



Content Analysis of Online Resources Regarding Needs for Advance Care Planning

Minju Kim, R.N., Ph.D. and Jieun Lee, R.N., Ph.D.*

College of Nursing, Dong-A University, Busan

*Department of Nursing, Choonhae College of Health Science, Ulsan, Korea

Purpose: This study aimed to investigate advance care planning needs expressed online.

Methods: This study collected data from online community posts and healthcare news sites. The search keywords included “death,” “euthanasia,” “life-sustaining medical care,” “life-sustaining treatment,” “advance directives,” “advance medical directives,” and “advance care planning.” Data collection spanned from February 2018 to February 14, 2020. Out of 2,288 posts, 1,190 were included in the final analysis. Data analysis was conducted using NVivo 12, a qualitative data analysis software program. **Results:** Content analysis categorized patients' advance care planning needs into eight themes, 11 theme clusters, and 33 meaningful statements. Similarly, care providers' advance care planning needs were categorized into eight themes, 14 theme clusters, and 42 meaningful statements. The identified themes of care needs included life-sustaining medical care, decision-making related to life-sustaining medical care, physical care, environmental care, supportive and spiritual care, respect, preparing for death, and family. **Conclusion:** This study identified care needs from the perspectives of patients and their families. The findings may serve as preliminary data for future research and clinical applications.

Key Words: Terminal care, Palliative care, Qualitative research

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Correspondence to

Jieun Lee

ORCID:

<https://orcid.org/0000-0001-9068-1433>

E-mail: jieun@ch.ac.kr

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INTRODUCTION

1. Background

Discussing death is challenging, particularly in cultures like Korea where family-centered decision-making prevails. This often makes it difficult for individuals to express their personal preferences for advance care planning openly. Consequently, patients may be excluded from making decisions about their own life-sustaining treatment and might be compelled to undergo treatments that contradict their wishes. However, in response to growing societal demand for self-determination

rights, the “Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life” (hereinafter referred to as “the Decisions on Life-Sustaining Treatment Act”) was established in 2018 [1]. This law provides legal protection for individuals' rights to make decisions about their life-sustaining treatment.

In the Decisions on Life-Sustaining Treatment Act, life-sustaining treatment is defined as cardiopulmonary resuscitation (CPR), hemodialysis, administering anticancer drugs, and mechanical ventilation. In contrast, the US Physician Orders for Life-Sustaining Treatment (POLST) form not only offers choices regarding CPR and medical interventions—ranging

from full, selective, to comfort-focused treatments—but also includes artificially administered nutrition as an option for life-sustaining treatment that individuals can choose. Aging with Dignity in the US has developed the Five Wishes form, an advance care planning tool that addresses personal preferences across five areas of care needs: 1) The person designated to make care decisions when the individual is unable to; 2) The type of medical treatment desired or not desired; 3) Desired comfort levels; 4) Preferred ways of being treated by others; and 5) Important messages the individual wishes to communicate to loved ones. Five Wishes is used in all 50 states in the United States and is legally recognized in some states [2]. In Korea, however, the advance statement on life-sustaining treatment is the only legally recognized form currently in use based on the Decisions on Life-Sustaining Treatment Act. This reflects a gap in the availability of tools for expressing one's care preferences beyond life-sustaining treatment.

Recent studies in Korea have utilized tools to assess the needs of community-dwelling end-of-life patients, focusing on older adults [3] and noncancer patients [4]. However, there remains a need for methods that facilitate easier discussions on challenging topics such as death and life-sustaining treatment. Outside Korea, various games like Go Wish cards [5,6] and Hello, Bucket List have been employed to simplify conversations about death and life-sustaining treatment, aiding in the exploration of advance care planning needs. These games help to comprehensively identify not only preferences for life-sustaining treatment but also other factors, such as the desired level of comfort at the time of death, the environment, and spirituality. When the Go Wish game was used to determine care needs, the needs deemed most important by patients included “to be at peace with God,” “to pray,” and “to have my family with me” [5]. In another study, the primary need identified was “to be free from pain” [6]. Proactively identifying various care needs can enhance the quality of life for end-of-life patients until their final moments, while also reducing medical costs associated with unnecessary life-sustaining treatments and alleviating the burden on caregiving family members.

