

End-of-life care decisions using a Korean advance directive among cancer patient–caregiver dyads

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ABSTRACT

Objective: The Korean advance directive (K–AD) comprises a value statement, treatment directives, preferences for cardiopulmonary resuscitation (CPR), artificial ventilation, tube feeding, and hospice care, as well as a proxy appointment. The K–AD can facilitate a patient’s decision making with respect to end-of-life (EoL) care. The present study aimed to examine the extent to which patient–caregiver dyads would use the K–AD and agree on EoL care decisions.

Methods: Using a descriptive study design, 81 cancer patients were invited to participate. The final sample consisted of 44 patient–caregiver dyads who completed survey questionnaires, including the K–AD. One patient did not complete all parts of the questionnaire, and 36 (44.4%) declined to participate. Content analysis was conducted to examine the K–AD value statements. Cohen’s kappa coefficient was calculated to determine the degree of patient–caregiver dyadic agreement on K–AD treatment directives (Sudore & Fried, 2010).

Results: Our patient participants had the following cancer diagnoses: colorectal 29.5%, breast 29.5%, and liver/biliary tract cancers, 15.9%. Half of the sample had advanced-stage disease. Spouses (70.5%) or adult children (20.4%) were the primary caregivers, with perceived bonding rated as fair (31.8%) or good (65.9%). Rejection of the K–AD was mainly due to the difficulty involved in deciding on EoL care (50%). Comfort while dying was the most common theme expressed by patients (73.8%) and caregivers (66.7%). In terms of treatment directives, dyads advocated for hospice care (66.7%) and reduced support for aggressive treatments of CPR or artificial ventilation. The use of CPR ($\kappa = 0.43$, $p = 0.004$) and artificial ventilation ($\kappa = 0.28$, $p = 0.046$) showed significantly mild to moderate concordance among the dyads. Some 16 of the 21 dyads identified their spouses as a proxy, with others designating their adult children.

Significance of results: The degree of patient–caregiver concordance on the K–AD seemed applicable, and achieved mild to moderate concordance. Our findings are exploratory but suggest the need for EoL discussions where patient–caregiver dyads are encouraged to participate in EoL care decision making.

KEYWORDS: Korean advance directives, Cancer patients, Caregivers, End-of-life decision making

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INTRODUCTION

Decision making for end-of-life (EoL) care in an era of extended longevity has received growing attention among those involved in research and clinical practice, as well as healthcare policymakers. Like other countries, Korea is examining these issues in the context of constantly advancing medical technology. Various channels of EoL decision making have been introduced in Korea to facilitate EoL care decision making, including advance directives (ADs), advance care planning (ACP), and the physician's order for life-sustaining-treatment (POLST). The most recently accepted paradigm in EoL care in Korea, ACP involves a statement of preferences, a living will, treatment directives, and appointment of a proxy. In the ACP process, all stakeholders in EoL care—including patients, family members, and healthcare professionals (HCPs)—engage in ongoing discussions about decision making about medical treatments in advance of their being required (Thomas, 2011).

Research, legislation, and policy making for EoL palliative care have evolved largely for patients with terminal cancer, a leading cause of death in Korea over the past decades (Jung et al., 2012). Several events increased widespread awareness of the need to secure patients' personal and social needs for respect, individual dignity, and autonomy in EoL decision making. This included discharge decisions against physicians' recommendations (Korean Supreme Court Ruling, 2004) and conflicts between family members and care providers about withdrawing life-sustaining treatments (LSTs) (Korean Supreme Court Ruling, 2009). These landmark episodes led to attempts to establish a fundamental social consensus about withdrawing or withholding futile LSTs (National Evidence-Based Healthcare Collaborating Agency, 2009) and the Cancer Management Act, Part 4 (Korean Ministry of Government Legislation, 2014). It was further recommended that either a POLST or AD be available, allowing persons to make informed decisions for treatment preferences with respect to futile LSTs (Ministry of Health & Welfare, 2013). These systems also aimed to extend the scope of palliative care recipients and establish ACP as a comprehensive support system for EoL care (Kim et al., 2015). The ACP process assists patients and their family members with informed decision making and preparation of ADs for future care. Effective EoL communication is a critical aspect, with all stakeholders actively engaged in EoL care discussions to maximize the quality of care delivered as an individual dies (Sleeman, 2013; Caswell et al., 2015).

