

Attitudes and Opinions of Elderly Patients and Family Caregivers on End-of-Life Care Discussion

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Background: End-of-life (EOL) care decisions have become an urgent issue in Korea in response to recent legislation called the Life-Sustaining Treatment Decision Act of 2016. The present study attempted to explore attitudes and opinions on EOL discussion among elderly patients and their family caregivers since communication regarding EOL care has been argued to be a major premise leading to the best decision making. **Methods:** The attitudes and opinions of elderly patients and their family caregivers were solicited through focus group interviews. The final sample consisted of 12 patients and 16 family members. **Results:** Guided by content analysis, 5 themes were revealed. The identified themes were individual approach for delivering bad news and stakeholders involved in the discussion, contradictory attitudes toward advance care planning, mutual understanding, hope for the EOL care discussion process, and resistance to discussion of hospice-palliative care. **Conclusion:** Study findings suggested that an approach focusing on the individualized needs of patients and family members is required in EOL care discussion for elderly patients.

Key Words: Elderly, End-of-life care, Communication, Advance care planning

INTRODUCTION

Communication between healthcare providers and patients and/or their family members is important for end-of-life (EOL) care decision making. In such communication, bad news is usually unavoidable. Deliverance of bad news along with other barriers is known to make EOL communication difficult to manage. Accordingly, strategies to deal with this private and complex process has been suggested in the form of guidelines^{1,2}, protocol³, and algorithm⁴.

In the EOL care decision-making process, self-determination is believed to be honored, and skepticism about this philosophy is rarely found; this is true in Korea as well. In fact, a previous report revealed that a majority of cancer patients⁵ and the general population⁶ in Korea believe that patients should be informed directly of terminal illnesses. Moreover, people in Korea revealed preference for advance directives (AD) and objection to meaningless life-sustaining treatment (LST)⁷⁻⁹. However, are these notions always true regardless of individual circumstance? Or is it always good or even possible to express one's preference about one's own EOL care? These questions emerged spontaneously throughout our research related to EOL care decision making.

Additionally, we believe that the time to confirm these notions is now, since the LST Decision Act will be enforced by 2018 in Korea. Self-determination underlies the LST Decision Act of Korea, and AD and physician's order of LST (POLST) are included in the Act as the main tools to specify one's own EOL care decision in the context of advance care planning (ACP).

Although the LST Decision Act was legislated upon long-time efforts for consensus from diverse groups, voices expressing concerns over the Act still exist. Some groups^{10,11} expressed concerns over the Act, claiming that this may promote the possibility of misusing the law. Some medical parties expressed skepticism about the feasibility of the Act¹². Nonetheless, the LST Decision Act will be enforced shortly, and the Act specifies physician's liability for explanation about terminal (or dying) state of disease, LST, hospice palliative care (HPC), AD, and POLST to the patient for EOL care decision making. This means that EOL care discussion with the patient him/herself will become inevitable in the clinical setting including geriatric settings. EOL care discussion should be considered important in the geriatric area because Korea is known to be a rapidly aging country, and the elderly population is estimated to reach 24.3% by 2030¹³. Therefore, EOL discussion is expected to be increased in geriatric circumstances because death and dying are not limited but, rather,

more prevalent in this population. In fact, 74.5% of all deaths in 2015 in Korea occurred in the population of those aged 65 years or older¹⁴. The voice of family members also needs to be explored since family members will remain stakeholders in EOL discussions for elderly patients due to the family-centered culture in Korea. While EOL care discussion is known to be essential for patients' and family members' wellbeing in the EOL period^{15,16}, it remains a challenging task for health-care providers¹⁷. Therefore, efforts to promote EOL care discussion are required.

In the present study, we tried to explore attitudes and opinions of elderly patients and their family members, and the purpose of this study was to identify the essential aspects to be considered while proceeding with EOL care discussions from the perspectives of elderly patients and their family caregivers. Specific aims included (1) ways to deliver bad news, such as terminal or dying state; (2) stakeholders involved in the discussion; (3) attitudes towards ACP; (4) important aspects to consider while discussing EOL care; and (5) attitudes towards HPC.

MATERIALS AND METHODS

1. Sample

Participants for the focus groups were recruited from a general hospital located in a metropolitan area of Korea. First, the purpose and procedure were described briefly to the potential participants by attending physicians, and then a research nurse contacted those who agreed to meet her for further explanation about the study. After face-to-face contact, elderly patients and family caregivers who agreed to participate in the study were invited to an interview at their convenience. The inclusion criteria were elderly inpatients with major diseases including cancer, family caregivers of elderly patients with major disease, elderly patients not necessarily in a terminal state, and elderly patients and family caregivers not necessarily as a dyad. A total of 28 participants (12 older patients and 16 family caregivers) were included as the study participants; they underwent seven focus group interviews held in January and February of 2016.