One international study explored the discrepancy between the care patients desire and the care they actually receive, aiming to assess if patient care needs are being met. The find-

ings indicated that 77% of patients received the care they had hoped for [7]. In contrast, research conducted in Korea revealed that patients who had signed a do-not-resuscitate (DNR) order still received life-sustaining treatments, such as mechanical ventilation, at a rate of 100% [8]. These results suggest a significant gap between the preferred care of patients and the care they ultimately receive. To tackle this issue, it is crucial to proactively determine patients' preferences regarding their end-of-life care.

Korea has an internet usage rate of 91.9%, meaning that most people communicate through the internet [9], and various online communities have been formed as platforms for communication. In particular, there are well-established online communities for cancer patients that provide opportunities for patients to reflect on death while living with cancer. As patients can express their own opinions through the internet as a communication channel, this study investigated opinions expressed as posts on online communities and websites. The anonymity provided by the internet enables individuals to express their views freely without the need to reveal their identity [10,11]. Consequently, individuals might feel more comfortable discussing sensitive topics such as end-of-life and death, which are often avoided in face-to-face conversations.

Accordingly, this study aimed to identify the needs for advance care planning expressed in online communities and websites, as a means of gathering opinions on end-of-life care.

METHODS

1. Study design

This study was designed as a qualitative analysis using Bengtsson's content analysis method [12] to identify the needs for advance care planning through the internet.

2. Subjects

This study examined content from online communities dedicated to cancer patients and their families, including “Beautiful Companionship” (<https://cafe.naver.com/livehope>), “Breath Love” (<https://cafe.naver.com/lung>), and “Am Winner” (<https://cafe.naver.com/amwinner>). These communities

are among the top-ranked Naver cafes, each boasting over 150,000 registered members. “Beautiful Companionship” and “Breath Love” are recognized as exemplary cafes within the Naver network, featuring posts that share experiences and discuss needs related to end-of-life care. Additionally, the study reviewed interview articles focused on end-of-life care needs published on various healthcare news websites, including The Korean Nursing Association News, Korean Hospital Association News, Doctors Times, Doctors News, Health Korea News, Medical Times, Medipana News, and Medifo News.

Patients diagnosed with various types of cancer—including gastric, colon, rectal, breast, hemangiosarcoma, lymphoma, lung, and cervical cancer—at any stage, from stage 1 to end-stage, are eligible to join these online communities. Family members and caregivers are also welcome to register.

3. Data collection

In this study, data collection was conducted through web crawling using an R package to identify specific keywords—“death,” “euthanasia,” “life-sustaining medical care,” “life-sustaining treatment,” “advance directives,” “advance medical directives,” and “advance care planning.” This search targeted online communities and healthcare news sites, spanning from the enactment of the Decisions on Life-Sustaining Treatment Act in February 2018 to February 14, 2020. Web crawling

involves using software to search for and retrieve web pages, extracting only the relevant data [13,14]. The content from online communities, which maintain anonymity, is accessible to anyone through simple searches on online portal sites [13,14]. Therefore, this study utilized only data that was publicly available. The researchers were granted access to view the posts as registered members of these online communities.

Data collected through web crawling were thoroughly reviewed by two researchers and categorized into posts by patients and caregivers. The inclusion criteria were established following a consensus between the researchers. These criteria included posts that shared personal experiences with end-of-life care, posts by caregivers detailing the end-of-life care they provided, and posts expressing the need for advance care planning. In this study, the advance care planning needs of patients referred to the care needs articulated by patients receiving end-of-life care for diseases, including cancer. Conversely, the advance care planning needs of caregivers pertained to the needs arising when family members provided care. Regarding the exclusion criteria, duplicates, book reviews related to the keywords, advertisements, and content unrelated to advance care planning were omitted. Out of a total of 2,288 posts collected, 913 unrelated to advance care planning and 161 duplicates were excluded from the analysis. As a result, a total of 1,190 posts were included in the final analysis (Figure 1).

