

The impact of awareness of terminal illness on quality of death and care decision making: a prospective nationwide survey of bereaved family members of advanced cancer patients

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Abstract

Objects: We aimed to assess whether awareness of a terminal illness can affect care decision making processes and the achievement of a good death in advanced cancer patients receiving palliative care services.

Methods: Awareness of terminal illness at the time of palliative care service admission was assessed by the health care professionals during the routine initial comprehensive assessment process and was recorded in the national terminal cancer patient registry. A follow-up nationwide bereavement survey was conducted, which contained questions regarding decision making processes and the Korean version of the Good Death Inventory.

Results: Among the 345 patients included in the final analysis, the majority (68.4%) of the patients were aware of the terminal illness. Awareness of the terminal illness tended to reduce discordances in care decision making (adjusted odds ratio=0.55; 95% CI: 0.29–1.07), and increased the patients' own decision making when there were discordances between patients and their families (adjusted odds ratio=3.79; 95% CI: 1.31–10.94). The Good Death Inventory score was significantly higher among patients who were aware of their terminal illnesses compared with those who were not (5.04 vs. 4.80; $p=0.013$) and especially in the domains of 'control over the future' (5.18 vs. 4.04; $p<0.001$), 'maintaining hope and pleasure' (4.55 vs. 3.92; $p=0.002$), and 'unawareness of death' (4.41 vs. 4.26; $p=0.024$).

Conclusion: Awareness of the terminal illness had beneficial effect on the harmonious decision making, patient autonomy, and patient's quality of death. Disclosure of terminal illness should be encouraged.

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Introduction

Preparing for death has been considered as a measure of good death in Western countries [1]. And there is a general consensus that awareness of the terminal illness is needed to make sound medical decisions and care choices [2,3]. However, in some cultures, both the preparation and unawareness of death are considered as a component of good death [4–6], and nondisclosure of terminal illness is still common. Family members might have concerns that information regarding the terminal status of a patient could reveal a discordance of care preferences between patients and their families [7,8] and can cause depression, anxiety, or despair, thereby contributing to a poor quality of death.

However, little empirical data are available on how the awareness of a terminal illness can affect care decision making processes in the end-of-life (EOL). Preferences for care decisions are often discordant between patients and their families [7–9]. However, surrogate decision making is commonly practiced based on the expectation that family members represent the best interests of the patient [10]. Therefore, it is important to evaluate how patient awareness of a terminal illness affects the care decision making processes in EOL.

In addition, little is known about whether the awareness of a terminal illness can help in achieving a good death. A few studies have investigated the influence of the awareness of a terminal illness on the patients' quality of life at their EOL, mostly with affirmative results [11–14].

However, these studies are limited in their ability to evaluate its impact on the quality of death because their measurement tools, such as the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire [11,14,15], cannot capture the moment of death [11,13–16] and are missing key questions in EOL including those regarding existential and spiritual issues, worries about family, and social support [17]. In addition, most of the studies are limited by a small sample size [11,13,16], recruitment from a general hospital [11,12,14–16], or the problems associated with a cross-sectional design [12,15,16].

Therefore, the aim of the present study was to assess how the awareness of a terminal illness can affect care decision making and the achievement of a good death in advanced cancer patients receiving inpatient palliative care services (PCSs).

Methods

Data collection

This study was performed as a part of a national initiative to evaluate the quality of care in inpatient PCSs designated by the Korean Ministry of Health and Welfare (MoHW). The institutional review board of the National Cancer Center and the study participating centers approved this study.

In Korea, MoHW began to promote palliative care with its second-term cancer control plan [18] and subsidizes designated PCSs, which are medically based and have a separate palliative care wards, adequate human resources, and proper facilities since 2005 [19]. To receive inpatient palliative care, a patient should be diagnosed as terminal status by physician. As of 2009, the number of inpatient

PCSs was 34, and approximately 8% of terminal cancer patients received palliative care from those services [20].