However, EoL care discussions are challenging in the family-centered care environment of Korean

culture. Family members are expected to make concerted efforts to extend the life of afflicted an family member, and that person is usually excluded from such discussions. The patient is often omitted from EoL discussions and may even be unaware of the fact of their imminent death (Kim et al., 2014; Koh et al., 2015). Many HCPs are also reluctant to communicate about death or dying with patients when this is contrary to the family's wishes (Kim et al., 2014) or if the prognosis is uncertain (Sleeman, 2013; Seoul National University Hospital, 2013).

Given such challenges for providing quality EoL care, a series of studies were conducted with the goal of developing a Korean advance directive (K-AD), which is a culturally sensitive, reality-based, and user-friendly set of guidelines based on the perspectives of both the general population and professional healthcare providers (Kim et al., 2012; 2013a; 2014). The prerequisites for the Korean AD model were proposed with specific features, including an introduction to the K-AD, a section comprised of a statement of values, a list of treatment options, and appointment of a proxy, with the signatures of a witness, the healthcare provider, and the declarant—compatible with the core contents of ACP (Kim et al., 2012). Amendment of the prototype was then undertaken in the light of expert perspectives (Kim et al., 2014) and to reflect the health literacy of the general population (Kim et al., 2013a) through Delphi and cognitive interviewing, respectively. The final version of the K-AD is a vehicle that can be employed to facilitate active engagement of stakeholders, including but not limited to patients, family members, and HCPs in EoL care discussions and documentation (see the Appendix).

The feasibility of this approach needs to be validated in the clinical environment endemic to Korea culture—for example, among patients with advanced cancers, where at present families predominantly make all EoL care decisions. Our present study was undertaken to examine the extent to which cancer patient-caregiver dyads would utilize the K-AD and their level of agreement about EoL decisions. We also examined the degree of patient-caregiver concordance surrounding the K-AD value statements, treatment directives, and proxy appointments.

METHODS

Design and Subjects

Our study employed a qualitative design in which face-to-face interviews were conducted to report the views of cancer patients and their caregivers.

Content analysis of their reasons for not using the K–AD and the content of their value statements were explored.

Cancer patients who had received care from one of two tertiary hospitals were represented in the sample and were invited to participate in EoL care discussions along with their primary caregivers. The inclusion criteria for patients were as follows: age ≥ 20 years, cancer diagnosis, self-awareness of their condition, inpatient or outpatient cancer treatment, and consent to participate with an understanding of the study protocol. The caregivers of eligible patients were invited to participate if: they identified themselves as the primary caregiver, were ≥ 20 years of age, and consented to participate with a full understanding of the study protocol. If one member of the dyad (either patient or caregiver) refused to participate, the dyad was disqualified. The result of this process was a sample of paired patients and caregivers. Our study was approved by the institutional review board of the relevant university-affiliated hospital. Each participant signed an informed consent statement prior to the face-to-face interviews.

Korean Advance Directives

The K–AD is a measure of an individual's wishes for preferred EoL treatments. It has three components: a value statement, a list of treatment options (cardio-pulmonary resuscitation [CPR], artificial ventilation, tube feeding, and hospice care), and a proxy appointment. The person can complete all or some of the components, with modifications permitted as a result of ongoing ACP discussions.