2. Design and Procedure

This is a qualitative study using focus group interviewing (FGI). Individuals' personal opinions or needs are difficult to quantify, and FGI allows interviewers to probe while allowing group dynamics¹⁸ and is an adequate method for those with common characteristics¹⁹ and for older adults²⁰. The study was approved by the Institutional Review Board of Ulsan University Hospital (approval number: 2015-02-025). Three researchers with expertise in EOL care discussion devel-

oped a semistructured interview protocol, which included an investigators' guide and 5 key research questions defined and delimited to EOL communication.

Usually, 6–8 participants are ideal per group for FGI¹⁸, and we tried to recruit participants to satisfy this size for each group. However, nonattendance in both caregiver and patient groups was very likely since the condition of older patients tended to change frequently. Consequently, a total of 7 focus group interviews (3 of older patients' and 4 of family caregivers'), each group ranging from 3 to 7 members per group, were held separately.

According to an interview protocol prepared earlier, each interview began with an introduction session that included a welcoming remark, an explanation of the topic, and ground rules. A question session proceeded in the order of opening question, introductory question, transition questions, key questions, and ending questions as proposed^{18,19}. Each interview lasted until the same statements were repeated and was usually held for about 90 minutes or less. Unlike expectations, repeated group interviews were almost impossible due to elderly patients' condition changes, and supplementary individual interviews were added until data saturation was achieved. Consistent with the FGI method, one moderator (SMK) led the interviews, following the protocol, and an assistant moderator (KEP) took part in the interview for recording, taking notes, and debriefing afterwards. All interviews were audiotaped upon participants' agreement and transcribed verbatim for analysis.

All statements and debriefing data were reviewed by 2 researchers and analyzed utilizing a qualitative content analysis, which allows the themes to be identified from text data and is a relevant method in studies related to EOL care²¹. Data analysis was carried out while still in the groups as well as after the interviews. The unit of analysis was mainly defined as study questions guided by an FGI guide book¹⁹, and researchers tried to develop coding schemes from the data separately for the initial coding. Words, context, frequency, intensity, specificity, and internal consistency of all statements were reviewed repeatedly by each researcher, and coding categories were derived directly and inductively from the raw data. The entire body of text was coded with same coding rules following pre and post coding consistency assessments. Once full text coding was completed, the researchers tried to classify coding or patterns systematically through identifying a similar property and/or context.

RESULTS

A total of 12 elderly patients and 16 family caregivers participated in the study as shown in Table 1. Elderly patients were in their 60s and 70s (range, 66–74 years), and the majority showed lower education level; 11 out of 12 were diagnosed

with cancer. The family caregiver group was generally younger (range, 38–66 years) than the patient group and showed a higher education level. Most caregivers (81.2%) were female — daughter (37.5%), daughter-in-law (25.0%), and spouse (18.8%), in descending order. Five themes emerged after analysis (Table 2).

1. Individual Approach

Elderly patients and family caregivers reported a wide range of diverse attitudes and opinions across all the study questions. Consequently, an individual approach emerged as the primary theme, particularly in delivering bad news and in relevant stakeholders of discussion. The individual approach meant acknowledgement of the unique value and context of each individual with appropriate response and

communicating with individuals while remembering their uniqueness. Among those statements regarding the deliverance of bad news, some participants stated that such information should be provided to the patient in person by physicians while others believed that such news would be better if delivered to family members first, and still others did not even want to know about the situation at all.

“I surely want to know about my condition no matter what it is, and it’s just right to tell the news to the ones in person.... If people around me do not tell the truth, and I realize it at the last minute, I’ll be really frustrated and embarrassed....”

“I don’t want to know or hear the news, because nothing will change even if I’m informed, and I think I’ll freak out....”

“As family members, I am afraid that my parents/spouse would give up hope and become depressed when a patient faces his/her condition....”

“I wish the attending physician would tell the patients in person because it’s too difficult for family members to bring up such news..., and the patient will get to know his/her condition sooner or later anyway....”