Patients were registered through the Korean Terminal Cancer Information System (KTCPIIS), a Web-based information gathering system (eVelos system, Velos Inc., Fremont, CA) developed to assist evidence-based policy making with funding from MoHW [21]. The MoHW mandated all 34 designated inpatient PCSs to register all new patients and prospectively collect data for evidence-based policy making [19,21]. Among the 5818 patients enrolled during 2009, only 3867 patients agreed to provide their clinical information (66.5% consent rate) including their awareness of the terminal illness at the time of PCS admission (Figure 1). There was no significant difference in the sociodemographic characteristics and the origin of the cancer between those who agreed to provide their clinical information and those who did not [22].

A nationwide bereavement survey was followed between September and December 2009. The list of potentially eligible patients was extracted from KTCPIIS regardless of the agreement to provide clinical information and sent to each PCS for convenience and consistency of the data collection process. Inclusion criteria were as follows: (1) if the patient was admitted to the PCSs at least 72 hours; (2) if the patient died 2–6 months before the survey date (regardless of the place of death); (3) the bereaved family member identified himself or herself as a main caregiver; and (4) if the bereaved family member was at least 18 years or older. Subjects were excluded from the study if (1) the patient was discharged or transferred to another hospital or general ward; (2) if the bereaved family member could not be contacted by telephone and the vital status of the patient could not be ascertained; (3) the subject explicitly refused to participate

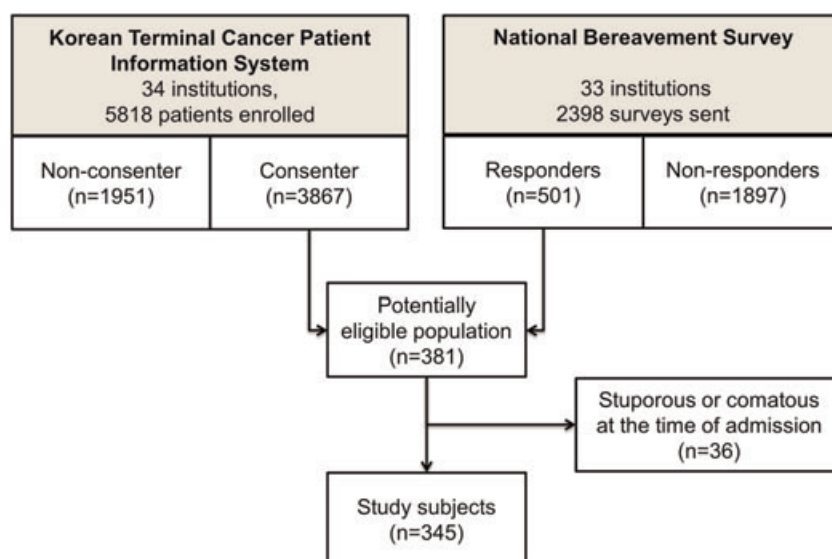


Figure 1. Subjects and data collection

upon telephone contact; and (4) the subject was regarded as not suitable for the study (e.g., if the subject was illiterate or at risk of severe psychological distress), as determined by a member of the staff. A total 2398 postal surveys were sent, 514 surveys were returned, and 501 respondents met the inclusion criteria. The effective response rate was 20.9% (501 of 2398; Figure 1). There were no significant differences between the respondents and non-respondents except for slight difference in gender (female 47.2% vs. male 41.7%, $p=0.028$), supporting the representativeness of the survey. Details of the survey design are described elsewhere [23,24].

Among the 501 respondents, 120 were missing the information about awareness of the terminal illness because they did not agree to provide clinical information in the KTCPIIS. A further 36 patients were stuporous or comatose at the time of submission. A total of 345 cases were included in the final analysis (Figure 1). There were no statistical differences in patient characteristics and caregiver characteristics between the included group ($n=345$) and the excluded group ($n=156$), with the exception of a slight difference in their distribution in the general hospital and community-based PCSs (68.2% vs. 31.8% in the included group and 84.7% vs. 15.3% in the excluded group respectively; $p=0.001$).