Procedure

Physician oncologists who had well-established relationships with patients and their caregivers obtained their consent to participate and then conducted face-to-face interviews with those who agreed. The interviewing oncologist began by explaining the patient's condition, the treatment process, and the prognosis to the patient and family members, as part of the usual course of care. The oncologist then introduced the K–AD, which could facilitate patient and family members in discussing EoL care, and inquired about patient/family member interest in completing the K–AD. If this option was accepted, physicians further explained the right of terminal cancer patients to have palliative care options, to make a proxy appointment when unable to make decisions about future care, and the responsibility of HCPs to explain palliative care. Based on such an informed decision-making process, physicians were thus able to assist patients and/or their family members to prepare

the K–AD if assistance was needed. If the option to complete the K–AD was rejected, the oncologist asked them the reason(s) for this decision and made a record of it.

Data Analyses

Descriptive statistics were conducted to describe the characteristics of the patients and their respective caregivers, and these included frequency, percentages, and means \pm standard deviations. To explore reasons for not completing or rejecting the K–AD, common themes were extracted applying conventional content analysis (Hsieh & Shannon, 2005), and the frequency of each theme was calculated. Content analysis was also employed to examine the content of the value statements after extracting the data from their narratives. These data were transcribed by a graduate student, and analysis of the transcribed narratives was performed independently by researchers, who worked together to reach a consensus on themes. Cohen's kappa coefficient (Landis & Koch, 1977; McHugh, 2012) was calculated to determine the degree of agreement about the K–AD between cancer patients and their family caregivers (Sudore & Fried, 2010). All statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS, v. 21). Statistical significance was set at a value of $p < 0.05$.

RESULTS

Characteristics of Cancer Patient–Caregivers Who Completed the K–AD

Patients and their caregivers took part in discussions about ACP. The initial number of participants approached was 81 patient–caregiver pairs, 45 of whom (55.6%) agreed to participate. One patient did not complete all the survey questionnaires, resulting in their being disqualified, leaving 44 pairs for our analysis. Therefore, our final sample included 44 patients and their 44 caregivers, who completed all of the survey questions.

The mean age of patients who completed the K–AD was 58.43 years: 22 (50%) subjects were male, most were married (93.2%), and 29 (65.9%) had at least a high school or higher education. More than half reported their religion as Buddhism (56.8%), followed by no professed religious affiliation or belief (18.2%). The mean time since cancer diagnosis was 22 months. The major diagnoses were colorectal (29.5%) and breast cancer (29.5%), followed by cancers of the liver and biliary duct system (15.9%). More than half had advanced stages of cancers (59.1%), with recurrence in 38.6% (Table 1).

Table 1. Demographic and clinical characteristics of the 44 cancer patients who completed the Korean Advance Directive (K-AD)

Characteristics	Categories	<i>n</i>	%	<i>M</i> ± <i>SD</i> (min–max)
Age (years)				58.43 ± 1.26 (33–74)
Gender	Male	22	50.0	
Marital status	Married	41	93.2	
Education	No education	2	4.5	
	≤ Middle school	13	29.6	
	High school	24	54.5	
	≥ College	5	11.4	
Occupation	Yes	14	31.8	
Religion	None	8	18.2	
	Christianity	8	18.2	
	Catholic	2	4.5	
	Buddhism	25	56.8	
	Missing	1	2.3	
Perceived health status	≥ Good	7	15.9	
	Fair	28	63.6	
	≤ Poor	9	20.2	
Hospice	Well known	4	9.1	
	Known	19	43.2	
	Don't know	21	47.7	
DNR	Yes	1	2.3	
Duration of diagnosis (months)				22.07 ± 30.49 (1–144)
Type of cancer	Colorectal	13	29.5	
	Breast cancer	13	29.5	
	Liver/biliary	7	15.9	
	Gastrointestinal	1	2.3	
	Lung cancer	1	2.3	
	Others	3	6.8	
Stage of cancer	Stage 2	14	31.8	
	Stage 3	10	22.7	
	Stage 4	16	36.4	
Recurrence	Yes	17	38.6	

DNR = do not resuscitate.