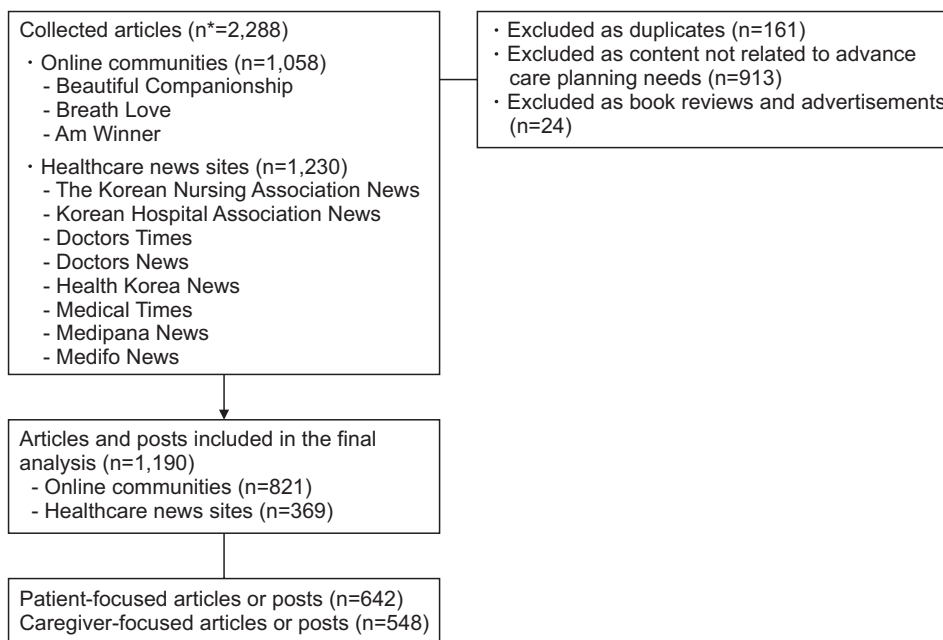


Figure 1. Data collected.
*The number of articles collected.

4. Ethical considerations

This study received an exemption from review by the Institutional Review Board (IRB) of “D” University (2-1040709-AB-N-01-202002-HR-002-02). It focused on analyzing text data from online communities and healthcare news sites. Data collection was limited to sites that permit web crawling. Sites that restrict web document searches have a management program that automatically disables the search function. For this study, only sites that allowed site searches were used. Both titles and contents of posts were gathered through web crawling. Since the posts on these sites were made anonymously, no sensitive data, such as personal information, were collected.

5. Data analysis

In this study, Bengtsson’s qualitative content analysis method was used to examine the needs associated with advance care planning [12,15]. We used NVivo 12 software for the data analysis. The process involved several steps: Initially, two researchers independently and thoroughly read the posts under analysis, identifying and coding significant statements (decontextualization). They also assigned numbers to distinguish between the needs of patients and caregivers. In the subsequent step, these coded statements were double-checked, and the entire content was reviewed again (recontextualization) to ensure no omissions. The codes were then reassessed by both researchers to confirm their appropriateness. The third step involved condensing and categorizing the data, where constructions of similar meanings were grouped to form theme clusters. Throughout the analysis, the researchers compared their findings, discussed any discrepancies until a consensus was reached, and then re-categorized the data into main themes. In the final step, to compile substantiated conclusions, the results were evaluated against the original text based on feedback from a nursing professor experienced in qualitative research who had not been involved in the analysis. This assessment determined the reasonableness of the findings. Additionally, triangulation was conducted for validation, involving analysis by an external researcher and consensus through discussion of the results [16]. The researchers involved in this study are experienced in qualitative research, having participated in relevant seminars and completed educational programs in this field.

RESULTS

This study analyzed content regarding advance care planning needs from patient and caregiver perspectives. The analysis yielded eight themes, 11 theme clusters, and 33 meaningful statements concerning the advance care planning needs of patients (Table 1), while eight themes, 14 theme clusters, and 41 meaningful statements were derived for the advance care planning needs of caregivers (Table 2). For the advance care planning needs of patients and caregivers, a total of eight themes were derived: needs for life-sustaining treatment, needs for making decisions about life-sustaining treatment, needs for physical care, needs for environmental care, needs for supportive and spiritual care, needs for respect, needs regarding preparation for death, and needs regarding family.