Regarding the stakeholders in the EOL care discussion, participants revealed diverse answers. Some said that physicians were the ones who should take initiative in such decision-making; some that the patient should make decisions; others that first-degree family members could make EOL care decisions; and others that patients, family members, and physicians should all take part in the decision-making process. Again, this issue could also not be standardized since the study participants expressed such various wishes and opinions.

Table 1. Participant characteristics

Characteristic	Older patients (n=12)	Family caregivers (n=16)
Age (yr), range	66-74	38-66
Education, n (%)		
<High school	9 (75.0)	5 (31.3)
≥High school	3 (25.0)	11 (68.8)
Male sex, n (%)	5 (41.7)	3 (18.8)
Cancer, n (%)	11 (91.7)	-
Relationship with patient, n (%)		
Spouse		3 (18.8)
Son		2 (12.5)
Daughter		6 (37.5)
Daughter-in-law		4 (25.0)
Sibling		1 (6.3)

Table 2. Themes derived by the study participants

Research question	Themes	Description
How to deliver bad news and to initiate EOL discussion? Who needs to be involved in EOL care decision making?	Individual approach	Acknowledge individual difference and respond differently. Practice individual case-specific discussion.
How do you feel about discussion related to advance care planning including advance directives and physician’s order of life-sustaining treatment?	Contradictory attitudes	Acceptable for oneself yet not for parents Consider it reasonable yet not during one’s illness. Consider it reasonable yet not acceptable because of uncertainty of future.
What are things considered important while discussing EOL care?	Mutual understanding Hope	Explain care options and anticipated benefit/burden. Ensure use of the same language among stakeholders. Let patients have hope for the rest of their lives. Reluctant to discuss with elderly patient due to concerns about his/her despair
How do you feel about discussion about hospice-palliative care?	Resistance	Consider it useful yet almost impossible to discuss with the patients since it means “the end.” Consider it meaningless as long as death is inevitable. Discharge from acute hospital itself is distressing.

EOL, end-of-life.

"Those kinds of decisions are surely made by physicians because he/she knows best... I'll just follow his/her decision... I think that's the best way for EOL care decision..."

"Physicians have hegemony over care decision making, and my spouse and children will decide upon physicians' opinions."

"My first son is the one who should decide my EOL care option."

"My family members will do it for me."

"I want my family members (spouse, children) to decide on my behalf when I am incapacitated...upon my preference toward EOL care."

2. Contradictory attitudes towards ACP

Elderly patients and their family caregivers showed contradictory attitudes toward the discussion about ACP. Interestingly, positive and negative attitudes coexisted between and within the individuals. Some participants opposed ACP — more specifically, AD — based on the expectation of new treatment options in the future and the possibility of a change of mind when facing death.

"When I was healthy, I sometimes thought about it, but I don't think it is necessary, and I feel sad... I just don't want to talk about it ever since I became sick."

"I might prepare AD for myself, but I don't dare discuss it with my parents."

"It may be helpful for my family members in the case that I become sick, but I might not want to talk about it if I really get sick..."

"I already talked to my children about how I want to be treated and to spend the rest of my life."

"I don't want to discuss or decide in advance because nobody knows what will happen in the future. New treatment could be introduced in the future, and I may change my mind even..."

3. Mutual understanding

Study participants argued that EOL care discussion must be processed based on mutual understanding in terms of (1) explaining the care options and anticipated results in detail, including the benefit and burden, and (2) ensuring use of the same language among stakeholders to avoid misunderstanding.

"I just want to know about my condition and treatment options accurately...for example, what kinds of benefit and/or burden I should expect with or without treatment... and to what extent I'll be suffering along with disease process..."

"Doctors don't talk about the situation much, and it's usually too difficult and confusing... We just assume what

will happen next... Sometimes, we depend upon other patients or their family caregivers for more information... I wish doctors or other healthcare providers would explain more precisely..."

4. Hope

Hope is revealed as an essential component that family caregivers, in particular, could not give up while discussing EOL care. They argued that "hope" had to be retained, especially for patients, until the end even though death was imminent. This did not mean that they denied the reality or expected cure; rather, they used the term "hope" contrary to the term "just end."

"Until the end, I wish healthcare providers give some hope to patients..., not just telling the patients about prognosis or remaining days and months in an official way... Rather, tell them that they could live through this and would be in good hands and so on..."

"My doctor said that chemotherapy wouldn't cure the disease but could slow down the disease process a little..., and my mother smiled upon the doctor's mention..., and she began to eat better and feel happier, and we all feel relieved..."