Table 2. Characteristics of the 44 caregivers who completed the Korean Advance Directive (K-AD)

Characteristics	Categories	<i>n</i>	%	<i>M</i> ± <i>SD</i> (min–max)
Age (years)				52.48 ± 14.19 (21–75)
Gender	Male	16	36.4	
Patient–caregiver relationship	Spouse	31	70.5	
	Descendants	9	20.4	
	Others	4	5.1	
Living together	Yes	35	79.5	
Patient–caregiver bonding	Good	29	65.9	
	Fair	14	31.8	
	Bad	1	2.3	
Weekly caregiving frequency				5.62 ± 11.19 (1–7)
Caregiving, hours/day				11.38 ± 11.38 (1–24)
Caregiving duration/month				12.26 ± 15.84 (1–60)
Hospice	Well-known	2	4.5	
	Known	21	61.4	
	Don't know	15	34.0	
Communication about life-sustaining treatment	Specific	16	36.4	
	Nonspecific	18	40.9	
	No	10	22.7	

The mean age of caregivers was 58.48 years (*SD* = 14.19; range = 21–75 years). Caregivers were predominantly female (63.6%). Their relationships with patients were as spouse (70.5%) and adult child (20.4%). Approximately two-thirds lived with their patients, with bonding reported as fair (31.8%) or good (65.9%). The time spent caregiving was substantial: 5.62 days a week, 11.38 hours a day. The majority of caregivers (77.3%) had some experience with LST communications, which were either specific (36.4%) or nonspecific (40.9%) (Table 2).

Reasons for K–AD Refusal

Some 36 dyads (44.4%) declined to participate in the study. The most common reason for not completing or rejecting the K–AD was the difficulty involved in making decisions about EoL care (50%), followed by frustration/hopelessness after an AD was documented (22.2%). Other reasons included lack of knowledge about ADs (8.3%), fear of withdrawal or stopping chemotherapy after completing an AD (5.6%), concern about the reaction of family members (5.6%), lack of AD preparedness (2.8%), a decision by a family member (2.8%), and no opinion about ADs (2.8%) (Table 3).

K–AD Feasibility in Cancer Patient–Caregiver Dyads

Value Statements

Among the 44 patient–caregiver dyads, 38 patients (86.4%) and 27 caregivers (61.4%) communicated their EoL beliefs and values. Some 23 dyads provided paired responses of EoL values, with their statements corresponding in 18 dyads (78.3%) and conflicting in 5 (21.7%). “Comfort while dying” was the most common theme in statements by patients (73.8%) and caregivers (66.7%). More specifically,

Table 3. Patients’ reasons for refusing to complete the Korean Advance Directive (K–AD) (n = 36)

	Frequency	Percentage
1. Difficulty making decisions about EoL care	18	50.0
2. Post-AD frustration or hopelessness	8	22.2
3. AD knowledge deficit	3	8.3
4. Fear of withholding or withdrawing chemotherapy after completing an AD	2	5.6
5. Concern about family reaction	2	5.6
6. Lack of AD preparedness	1	2.8
7. Family decision	1	2.8
8. No opinion about AD	1	2.8
Total	36	100.0

AD = advance directive.

“comfort while dying with pain control” was important for 47.4 and 44.5%, respectively; “dying with no family burdens” for 21.1 and 7.4%, respectively; and “dying with no pain or burden to family” for 5.3 and 11.1%, respectively. Second, both patients and caregivers expressed a wish for continuation of treatment with concurrent pain management (18.4 vs. 14.8%, respectively; Table 4). Finally, “no pain” or “pain control” were merged into a single theme and became important subthemes of “comfort while dying” and “continuous treatment.”

Treatment Directives

The four treatment options on the K–AD were CPR, artificial ventilation, tube feeding, and hospice care. Hospice care was the EoL care choice that both patients and caregivers desired most often (79.5 vs.