1. Advance care planning needs among patients

1) Theme 1: Needs for life-sustaining treatment

With respect to the needs for life-sustaining treatment among patients, four meaningful statements were desired within the theme cluster “choices for life-sustaining treatment.” The statements regarding choices for life-sustaining treatment expressed whether patients wanted to continue to receive or refuse life-sustaining treatment by CPR, chemotherapy, and/or mechanical ventilation.

... in the end, I don’t want to be fed through a nasal tube and I told that to my family... (Patient 1)

2) Theme 2: Needs for making decisions about life-sustaining treatment

Regarding patients’ needs for making decisions about life-sustaining treatment, two statements within the theme cluster “self-determination about life-sustaining treatment” were desired. The needs of patients reflected their desire to make their own decisions about life-sustaining treatment and prepare a document about life-sustaining treatment in advance.

I always ask my husband—I just want to be home with family, but never in a hospital. I don’t want an IV infusion with a needle stuck in me and having a nasal tube inserted. [I ask him] to help me make my own decisions and choices when the

Table 1. Patient Needs for Advance Care Planning (N=262).

Theme	Theme clusters	Meaningful statements	n(%)*
Needs for life-sustaining treatment	Choices for life-sustaining treatment	The patient wants to make their own choices about CPR	3(1.1)
		The patient wants to make their own choices about chemotherapy	15(5.7)
		The patient wants to make their own choices about the ventilator	5(1.9)
		The patient wants to make their own choices about artificial nutrition	4(1.5)
Needs for making decisions about life-sustaining treatment	Self-determination about life-sustaining treatment	I want to make my own decisions on end-of-life care	6(2.3)
Needs for physical care	Painless death	I want to create a document for end-of-life care	41(15.6)
		I do not want to feel pain	39(14.9)
	Preferences for the body	I want pain medication	4(1.5)
		I want to eat anything I desire	1(0.4)
	Physical activities	I want myself to look neat	2(0.8)
		The patient wants to go on a trip	3(1.1)
		The patient wants to take rest	2(0.8)
		I want to go for a walk	3(1.1)
Needs for environmental care	The environment in which to spend the end-of-life care	I want to engage in regular exercise	6(2.3)
		I want to meditate	1(0.4)
		The patient wants to spend their last days in a nursing home	5(1.9)
		The patient wants to spend their last days in a hospice facility	20(7.6)
Needs for supportive and spiritual care	Religious care	The patient wants to spend their last days at home	22(8.4)
		I want to pray	2(0.8)
Needs for respect	Humane respect	I want someone who is considerate to provide care for me	4(1.5)
Needs regarding preparation for death	Organizing life	The patient wants to organize their thoughts and feelings	5(1.9)
		I want my home, room, etc. to be tidy	28(10.7)
		I want to reflect on my relationships	3(1.1)
		I want to prepare a portrait photo	4(1.5)
	Preparing for after death	I want to talk about how my body will be treated after death	13(5.0)
		The patient wants a funeral without too much sadness	4(1.5)
		I want to donate my body	2(0.8)
		I want to plan my will and estate	3(1.1)
Needs regarding family	Care the patients want to receive from their families	The patient wants to spend most time with their family	3(1.1)
		The patient wants to visit with family, friends, etc.	1(0.4)
		The patient wants to say goodbye to their family	2(0.8)
		The patient wants to forgive and be forgiven by and reconcile with their family	2(0.8)
		The patient wants the family to remember them in a good light	4(1.5)
		Total	

*The number of derived meaningful statements.

Table 2. Caregiver Needs for Advance Care Planning (N=219).