5. Resistance to discussion of the hospice/palliative care

Study participants showed a complicated attitude toward HPC with relatively higher preference for acute hospital care. Attitude towards HPC itself was divided in 2 opposing ways: positive and negative perspectives. However, whatever the attitude, the majority of the participants reported that discussing HPC would be very unlikely due to the prevailing negative image of HPC, such as "no cure," "giving up treatment," and "the end."

"It seems good, but even HPC won't do any good when death is imminent and/or patient is unconscious... Then, there is no reason to talk about HPC anyway..., and discharge from an acute hospital itself would take away hope..., and what if there arises an emergent situation?"

"I might use HPC service for myself, but as an adult child, I'll never be able to tell my parents about HPC because it has same meaning as death to us."

"Family members as well as the patient would be terrified of possible medical crisis if discharge from the acute hospital is offered..."

"The HPC ward is a dying place, no matter how softly speaking..."

"I prefer hospitalization in an acute hospital to HPC; I'll feel more secure in an acute hospital..."

DISCUSSION

In Korea, EOL care decision making will become important with the upcoming LST Decision Act enforcement in 2018, and elders are a major population related to this issue as the country transitions into an aged society. Korea is known to be a typical Confucianism community and rather homogeneous in cultural and ethnic background. However, diversity in values has been growing with modernization and globalization, and a shift in values related to EOL care may also be likely in light of societal value changes. Moreover, the LST Decision Act values self-determination, different from the conventional family-centered decision-making in Korea. Therefore, people's perspectives toward EOL care decision making need to be identified prior to law enforcement, and the present study tried to explore the attitudes and opinions of elderly patients and their family caregivers regarding EOL care decision making through focus group interviews. Guided by content analysis method, 5 themes were revealed.

According to the study results, an individualized approach would be required for Korean elderly patients because of inconsistent attitudes and opinions among study participants. First of all, study participants revealed a diverse array of attitudes regarding the deliverance of bad news and stakeholders included in EOL care discussion. The LST Decision Act in Korea encourages attending physicians to provide explanations regarding LST, AD, POLST, and HPC to terminal (or dying) patients with respect to self-determination. Deliverance of bad news to the patient will be inevitable in explaining these options and advocating self-determination, but this might not be always feasible in Korea. From the present study results, some elderly patients wanted to hear bad news in person and were willing to participate in their own EOL care discussion, while others were not so willing. In addition, some family caregivers thought that patients' awareness of their own medical condition was important in deciding EOL care; however, they were not comfortable discussing EOL issues with their older loved ones and expressed worries about elderly patients' disappointment. A previous study²²⁾ reported that Korean older adults tended not to discuss death and that they regarded preparation for death in advance as unnecessary. Moreover, older people have passive expectation that family members, God, others²³⁾, and physicians²⁴⁾ would play an active role in EOL care decision on their behalf. These attitudes of older adults were also true at least in some elderly patients in this study; they believed that physicians or family members would make such decisions for them. Diverse perspectives of patients and their family members were supported by a previous study⁴⁾ of terminal cancer care experts, which proposed a context-oriented communication algorithm for EOL care discussion based upon the unique context of each patient. Inconsistent

and diverse attitudes toward EOL care discussion among elderly patients and family caregivers must be acknowledged, because each individual's value and preference could not or should not be standardized.

Next, even in the case of elderly patients wanting to discuss EOL care, their participation in the discussion seemed unlikely. A systematic review²³⁾ reported that only 2%–29% of older people had chances to discuss EOL care while 61%–91% wanted to. The common barriers of EOL care discussion identified were family members' reluctance for EOL conversation with elderly patients and older adults' passive expectation for others to decide for them²³⁾. Therefore, an individualized approach to EOL care discussion would be key to adhering to the interests of the patient.

Study participants showed contradictory and mixed attitudes toward ACP, including AD. Interestingly, along with positive attitudes, their preference was limited to themselves and not their loved ones. Adult children in this study considered EOL care discussion with their parents as an undutiful behavior, showing reluctance to discuss these issues with their parents. This unwillingness was consistent with the result of a narrative synthesis study²³⁾ as well as a Korean study²²⁾. In Korea, the reluctance for family members to discuss EOL care with their parents could be explained by cultural attitudes of filial piety and the passive expectation from older adults about the role of family decisions on their behalf as well as the trust in physicians^{22,24,25)}. Moreover, elders tended to believe that their children would already be aware of their wishes regardless of conversation on this matter^{25,26)}. Whatever the reasons may be, family members' reluctance was the most common barrier to EOL discussion, as aforementioned²²⁾, and strategies to overcome this barrier are necessary. Another interesting statement reported by study participants was that AD as ACP would be acceptable only when they were healthy. This attitude seems to have great implication especially considering the POLST listed in the LST Decision Act in Korea. Contrary to AD, a POLST is supposed to be documented by physicians only in the terminal (or dying) stage through conversation only with the patient. Obviously, preparing the POLST document is expected to become a challenging task for physicians in geriatric setting from the study result. Therefore, effort to deal with this issue should be encouraged and supported for individuals and society as a whole.