Table 4. K–AD value statements of patient–caregiver dyads*

Value statement		Patient Frequency (%)	Caregiver Frequency (%)
Comfort with dying	With no pain	18 (47.4%)	12 (44.5%)
	With no burden to family	8 (21.1%)	2 (7.4%)
	With no pain and no burden to family	2 (5.3%)	3 (11.1%)
	In hospice care	–	1 (3.7%)
Continuous treatment	With pain control	7 (18.4%)	4 (14.8%)
	With no burden to family	1 (2.6%)	
	Regardless of burden to family		1 (3.7%)
Pain control*		1 (2.6%)	3 (11.1%)
Dying in presence of family		1 (2.6%)	1 (3.7%)
Total responses		38	27

* Pain control emerged as a single theme but also in the context of other themes, e.g., “comfort while dying” and “continuous treatment.”

Table 5. Preferences on the Korean Advance Directive (K-AD) among 42 patient-caregiver dyads

Treatment options	Patients	Caregivers		Patient-caregiver concordance	
		No <i>n</i> (%)	Yes <i>n</i> (%)	Value of kappa (κ)	Value of <i>p</i>
CPR	No, <i>n</i> (%)	27 (64.3%)	6 (14.3%)	0.43	0.004*
	Yes, <i>n</i> (%)	3 (7.1%)	6 (14.3%)		
Artificial ventilation	No, <i>n</i> (%)	23 (54.8%)	10 (23.8%)	0.28	0.046*
	Yes, <i>n</i> (%)	3 (7.1%)	6 (14.3%)		
Tube feeding	No, <i>n</i> (%)	23 (54.8%)	9 (21.4%)	0.018	0.909
	Yes, <i>n</i> (%)	7 (16.7%)	3 (7.1%)		
Hospice care	No, <i>n</i> (%)	1 (2.4%)	7 (16.7%)	-0.54	0.725
	Yes, <i>n</i> (%)	6 (14.3%)	28 (66.7%)		

CPR = cardiopulmonary resuscitation. Bold numbers indicate favorable percentage for each EoL option.

* Significant agreement between patients and caregivers about end-of-life (EoL) treatment preferences ($p < 0.05$).

81.8%, respectively). This was followed by tube feeding (22.7 vs. 27.3%), CPR (20.5 vs. 27.3%), and artificial ventilation (20.5 vs. 36.4%).

Patient-caregiver dyad treatment preferences were similar, with approximately two-thirds of both groups preferring hospice care and 20.5–36.4% opting for aggressive treatment. The differences between patients and caregivers were found with respect to more caregivers wanting CPR and artificial ventilation. Agreement on each of the four EoL care options ranged from 7.1% for tube feeding to 66.7% for hospice care. Patient-caregiver dyad agreement indicated by the kappa coefficient for extent of concordance ranged from -0.54 to 0.43, with significant concordance of mild to moderate consistency obtaining with respect to CPR ($\kappa = 0.43$, $p = 0.004$) and artificial ventilation ($\kappa = 0.28$, $p = 0.046$) (Table 5).

Proxy Appointment

Some 35 patients (79.5%) designated a proxy in case they were unable to make a decision, and 27 caregivers (61.4%) identified themselves as a proxy. A patient's spouse was most frequently named as a proxy by patients and caregivers (55 and 41%, respectively), followed by adult children (23 and 16%) and siblings (2 and 2%). A total of 21 patient-caregiver dyads reported a proxy appointment (47.7%); 16 dyads agreed on proxy appointments, with spouses named in 14 responses and adult children named in the other two.

DISCUSSION

A shift away from meaningless and sometimes painful prolongation of life toward quality EoL care has occurred in Korea over the past several decades, leading to enactment of legislation that acknowledges the

individual's own wishes and self-determination (National Law Information Center, 2016). Communication about EoL issues is crucial in this paradigm shift, and ACP assists patients and families to prepare for in-the-moment decision making (Sudore & Fried, 2010; Lee et al., 2013; Mitchell et al., 2015). Advance directives can also be useful in facilitating ACP. In our descriptive exploratory study, the feasibility of a culturally sensitive form of an AD (the K-AD) was tested in clinical practice to determine the extent to which the K-AD could be applicable for patients with advanced cancers and their caregivers.