Theme	Theme clusters	Meaningful statements	n(%)*	
Needs for life-sustaining treatment	Choices for life-sustaining treatment	The patient wants to make their own choices about CPR	2(0.9)	
		The patient wants to make their own choices about hemodialysis	3(1.4)	
		The patient wants to make their own choices about chemotherapy	7(3.2)	
		The patient wants to make their own choices about the ventilator	5(2.3)	
		The patient wants to make their own choices about artificial nutrition	2(0.9)	
Needs for making decisions about life-sustaining treatment	Self-determination about life-sustaining treatment	The patient wants to make their own decisions on end-of-life care	3(1.4)	
		The patient wants to create a document for end-of-life care	20(9.1)	
Needs for physical care	Family decision-making about life-sustaining treatment	The patient wants decisions on end-of-life care to be made in consultation with their family (and healthcare providers)	18(8.2)	
		Painless death	The patient wants to be pain-free	7(3.2)
Needs for physical care	Preferences for the body	The patient wants pain medication	4(1.8)	
		The patient wants to wear what they desire	2(0.9)	
		The patient wants their body to not be damaged	3(1.4)	
		The patient wants to eat what they desire	2(0.9)	
		The patient wants to look neat	2(0.9)	
		Physical activities	The patient wants to go on a trip	6(2.7)
		The patient wants to take rest	1(0.5)	
Needs for environmental care	The environment in which to spend the end-of-life care	The patient wants their own space	12(5.5)	
		The patient wants a place to listen to the music of their liking	3(1.4)	
		The patient wants to spend their last days in the hospital	2(0.9)	
		The patient wants to spend their last days in a nursing home	22(10.0)	
		The patient wants to spend their last days in a hospice facility	20(9.1)	
Needs for supportive and spiritual care	Religious care	The patient wants to spend their last days at home	6(2.7)	
		The patient wants a clergy visit	7(3.2)	
		The patient wants to listen to hymns	2(0.9)	
		The patient wants someone to pray with/for them	4(1.8)	
		Supportive care	The patient wants to be hugged often	2(0.9)
Needs for respect	Humane respect	The patient wants to be gently stroked	2(0.9)	
		The patient wants their hand to be held	1(0.5)	
Needs regarding preparation for death	Organizing life	The patient wants to be cared for by someone considerate	10(4.6)	
		Preparing for after death	The patient wants to organize their thoughts and feelings	2(0.9)
		The patient wants to prepare a portrait photo	1(0.5)	
Needs regarding family	Care the families want to give to the patients	The patient wants to talk about how their body will be treated after death	2(0.9)	
		The patient wants a funeral without too much sadness	2(0.9)	
		The family wants to tell the patient they love them	3(1.4)	
		The family wants to fully express words, thoughts, and feelings to the patient	6(2.7)	
		The family wants to make memories by taking lots of photos and videos of the patient	8(3.7)	

time comes. (Patient 2)

I am also planning to fill out an advance statement on life-

sustaining treatment soon to refuse life-sustaining treatment. If there is no possibility of resuscitation, I think it would be best to terminate life-sustaining treatment. Of course, this is just

Table 2. Continued.

Theme	Theme clusters	Meaningful statements	n(%)*
	Care the caregivers want to receive from their family	The patient wants to spend most time with their family The patient wants to visit with family, friends, etc. The patient wants to say goodbye to their family The patient wants to forgive and be forgiven by and reconcile with their family The patient wants the family to remember them in a good light	5(2.3) 1(0.5) 7(3.2) 1(0.5) 1(0.5)
Total			219(100)

*The number of derived meaningful statements.

my personal opinion. (Patient 3)

3) Theme 3: Needs for physical care

With respect to the needs for physical care among patients, nine meaningful statements were desired within three theme clusters: “painless death,” “preferences for the body,” and “physical activities.” Patients expressed a desire for a pain-free end of life and preferred to manage pain using medication. Additionally, they wanted to continue eating their favorite foods and maintain a neat appearance until their final moments.

I am thinking that if the pain gets too severe, I will discontinue chemotherapy and go to the clinic to get morphine to control the pain and just close my eyes. Pain is scarier than cancer. (Patient 4)

I don’t want to face death looking pitiful in anyone’s eyes. Even if I can’t look beautiful, I want to at least keep a neat appearance. (Patient 5)

4) Theme 4: Needs for environmental care

Regarding the needs for environmental care, three meaningful statements within the theme cluster “the environment in which to spend the end of life” were desired. Varying preferences were expressed, with some patients wanting to spend the end of their life at a nursing home or a hospice facility, while others wanted to spend time in a familiar setting at home.