Measurements

The main independent variable, awareness of terminal illness at the time of PCS enrollment, was assessed by health care professionals, typically the nurse coordinator or social worker in charge of the patients. During the routine initial assessment process, they comprehensively interviewed the patient and his or her family members and assessed what they knew and what they wanted to know [25]. Patients' expectations on their treatment and the emotional reaction to their disease, as well as, the knowledge of their stage, were considered in determining awareness of terminal illness. A patient was aware of terminal cancer if he or she recognized the anti-cancer treatment as ineffective, and that he or she is expected to die within few months [14,21,26]. For example, the patient who responded as 'I know I've tried every possible treatment' was considered as 'aware' and the patient who had commented as 'I'll restart anti-cancer treatment if my conditions get better' was considered as 'not aware'. The assessment results were recorded in the KCTPIIS.

The survey to bereaved family members contained questions regarding decision making processes and the quality of death of the patients. Care decision making processes were addressed by two questions. The first question was 'Was there discordance in the care decision making between patient and family members?' with responses recorded as either 'Yes' or 'No'. The second question was 'If there was discordance, who made the

final decision?' Respondents were asked to select one of the following four options: patient, family members, medical staff, or others.

Patient quality of death was measured by the Korean version of the Good Death Inventory (GDI) tools [6,27]. The GDI was developed in Japan through qualitative study and rigorous psychometric validation and has been widely used in nationwide surveys [28,29]. The Korean version of GDI has been validated through the standard translation-back translation process and the testing of its psychometric properties [27]. The GDI (54 items in 18 domains) measured the quality of death from the bereaved family member's perspective on a 7-point Likert scale (1: strongly agree to 7: strongly disagree) [6]. The 18 domains were as follows: physical and psychological comfort, dying in a favorite place, maintaining hope and pleasure, good relationship with staff, not being a burden to others, good relationship with family, independence, environmental comfort, being respected as an individual, life completion, receiving enough treatment, natural death, preparation for death, control over the future, unawareness of death, pride and beauty, feeling the worth of one's life, and religious and spiritual comfort.

Statistical analysis

Descriptive data were presented to analyze the characteristics of participants. Multivariate logistic regression models were constructed to calculate the odds ratios (ORs) for the discordance in care decision making and the patient's own decision making between two groups. An analysis of covariance was performed to determine differences in the quality of death between the two groups. We used STATA version 12.0 (StatCorp. Houston, TX), with statistical significance defined as $p \leq 0.05$.

Results

Characteristics of the patients and bereaved family members

Table 1 summarizes the patients' demographic and clinical characteristics. Of the 345 patients, 236 (68.4%) were aware of their terminal illness. Patients in the awareness group were more likely to be younger (62.8 years old vs. 68.6 years old), married, highly educated, and Christian compared with the non-awareness group. There were no significant differences between two groups in the length of survival after PCS enrollment, sex, origin of the cancer, performance status, mental status, or type of PCS. The bereaved family members of the awareness group were more likely to be highly educated, Christian, unmarried, and less affluent compared with those in the non-awareness group. There were no significant differences in the sex or age of bereaved family members between the two groups.

Table 1. Characteristics of terminal cancer patients at the time of palliative care unit admission