Negative attitude toward AD due to uncertainty of the future was also noteworthy. Although an AD document can be amended and abolished whenever and wherever, people do not seem to acknowledge this. Furthermore, a wide gap between preference and completion rate of AD has been pointed out continuously in the United States^{27,28)}. AD and POLST as the ACP documentation intend to support self-termination and the best interests of dying patients; there-

fore, an individualized approach to facilitate ACP followed by either AD or POLST completion will be desirable. In the meantime, social marketing and organizational preparation also are needed in accordance with the law²⁹⁾.

While discussing EOL care, elderly patients and their family caregivers wanted to “know about” the illness and treatment process exactly and precisely, suggesting that much of what they wanted to know was left in the dark. Uncertainty concerning illness trajectory was another barrier to EOL conversation, particularly in frail older people¹⁹⁾. However, uncertain illness trajectory is the reason why ACP is more necessary for the older population than for any other age group. In addition to uncertainty, implicit and nonverbal communication patterns in Korea^{25,26)} may hinder clear mutual understanding. Furthermore, ACP and EOL care discussion is a relatively new paradigm in Korea. Therefore, strategies including education for the general population and healthcare providers, organizational affiliates, and policymakers are necessary to bridge the gap between needs and reality.

Study respondents considered hope the ultimate virtue to hold until the end. Hope in these interviews did not mean cure or avoidance of death but the ability to have as normal a daily life as possible. Family caregivers, in particular, highlighted that hoping for the best could strengthen elderly patients against despair, allowing better quality of daily life during the remaining days. Family members worried that elderly patients would give up hope upon receiving bad news and discussing EOL care. Family caregivers also argued that individualized and gradual approaches were essential. In addition, EOL care discussion should focus on life instead of death and dying.

HPC is incorporated in the LST Decision Act in Korea, making utilization of HPC service a part of EOL care planning. More than half of the general population reported a positive attitude toward HPC³⁰⁾ in Korea, yet further studies with patients and their family caregivers are required since the present study explored rather strong negative attitudes towards HPC. Family caregivers revealed different attitudes toward different subjects regarding HPC. That is, they reported a positive attitude for themselves but a negative attitude for their loved ones. Negative image of “the end” of HPC was the most important reason to resist discussing this care option with patients. Some patients reported HPC itself as positive yet regarded it as useless at the end of life. Negative image across all study participants prevailed regardless of preference, which is expected to hinder HPC utilization despite law enforcement. Moreover, lack of trust about HPC services was also common. Study participants tended to believe HPC was just a “let go” service and not an area of medical expertise. In accordance with the study results, social marketing focusing on life with HPC, and not death, would be required. In particular, with respect to the

LST Decision Act, it is necessary to emphasize that the Act is not to determine life or death but to determine how to live a life during the last months, weeks, or days. HPC should be presented as one medical option that could guarantee a better quality of life during the EOL period.

This study attempted to explore the attitudes and opinions towards EOL care discussion among elderly patients and their family caregivers in response to the LST Decision Act. In this study, respondents were recruited from diverse medical wards, yet most respondents were cancer patients and their family caregivers. Consequently, caution should be taken in generalizing the study results. Nonetheless, communication among stakeholders will become a core aspect in determining EOL care options, and strategies to improve EOL care discussion are called for.

In conclusion, death and dying are both individual and social matters due to the advancement in medicine and longevity, and the EOL issue has garnered much attention in Korea recently. As a result, the LST Decision Act was established, and EOL care discussion will become important in the process of making EOL care decisions. Regarding EOL care discussion, elderly patients and their family caregivers revealed individual differences in all study queries. While individual differences prevailed, the need to understand illness and treatment options and to maintain hope until the end was also recognized along with multifold attitudes towards ACP and HPC. Laws and policies are rather standardized and rigid in nature; an individualized approach incorporating the needs and unique circumstances of patients and their family members must be emphasized in EOL care discussion for the best result.

Conflicts of Interest Disclosures: The researchers claim no conflicts of interest.

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