I just want to spend the rest of my life in a humane way in a hospice, comfortably and without suffering, instead of dealing

with so much suffering from chemotherapy. (Patient 6)

5) Theme 5: Needs for supportive and spiritual care

With respect to patients’ needs for supportive and spiritual care, there was one meaningful statement within the theme cluster “religious care.” Patients relied on religion and wanted prayers for themselves.

It’s so nice that the pastor comes every day to pray for me. (Patient 7)

6) Theme 6: Needs for respect

Regarding the needs for respect among patients, one meaningful statement was identified within the theme cluster “humane respect.” Patients expressed a desire for considerate words and attitudes from medical staff and other caregivers.

The nurses were kind and did everything for me, from bathing me to cutting my hair, and I liked the feeling of being cared for. (Patient 8)

7) Theme 7: Needs regarding preparation for death

With respect to the needs regarding preparation for death among patients, eight meaningful statements were desired within two theme clusters: “organizing life” and “preparing for after death.” Patients expressed a desire to prepare for death by organizing their physical environments, including their homes and rooms, as well as managing their emotions and personal relationships. Additionally, patients expressed intentions to donate their bodies or create a will.

When I was first diagnosed with cancer and started receiving treatment, such as surgery and chemotherapy, there were many things I wanted to do and I was sad and desperate, but still full of hope. Even as I continued with endless chemotherapy after my relapse, I was organizing my room and thoughts, cried, settled my emotions, and had places I wanted to go to, but... (Patient 9)

I believe cancer patients can't donate their organs. If they can accept the cornea, I want to donate it. (Patient 10)

8) Theme 8: Needs regarding family

In terms of patients' needs regarding family, five meaningful statements within the theme cluster "care the patients want to receive from their families" were desired. They wanted to spend as much time as possible with their families in the end, while wanting to forgive and reconcile with each other. They also wanted the family members they leave behind to remember them in a good light rather than when they were sick.

Only with my family, in this room, in my bed where I would always lie down. I don't want anyone else. That is my biggest wish. (Patient 11)

... Remember me sitting in the parent's seat wearing a pretty hanbok on your wedding day. I wish you would remember me as I was in your wedding photos. Not my sick appearance now... (Patient 12)

2. Advance care planning needs among caregivers

1) Theme 1: Needs for life-sustaining treatment

With respect to caregivers' needs for life-sustaining treatment, five meaningful statements within the theme cluster "choices for life-sustaining treatment" were desired. The statements expressed choices about CPR, hemodialysis, chemotherapy, mechanical ventilation, and artificial nutrition.

After being suddenly diagnosed with cancer and hearing about inoperable life-sustaining treatment, he got the train of chemotherapy without understanding what that meant. The outcome was miserable. He suffered from terrible pain while still believing in the possibility of a miracle, his quality

of life hit rock bottom, and he endured that suffering until he passed away. Then, I started thinking—is this the best option? Wouldn't it be better to spend meaningful time with family while just controlling pain? ... However, even if that time comes again, I think I will choose chemotherapy. (Caregiver 1)

2) Theme 2: Needs for making decisions about life-sustaining treatment

In terms of needs for making decisions about life-sustaining treatment among caregivers, there were three statements within two theme clusters: "self-determination about life-sustaining treatment" and "family decision-making about life-sustaining treatment." Caregivers expressed a preference for patients to make their own decisions regarding life-sustaining treatment and to prepare the necessary documentation. However, they also emphasized that decisions about such treatments should involve family consultations, given the associated financial burdens.

Family and relatives... They don't want tracheostomy while intubated since it can't be treated and the patient isn't conscious, while the burden of hospital bills increases due to prolongation of treatment... (Caregiver 2)

3) Theme 3: Needs for physical care

With respect to physical care that caregivers wanted, eight meaningful statements were desired within three theme clusters: "painless death," "preferences for the body," and "physical activities," similar to those of patients. Caregivers wanted the patients to not be in pain and wanted to dress them in their favorite clothes, to spend the final days with a neat appearance. In addition, caregivers wanted the patients to travel and rest.

I wish I could go back to just one year ago... Then, I can travel more with my data and talk to him more. (Caregiver 3)

4) Theme 4: Needs for environmental care

Regarding the needs for environmental care among caregivers, six meaningful statements within the theme cluster "the environment in which to spend the end of life" were desired. Caregivers expressed a desire for a secluded space, such as a private room, where caregivers could spend the final days

with family, away from others, and where they could listen to music. Additionally, they indicated a preference for receiving professional care at a hospital or hospice facility, aside from the home setting.