Characteristics	Awareness of the terminal illness (n = 345)		p
	Yes (n = 236) No. (%)	No (n = 109) No. (%)	
Patient			
Age, years (mean ± SD)	62.77 ± 13.00	68.59 ± 14.54	
18–59	90 (38.1)	25 (22.9)	
60–79	127 (53.8)	57 (52.3)	
80–older	19 (8.0)	27 (24.8)	<0.001
Length of survival after PCS admission			
Days (mean ± SD)	33.22 ± 43.31	28.78 ± 33.74	0.347
Sex			
Male	131 (55.5)	52 (47.7)	
Female	105 (44.5)	57 (52.3)	0.177
Origin of cancer			
Lung	39 (16.5)	20 (18.3)	
Gastrointestinal	70 (29.7)	34 (31.2)	
Hepato-biliary-pancreatic	57 (24.2)	24 (22.0)	
Others	70 (29.7)	31 (28.4)	0.943
ECOG PS			
0–2	93 (39.4)	40 (36.7)	
3–4	143 (60.6)	69 (63.3)	0.631
Mental status			
Alert	178 (75.4)	78 (71.6)	
Drowsy	58 (24.6)	31 (28.4)	0.508
Marital status			
Married	172 (74.8)	59 (56.7)	
Unmarried	58 (25.2)	45 (43.3)	0.001
Religion			
Christian/Catholic	160 (63.8)	57 (47.5)	
Buddhist	42 (16.7)	34 (23.8)	
None	46 (18.3)	22 (18.3)	
Others	3 (1.2)	7 (5.8)	0.001
Educational status (years)			
≤9	114 (49.6)	70 (67.3)	
≥10	116 (50.3)	34 (32.7)	0.003
Bereaved family members			
Age, years (mean ± SD)	52.84 ± 12.14	53.72 ± 12.31	
18–59	157 (66.5)	75 (68.8)	
60–older	79 (33.5)	34 (31.2)	0.675
Sex			
Male	95 (40.6)	48 (44.0)	
Female	139 (59.4)	61 (56.0)	0.548
Educational status (years)			
≤9	114 (49.6)	70 (67.3)	
≥10	116 (50.4)	34 (32.7)	0.003
Marital status			
Married	109 (47.4)	63 (60.6)	
Unmarried	121 (52.6)	41 (39.4)	0.026
Income, monthly (KRW)			
<200	104 (48.6)	33 (33.3)	
≥200	110 (51.4)	66 (66.7)	0.011
Religion			
Christian/Catholic	136 (54.6)	53 (43.8)	
Buddhist	44 (17.7)	28 (23.1)	
None	67 (26.9)	34 (28.1)	
Others	2 (0.8)	6 (5.0)	0.024
Type of PCSs			
General hospital	154 (65.3)	82 (75.2)	
Others	82 (34.8)	27 (24.8)	0.064

p values calculated from t-tests for continuous variables and the chi-square test for categorical variables.

SD, standard deviation; PCS, palliative care service; ECOG, Eastern Cooperative Oncology Group; PS performance status; KRW, Korean Won.

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Discordance in care decision making

Discordance in care decision making tended to be less frequent in the awareness group than the non-awareness group, though the difference was not statistically significant (25.1% vs. 31.5%; aOR=0.55; 95% CI: 0.29–1.07). When there was discordance, the final decision was more frequently made by patients in the awareness group (48.9% vs. 24.1%; aOR=3.79; 95% CI: 1.31–10.94) (Table 2).

Quality of death

The GDI total score was significantly higher among patients who were aware of their terminal illnesses compared with those who were not (5.04 vs. 4.80; $p=0.013$). When examined by domain, the awareness group had higher scores for nine domains: control over the future (5.18 vs. 4.04; $p<0.001$), physical and psychological comfort (5.08 vs. 4.45; $p=0.001$), dying in a favorite place (5.49 vs. 5.03; $p=0.005$), good relationship with staff (5.88 vs. 5.55; $p=0.020$), maintaining hope and pleasure (4.55 vs. 3.92; $p=0.002$), independence (3.83 vs. 3.35; $p=0.007$), life completion (4.89 vs. 4.42; $p=0.005$), natural death (5.72 vs. 5.49; $p=0.026$), preparation for death (5.31 vs. 4.89; $p=0.014$), and unawareness of death (4.41 vs. 4.26; $p=0.024$). However, there were no difference in the remaining nine domains: not being a burden to others, good relationship with family, environmental comfort, being respected as an individual, receiving enough treatment, unawareness of death, pride and beauty, feeling the worth of one's life, and religious and spiritual comfort (Table 3).