Approximately one in two cancer patients and their families who were approached about participating completed the K-AD. In a recent study conducted in Korea, cancer patients, family caregivers, and oncologists strongly supported the formulation of an AD, with the majority having a positive attitude about its necessity (Keam et al., 2013). The specifics of AD conversations were significantly different concerning the right time for making such decisions, with oncologists preferring the terminal stage while other stakeholders stressed the importance of this type of communication at earlier points in the course of the disease process (Keam et al., 2013).

Our findings indicate that an AD could be applicable to patients not yet in the terminal stage of their cancer, but about half of our patients were reluctant to complete an AD due to the difficulty involved in making decisions about EoL care. On the other hand, a lack of associated policy and system support was a major barrier for professionals to using an AD (Kim et al., 2013b). Other reasons included concerns about frustration/hopelessness, withdrawal, or ceasing chemotherapy after issuance of an AD. In another study, 45% of 205 elderly persons with a chronic illness reported decisional uncertainty when they made advance decisions about treatment preferences

(Sudore et al., 2010). Despite positive attitudes, the considerable misunderstanding of ADs suggests a need for strategic plans that overcome or consider the perceived barriers to AD usage for all stakeholders in EoL care. The ACP process with the K–AD as a vehicle is encouraged for those with various cancers during the early stages, with subsequent modification or revocation of decisions allowed at any stage of the process (Hong & Kim, 2013; American Cancer Society, 2015; Mitchell et al., 2015).

The statement of values is a unique feature of the K–AD, something that is not included in most AD or POLST documents, even though it is an essential part of ACP (Thomas, 2011). People in Korea have shown a strong preference for value statements regarding future EoL care (Kim et al., 2013a). In our present study, more patients ($n = 38$, 86.4%) than caregivers ($n = 27$, 61.4%) stated personal preferences about their EoL care, with both groups choosing “comfort while dying” along with pain relief (52.7 vs. 55.6%, respectively). Among the 23 patient–caregiver dyads providing value statements, the agreement rate was 78.3% (18/23). Regardless of the presence of a value statement or proxy appointment, the high correspondence rates indicated that most caregivers knew how patients would like to be treated and were likely to respect the individual’s beliefs about EoL care when decisions about future treatment were not forthcoming.

There were conflicting values between patients and caregivers in five cases (e.g., comfort care vs. aggressive EoL medical treatment). Such conflicting values are reasons for the need to document values and priorities in a person’s life, particularly at a time of impending death. There is great concern when a dying person has not stated their EoL values and family members ultimately are thus forced to make EoL care decisions without clarity about a patient’s wishes. This situation is common in Korea, where EoL care decisions are often made within a month of death (Lee et al., 2013). A recent press release from a leading hospital also indicated that families make the decisions about LSTs in 83.1% cases within a week of death, while only 0.6% of patients make their own LST decisions (Seoul National University Hospital, 2013). Our findings further support the need for an informed decisional process based on patient values and treatment wishes, particularly when conflicts about EoL care exist (Keam et al., 2013).

Among the four treatment directives in the K–AD, both the patients and caregivers in our study strongly advocated for hospice care, while fewer supported aggressive treatments like CPR, artificial ventilation, and tube feeding. Patient–caregiver dyadic preferences for treatment directives were significantly different, with more caregivers preferring aggressive

treatments like CPR and artificial ventilation. These findings suggest the need for ACP that affords patients time to make their own treatment decisions and communicate with significant others as early as possible. Similar results have been obtained in past studies (see Oh et al., 2004; Tang et al., 2005). Tang et al. (2005) examined agreement about EoL treatment decisions between 617 dyads of terminally ill patients and their surrogates and found that they were generally in agreement, with a kappa value for minimal concordance of 0.29. Oh and colleagues (2004) compared treatment choices in families with advanced or terminal cancer patients and physicians. They found that families more than physicians supported more aggressive treatments (e.g., chemotherapy with new agents). Their concordance rate was 42%, with modest levels of concordance observed particularly for such aggressive treatments as artificial ventilation, new chemotherapy, and CPR.

