Dongguk University Ilsan Hospital, Goyang, Republic of Korea

³ Dongguk University College of Medicine, Goyang, Republic of Korea

⁴ Division of Nephrology, Dongguk University Ilsan Hospital, Goyang, Republic of Korea

⁵ Department of Internal Medicine, Dongguk University College of Medicine, Gyeongju, Republic of Korea

⁶ Department of Internal Medicine, Chungnam National University College of Medicine, Daejeon, Republic of Korea

⁷ Department of Internal Medicine, Chungnam National University Sejong Hospital, Sejong, Republic of Korea

⁸ Daejeon Regional Cancer Center, Daejeon, Republic of Korea

⁹ College of Nursing, The Research Institute of Nursing Science, Center for Human-Caring Nurse Leaders for the Future By Brain Korea 21 (BK 21) Four Project, Seoul National University, Seoul, Republic of Korea