Table 3. Quality of death by patient's awareness of terminal illness from the perspective of bereaved family members

Good Death Inventory	Patient's awareness of terminal illness				<i>p</i>
	Yes		No		
	LS mean	SD	LS mean	SD	
Total score	5.04	0.84	4.80	0.90	0.013
Physical and psychological comfort	5.08	1.32	4.45	1.69	0.001
Dying in a favorite place	5.49	1.31	5.03	1.57	0.005
Maintaining hope and pleasure	4.55	1.59	3.92	1.67	0.002
Good relationship with staff	5.88	0.99	5.55	1.28	0.020
Not being a burden to others	4.25	1.71	4.47	1.68	0.374
Good relationship with family	5.30	1.40	5.03	1.38	0.173
Independence	3.83	1.77	3.35	1.67	0.007
Environmental comfort	5.44	1.32	5.21	1.36	0.133
Being respected as an individual	5.87	1.03	5.83	1.09	0.521
Life completion	4.89	1.62	4.42	1.65	0.005
Receiving enough treatment	5.19	1.36	5.13	1.40	0.849
Natural death	5.72	1.07	5.49	1.07	0.026
Preparation for death	5.31	1.42	4.89	1.43	0.014
Control over the future	5.18	1.33	4.04	1.64	<0.001
Unawareness of death	4.41	1.50	4.26	1.56	0.024
Pride and beauty	3.75	1.55	4.03	1.57	0.455
Feeling the worth of one's life	4.90	1.49	4.65	1.51	0.071
Religious and spiritual comfort	5.43	1.65	5.07	1.71	0.802

p values calculated by analysis of covariance, adjusted for patient characteristics (i.e., sex, age, educational status, marital status, and religion), and bereaved family members (i.e., educational status, marital status, religion, and monthly household income). LS mean, least square mean; SD, standard deviation.

Discussion

To our knowledge, this study is the first nationwide study, which shows that the influence of the awareness of terminal illness on care decision making processes and the

Table 2. Decision making about medical treatment by patient awareness of terminal illness from the perspective of bereaved family members

Questions	Patient awareness of terminal illness (n = 345)		Unadjusted OR (95%CI)	Adjusted OR ^b (95%CI)
	Yes (n = 236) No. (%)	No (n = 109) No. (%)		
Discordance regarding medical treatment between patient and family members				
Yes	52 (25.1)	29 (31.5)	0.73 (0.42–1.25)	0.55 (0.29–1.07)
No	155 (74.9)	63 (68.5)	1 (reference)	1 (reference)
Final decision maker after the discordance ^a				
Patient	23 (48.9)	7 (24.1)	2.57 (1.17–5.68)	3.79 (1.31–10.94)
Non-patient	24 (51.1)	22 (75.9)	1 (reference)	1 (reference)
Family	17 (36.2)	13 (44.8)		
Medical staff	5 (10.6)	6 (20.7)		
Other	2 (4.3)	3 (10.3)		

OR, odds ratio; CI, confidence interval.

^aAsked only when there was decisional discordance between patient and family members.

^badjusted for patient characteristics (i.e., sex, age, educational status, marital status, and religion) and bereaved family members (i.e., educational status, marital status, religion, and monthly household income).

quality of death in advanced cancer patients. Strengths also include validated outcome measures of the quality of death.

Our findings revealed that approximately one third of advanced cancer patients are admitted to PCSs not knowing their prognosis. This finding is consistent with a recent multicenter study in which only 58% of the advanced cancer patients in the oncology ward were aware of their terminal status [14] as well as a nationwide study indicating that 78.5% of the patients in the inpatient PCSs were aware of their terminal status [16]. In Asian cultures, family members often believe that it is a filial responsibility to keep burdensome information from patients and to make EOL decisions on behalf of the patient [10]. Consequently, surrogate decision making frequently occurs and often leads to more aggressive life-sustaining treatment [8,10]. The families might be concerned that the patients would choose comfort care if they knew of their terminal status because the patients would not want to be a burden to the family [5,6].