Also, because it was not a ward or intensive care unit, our family was able to have enough time in the private room to talk things over and say our final farewell. (Caregiver 4)

5) Theme 5: Needs for supportive and spiritual care

With respect to caregivers' needs for supportive and spiritual care, six meaningful statements were desired within two theme clusters: "religious care" and "supportive care." Caregivers expressed a desire for a human touch, specifically wanting to hold, caress, and hold hands with the patients as much as possible. Additionally, they sought religious care, including visits from clergy to pray and worship together.

I was with my dad to hold his hands more as he was fighting alone, in fear of death. (Caregiver 5)

...on the fourth day, I saw the minister from another church who was visiting a patient, so I asked for prayer again and sang hymns in his ears. (Caregiver 6)

6) Theme 6: Needs for respect

In terms of the needs for respect among caregivers, one meaningful statement within the theme cluster "humane respect" was identified, similar to that of patients. From the caregiver's perspective, they wanted patients to receive care with consideration.

What I'm thankful about is that when we went to the hospice, they were warm and we have many fond memories. Warm care from the staff was good and having time to organize things with mom was a great happiness. (Caregiver 7)

7) Theme 7: Needs regarding preparation for death

With respect to caregivers' needs regarding preparation for death, four meaningful statements were desired within two theme clusters – "organizing life" and "preparing for after death." Caregivers expressed a desire to take a portrait photo

of the patient for the funeral and to discuss with the patient what should be done with their body after death. Additionally, they stated that they did not want the funeral to be a sad event.

When people came to my husband's funeral, I just wanted them to laugh together and remember the happy times as they watched videos of our family and feel the love of our family instead of just eating food in a heavy atmosphere. (Caregiver 8)

8) Theme 8: Needs regarding family

Regarding the needs regarding family among caregivers, eight meaningful statements within two theme clusters—"care the families want to give to the patients" and "care the caregivers want to receive from their family"—were desired. Similar to the advance care planning needs of patients, caregivers expressed a desire to spend ample time with their families. They also wished to have opportunities for final farewells, to offer forgiveness, and to achieve reconciliation. Additionally, caregivers wanted to express their love to the patients, communicate previously unspoken thoughts, and cherish memories through photos and videos left behind.

During the final week, I whispered in my dad's ears about how much I love him and how grateful I am for raising me so well. I should have done it sooner, but I stood by till the end until he closed his eyes. (Caregiver 9)

DISCUSSION

This study analyzed the needs for advance care planning as expressed in online communities, distinguishing between the perspectives of patients and caregivers. It explored the type of care individuals anticipated needing once they became patients, as well as the care they expected to provide when acting as caregivers to patients.

With respect to the needs for life-sustaining treatment, patients and caregivers expressed a desire to choose options such as artificial nutrition, in addition to CPR, mechanical ventilation, hemodialysis, and the administration of anticancer drugs, all of which are specified as life-sustaining treatments in the Decisions on Life-Sustaining Treatment Act. In Korea, Article

19–2 of this Act mandates that “In implementing determination to terminate, etc., life-sustaining treatment, the medical care for pain relief and simple provision of nutrients, water, and oxygen shall be provided without ceasing” [1]. The exclusion of artificial nutrition from life-sustaining treatments is based on the view that providing nutrition is a basic human right and not subject to individual self-determination. In contrast, the US culture strongly supports self-determination rights, thereby considering artificial nutrition as an option that individuals can choose. Previous studies have indicated that patients desire the option of artificial nutrition as one of the factors in terminating life-sustaining treatment [17], a finding that this study also supports. Consequently, there is a need to further explore social awareness regarding the inclusion of artificial nutrition in life-sustaining treatment.