Another concern regarding the use of treatment directives in Korea is the tendency of family members to wait to make EoL decisions until death is imminent. Since the publication of Oh et al.’s work (2004), where 14% of families with patients who had advanced or terminal cancers consented to allow patients access to participation in EoL care discussions, EoL decision making has largely remained the responsibility of caregivers and surrogates (Lee et al., 2013; 2014). Korean patients admitted in a near-terminal condition tended to rely on their caregivers for such EoL decisions as resuscitation and AD documentation (Lee et al., 2014). Korean surrogates, primarily family members, also made such EoL medical decisions as do not resuscitate, with 40.3% of surrogate decision making occurring on behalf of 572 of patients with advanced cancer (Lee et al., 2013). Such EoL care decision making most often occurred at the time of impending death (Lee et al., 2013; Seoul National University Hospital, 2013). The incidence of aggressive treatments for terminal cancer patients has also remained high, resulting in delayed decisions for withholding or withdrawal of chemotherapy and proper referral for hospice care, which resulted in poor-quality EoL care (Choi et al., 2015).

Conflicts about EoL care decision making among stakeholders often exist in the Korean clinical environment. Patients frequently depend on family caregivers for EoL medical care decisions, and they are themselves even excluded from such discussions. This situation is not desirable and calls for fewer discrepancies with respect to decision making among stakeholders. Heo (2008) reported that there is some concern about EoL care decisions made by family and physicians without consulting patients. Healthcare professionals should understand the family dynamics related to EoL care, consider the

primary caregiver's decisions, and take account of probable patient–caregiver decision conflicts about EoL care (Sudore & Fried, 2010). Ongoing and open EoL communication and decision making by patients and family members are needed (Heyland et al., 2010). Such mutual decisions will decrease the discrepancies in EoL decision making through the active involvement of the patient and should make it possible to make the best possible decisions about quality of EoL care (Tang et al., 2005). To meet the need for patient–family EoL communication and narrow the gaps in EoL decision making, a context-oriented communication algorithm has been developed by Koh and colleagues (2015), where both patients and families are encouraged to participate in EoL decisions.

Another feature of the K–AD is the option to appoint a proxy. Our patients and their caregivers most often designated a spouse as their proxy (55 and 41%, respectively), followed by descendants (23 vs. 16%, respectively). A higher percentage of patient–caregiver dyads whose proxy appointment was their spouse was found in 14 of 16 (87.5%) dyads.

A study in a tertiary hospital in Korea recently reported that virtually all LST decisions are made by family members—descendant (48.4%), spouse (43.3%), parent (2.6%), or other family member (5.6%)—while very few (0.6%) cancer patients made their own LST decisions (Seoul National University Hospital, 2013). In our study, 79.5% of cancer patients designated as proxy an individual who would make advance decisions that respected their own values when the time came.

In conclusion, a culturally sensitive form of the advance directive (the K–AD), which is designed to facilitate ACP, seems applicable for half of our patient–caregiver dyads. Patient–family caregiver discordance on each feature of the K–AD was found to be modest, which highlights a need for interventions to narrow such discrepancies. Specifically, the most frequently stated value of patient–caregiver dyads was “comfort while dying.” In terms of treatment directives, more family members than patients advocated for aggressive treatments, with CPR and artificial ventilation showing mild to moderate concordance. Only half of our dyads (21 of 44) appointed a proxy, with a spouse being the most-often nominated.

LIMITATIONS OF THE STUDY

This study had several limitations. First, it is an exploratory study with a small sample of patient–caregiver dyads. There were limited details about those who declined to participate, and this information could have offered considerably more insight into planning population-specific approaches to help these patients and their caregivers. Due to the small,

and possibly unrepresentative sample, generalizations to larger mixed groups of Koreans and those faced with other life-threatening illnesses cannot be made. Further studies to examine the use of ADs, their documentation, and modifications are warranted. Additionally, concordance between patients and caregivers, and in fact all stakeholders, is vital information and should be the topic of future research. These data might reveal communication barriers that need to be addressed.