However, our study results show that patient awareness does not increase discordances in decision making between patients and families. Indeed, our findings here indicate that patient awareness helps to maintain patient's autonomous decision making in cases of discordance. This suggests that failing to disclose terminal illness inhibits open discussion regarding the best care options, and therefore, increases the chance for discordances as shown in the non-significant trend in our study [30]. Furthermore, such open discussions might reveal patient wishes to the family members, leading to a more active engagement of the patients in the EOL planning [30]. If we hypothesize that patients are in the best position to decide what is in their own best interests, we can conclude that patient awareness of terminal illness will lead to the best patient care.

It seems natural that the awareness of a terminal illness improves the quality of death, especially in domains such as control over the future, independence, dying in a favorite place, preparation of death, and life completion because these domains reflect the patients' own decisions and existential issues [6]. On the other hand, it is particularly interesting that the awareness also improved GDI scores in domains about unawareness of death, maintaining hope and pleasure, and natural death, contrary to the usual expectations in Asian cultures. One possible explanation is that the awareness of terminal illness leads to the opportunity for the patients to have a more realistic hope [31], instead of losing hope. It has been reported that even though family members have tried to shield patients from the reality of their situation, almost 30% of advanced cancer patients eventually guess their prognosis from their worsening condition and thus ultimately experience more emotional distress than patients informed of their terminal diagnosis [14]. Therefore, we think that the timely disclosure of terminal illnesses to patients is critical not only for advocating patient autonomy, but also for the maintenance of realistic

hope, existential well-being, and the achievement of a sound closure to their lives.

Several limitations should be considered. First, one might argue that using a bereaved family member survey to assess the quality of death is not the best approach to addressing the current issue. Although we need to consider recall bias and the validity of proxy ratings [32], the quality of death might be better evaluated instead by bereaved family members by including the moment of death. Moreover, the assessments of bereaved family members are an important outcome in palliative care by itself because bereaved family members are also an important target of palliative care [33]. Second, validity and reliability of our assessment of terminal illness by health care professionals are unknown. There is ethical and methodological dilemma in assessing patients' awareness of terminal illness. Whereas self-report questionnaire approach has been used in some previous study, it has several problems: (1) awareness and simple knowledge might not be the same [30]; (2) patients might not correctly discriminate 'terminal' from 'advanced' [11,14]; and (3) the administration of questionnaire or non-routine interview can unintentionally make them to be aware of their terminal status from guessing [14], which would result in emotional distress. Therefore, detailed and tactful interviews with patients and families can be a good alternative to circumvent such issues [26,34,35]. In addition, it had been better to check validity and reliability across healthcare professionals to secure the accuracy though it was not routinely performed in the KTCPI system. Third, we adopted a binary assessment of awareness of terminal illness, based on the previous studies—although some cases could not be clearly classified. Uses of interval scaling can be considered in further studies. Fourth, low-response rate of this study can raise concern for the quality of survey such as potential selection bias. However, good balance has been achieved in our study sample, and further discussion for representativeness of the study sample is in detail discussed in our previous study [23]. Fifth, although the study sample would be representative of patients who were admitted to PCSs, only an estimated 8% of terminal cancer patients used inpatient PCSs in Korea [23]. Therefore, we compared our study sample with patients who died in 2009 because of cancer, and there was not much difference in age, sex, and cancer type. Yet, similar study is necessary with larger and nationally representative sample in the future.

Despite these limitations, our study result suggests that careful disclosure of the terminal status could promote harmonious decision making, patient autonomy, and good death in Asian culture. It would be necessary to provide a guide for specific occasions and topics as a routine care program to discuss at important points of time during the course of a disease. Making decisions for a discussion about terminal disease status [36] and for setting a family conference mediated by health care professionals [37] could be good options. Further studies are warranted to address how to best individualize the manner of breaking bad news to respect

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cultural preferences of patient and family [38]. Meanwhile, public education to promote the awareness of benefit of disclosure and training of health professionals for mutual communication and support skills would be necessary [39].

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Conflict of interest

The authors have no conflict of interest.

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