Regarding decisions about life-sustaining treatment, various preferences have been identified concerning who should make these decisions. Some individuals emphasize the importance of self-determination in their own life-sustaining treatment, while others prefer that family members or medical professionals make these decisions. According to a July 2023 report by the National Agency for Management of Life-Sustaining Treatment, there were instances where the decision to terminate life-sustaining treatment was made directly by the patient through a documented intent form, such as an advance statement on life-sustaining treatment ($n=20,649$). In contrast, decisions made in agreement with the family were more common ($n=79,631$), highlighting a cultural emphasis on family-centered decision-making [18]. This underscores the need for a procedure to verify the role patients wish to play in the decision-making process regarding their life-sustaining treatment.

With respect to physical care, needs related to the desire for a painless death, physical activities, and body preferences were identified. There was an expressed desire for pain medication to ensure a pain-free state. This aligns with findings from studies by Chung and Cho [19] and Yoo [20], which reported that experiencing severe pain at the end of life is not considered a dignified death. Similarly, this study revealed that patients wanted to be free from pain. Additionally, care needs encompassing basic human desires, such as maintaining a neat appearance, wearing favorite clothes, and eating preferred

foods, were also identified. These findings echo those of other studies that emphasized the importance of clean clothes and physical care, including bathing [17]. Physical care includes not only medical treatment needs, such as pain management, but also basic care needs. To provide adequate care that meets these needs, it is essential to regularly assess the care requirements.

Regarding environmental care needs, there was significant interest in the preferred location for patients to spend their final days. Many patients expressed a desire to be at home, while others preferred a hospital, nursing home, or hospice facility. Some sought an isolated space or a place where they could enjoy their favorite music. Although previous studies have described dying at home with a “good death” [21], statistics show that 74.8% of patients pass away in medical institutions, significantly more than the 16.1% who die at home [22]. In addition, patients often are hospitalized as they near their end of life [23]. These findings reflect a dichotomy between the comfort of a familiar home environment [19] and the need for professional care in a medical facility as life ends. Furthermore, there is a growing need for specialized care in hospice facilities, spurred by the enactment of the Decisions on Life-Sustaining Treatment Act. Interest in hospice care is increasing, and perceptions of these facilities are evolving to view them as places for a dignified or respectful death [24]. Therefore, expanding hospice facilities should be considered to meet the environmental care needs at the end of life.

Needs regarding family encompassed the care that family members wished to provide to the patient and the care that the patient desired to receive from family members during their end-of-life period. Caregivers expressed a desire to convey their love to the patients and to share sentiments previously unspoken, while also hoping to preserve memories of the patients through photographs or videos. According to Five Wishes [2], patients often want to tell their families about their love for them. Contrastingly, a study by Lee and Kim [21] reported that patients wished to pass away without imposing burdens or causing suffering to their families. However, the findings of this study diverged from those of earlier research, revealing that both end-of-life patients and their family members sought to express love and create lasting memories. While recognizing the importance of addressing patient care needs, it

is equally crucial to evaluate and facilitate the care that family members are eager to provide. Providing opportunities for family members to participate in patient care is believed to potentially alleviate complicated grief and ease difficulties among bereaved families in the future.

This study analyzed posts from online communities frequented by cancer patients who often contemplate death, aiming to identify the advance care planning needs of both patients and caregivers. Given that the care planning needs may vary between patients and caregivers, it is crucial to assess these needs regularly. Moreover, to ensure that patients receive the care they desire at the end of life, there should be provisions for early discussions about preferred care options with family members. The findings from this study could serve as foundational data to initiate such conversations. Consequently, there is a perceived need to develop a tool that facilitates easy discussions on these profound topics. Identifying advance care planning needs can not only provide comfort at the time of death but also help in reducing unnecessary medical expenditures. The strengths of this study include its ability to capture a wide range of opinions on care without relying on a standardized tool. However, it is limited by its inability to conduct follow-up interviews or delve deeper into the topics, unlike

some prior studies.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

ORCID

Minju Kim, <https://orcid.org/0000-0002-1135-7262>

Jieun Lee, <https://orcid.org/0000-0001-9068-1433>

AUTHOR'S CONTRIBUTIONS

Conception or design of the work: MK. Data collection: MK, JL. Data analysis and interpretation: MK, JL. Drafting the article: JL. Critical revision of the article: MK. Final approval of the version to be published: JL.

SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/jhpc.2024.27.3.87>.

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