CONCLUSIONS

This exploratory study has shown evidence for the need to support patients and their family caregivers in discussing and planning for EoL care, and this should include using the K–AD and modifying decisions flexibly, as needed. One strategy is to foster ongoing EoL discussions as part of the ACP process where all stakeholders are actively engaged and where patients are given enough assistance to guide their own decision-making process about future care.

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CONFLICTS OF INTEREST

The authors hereby state that they have no conflicts of interest to declare.

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APPENDIX

The Korean Advance Directive

사전(事前)의료의향서

본 문서는 개인의 상태가 의사의 진단 결과 치료나 회복이 불가능 (소생 불가능)하고 연명 치료가 아니고는 사망을 피할 수 없는 상태 (임종기)에서 스스로 의료에 대한 결정을 할 수 없게 되는 경우에 대비하여 자신의 임종기에 이루어지기 바라는 의료행위에 대한 의사를 미리 밝히는 문서입니다

본 문서에서 결정한 내용과 관계없이 통증완화, 개인위생 및 편안함을 위한 서비스는 계속 됩니다

- ① 본 문서는 3 부분 (임종기 의료에 대한 가치관, 의료에 대한 바램, 의료 결정 대리인)으로 되어 있고 이 문서 전체 또는 일부분 작성하셔도 됩니다.
- ② 본 문서는 언제든지 변경과 폐기가 가능합니다.
- ③ 본 문서를 작성, 변경 또는 폐기하는 경우 그 내용을 의료결정 대리인, 가족, 의료인에게 말하거나 문서를 통하여 알려주시기 바랍니다.

1. 임종기 동안에 내가 가장 중요하게 생각하는 것은 다음과 같습니다 (가치관):

(예: 편안하게 임종을 맞이하고 싶다, 가족에게 부담이 안되기 바란다 등)

2. 임종기 동안 원하는 혹은 원하지 않는 의료 (임종기 의료에 대한 바램)

스스로 의사결정을 할 수 없게 된 임종기 상태를 가정하고 응답해 주시기 바랍니다.

- 1) 스스로 의사결정을 할 수 없게 된 임종기 상태에서 심장이 멈추게 된다면, 나는 심폐소생술을 원합니다 원하지 않습니다.
- 2) 스스로 의사결정을 할 수 없게 된 임종기 상태에서 호흡이 멈추게 된다면, 나는 인공호흡기를 원합니다 원하지 않습니다.
- 3) 스스로 의사결정을 할 수 없게 된 임종기 상태에서 입으로 음식이나 물을 먹을 수 없게 되는 경우, 나는 관을 통해 음식이나 수분이 투여되기를 원합니다 원하지 않습니다.
- 4) 스스로 의사결정을 할 수 없게 된 임종기 상태에서 나는 삶의 마지막 순간을 편안하게 맞이할 수 있게 돕는 의료서비스(호스피스완화의료)를 원합니다 원하지 않습니다.

3. 의료결정 대리인

내가 스스로 의사결정을 할 수 없는 임종기 상태에 처하게 되는 경우, 나는 아래 적혀 있는 사람이 나를 위해 의료에 대한 결정을 내려주기 바랍니다.

대리인 이름: _____ 관계: _____ 전화번호: _____

주소 _____

관계자 서명

○ 증인 서명

나는 작성자 본인이 본 문서의 용도와 내용에 대한 이해를 바탕으로 스스로 본 문서를 작성하는 것을 확인하였으므로 이에 서명합니다.

증인 이름: _____ 서명: _____

날짜: _____ 전화번호: _____

○ 상담자 서명

나는 작성자 본인과 본 문서의 내용과 용도에 대해 상담하였으므로 이에 서명합니다.

상담자 이름: _____ 서명: _____

날짜: _____ 전화번호: _____

○ 작성자 서명

나는 본 문서의 용도와 내용에 대해 이해했으며, 그 이해를 바탕으로 스스로 본 문서를 작성했으므로 이에 서명합니다.

작성자 이름: _____ 서명: _____

날짜: _____ 전화번호: _____