

# Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end-of-life choices

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## Abstract

**Background:** The complexity of end-of-life (EOL) communication in cancer care is often increased by family caregivers, who frequently affect the information and decision-making process. We assessed cancer patient preferences (PP), family caregiver preferences (FCP), and family caregiver predictions of patient preferences (FCPPP) regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices, and we evaluated the concordances among them.

**Methods:** A national, multicenter, cross-sectional survey of 990 patient-caregiver dyads (participation rate = 76.2%) was performed. A set of paired questionnaires was independently administered to patients and their caregivers.

**Results:** While patients and family caregivers had wide spectra of preferences, patients significantly preferred disclosure, direct disclosure by a physician, and palliative care options (all  $P < 0.001$ ). Family caregiver predictions were similar to PP with regard to terminal disclosure ( $P = 0.35$ ) but significantly different with regard to family involvement in the disclosure process and EOL choices ( $P < 0.001$ ). The concordances of PP and FCP ( $\kappa = 0.08$ – $0.13$ ), and those of PP and FCPPP ( $\kappa = 0.09$ – $0.17$ ), were poor. The concordances of FCP and FCPPP were fair to moderate ( $\kappa = 0.35$ – $0.67$ ). Discrepancies between PP and FCP and between PP and FCPPP were associated with dysfunctional family communication.

**Conclusions:** Family caregivers do not generally concur with patients in their preferences, nor do they reliably predict PP. Open dialogue between patient and family caregivers would reduce the discrepancy. More emphasis on incorporating family caregivers in EOL communication is needed from clinical, research, and training perspectives.

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## Introduction

Informing patients about their end-of-life (EOL) status and helping them to choose care options they prefer are key communication tasks in EOL decision making. The complexity of such communication is often increased by family caregivers as the patients status worsens: family caregivers often function as a communication channel between patients and physicians, controlling the information given to patients [1–4]; they frequently affect the decision-making process regarding patient care [5]; moreover, families frequently need to make difficult decisions as a surrogate for their loved one when the patients become incapable.

As most care decisions are made within the context of family care and obligation [6], understanding family member views in a dyadic context is critical in developing communication strategies for harmonious decisions. Studies have revealed poor concordance between patient preference (PP) and family caregiver preference (FCP) for life-sustaining treatment [4–7] or place of death [8]. In addition, the inaccuracy of family caregiver predictions of patient preferences (FCPPP) for the life-sustaining treatment is well noted [9–11]. However, no study has examined FCP and FCPPP simultaneously.

In addition, issue of disclosure of terminal status and family involvement in the process have been important issue in EOL decision making in many cultures [2,3,12–15]

and are a potential source for ethical problems and family conflicts. However, to our knowledge, no study addressed preferences for these issues in a dyadic context.

The issue of understanding concordance or discordance between patients and family members regarding breaking bad news and making hard decisions is relevant for cancer clinicians, especially in some cultures like Korea, where family members are highly expected to participate in caregiving and treatment decision. In this study, we sought to assess PP, FCP, and FCPFP regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices, and to evaluate the concordances among them. We also explored the predictors of such concordances.

## Methods

### Study population and data collection procedure

This study was part of the CaPE (Cancer Patient Experience) study, which is an annual nationwide survey of cancer patient experience in Korea. In 2011, the study was conducted with patient-caregiver dyads, to explore the disparate views of cancer patients and their family caregivers. The study, which was conducted at the National Cancer Center and all government-designated Regional Cancer Centers ( $n=9$ ) in Korea, aimed to provide a large and representative sample. None of the ten participating institutions had an official organizational policy regarding the disclosure of terminal status, but all had either in-house palliative care units or a palliative care referral system.

Patients and their family caregivers were recruited by trained interviewers at outpatient clinic waiting areas or inpatient wards, and the interviewer explained the purpose and procedure of the survey. The inclusion criteria for patients were (a) over 18 years old, (b) cancer diagnosis, (c) currently receiving treatment or follow-up, and (d) in proper physical and mental condition to complete a questionnaire. Inclusion criteria for caregivers were (a) an accompanying family member of a cancer patient and (b) over 18 years of age.

We counted a patient-caregiver dyad when both the patient and family agreed to participate and provided informed consent separately. We approached 1299 dyads, and 990 dyads (participation rate = 76.2%) agreed to participate. The study was approved by the Institutional Review Board of the National Cancer Center, Korea.

After obtaining consent, the patients and family members were instructed to answer the survey in separate places so that information was not shared and responses by one would not be influenced by the presence of the other. Clinical information such as primary cancer diagnosis; Surveillance, Epidemiology, and End Results (SEER) stage; and time since cancer diagnosis were retrieved from hospital information systems at the participating centers.

## Measures

For this study, we developed a set of paired questionnaires examining preferences regarding the disclosure of terminal status, family involvement in the disclosure process, and EOL choices through a literature review [4,12–14,16–18] and expert discussion. Patients were asked to provide their own preferences on those issues. Similarly, caregivers were asked about their preferences on those issues and their predictions of PP. Details of the questionnaires and response choices are provided in Appendix 1 in Supporting information. The instrument was reviewed by a group of experts in survey research methodology, palliative care, and communications research. Additionally, a pilot study was conducted with 30 cancer patients and their caregivers.

To examine the influence of family communication on concordance, the 18-item Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) Scale was administered to the dyads [19]. The reliability and validity of Korean version were satisfactory, and Cronbach's alpha for CCAT-PF with our data was 0.60 (similar to 0.49 of the original US study). The survey questionnaire also included questions regarding socio-demographics and medical information.

## Statistical analyses

We described the distributions of the patient and caregiver responses, and compared the differences between them with the McNemar test or Friedman test. The extents of concordances were determined by kappa coefficients to correct for the amount of agreement that could be expected by chance alone [20]. The strength of agreement, measured by kappa, was determined by the following criteria: <0.20, poor; 0.21–0.40, fair; 0.41–0.60, moderate; 0.61–0.80, substantial; and 0.81–1.00, almost perfect [21].

Predictors of each concordance were identified by a series of multivariate logistic regression models that included age, gender, education level, patient disease stage (local, regional, advanced), family caregiver's relationship to the patient (spouse, adult child, parent, or other), and the level of discordance in patient-family caregiver cancer communication measured by CCAT-PF. To confirm the robustness of our finding, subgroup analyses were done with patients who have an advanced stage of cancer and their families that might be the most relevant sample to document the preference on disclosure and EOL treatment. All statistical analyses were conducted using STATA software (ver. 12.0; STATA Corp., Houston, TX).  $P$ -values <0.05 were considered to indicate statistical significance.

## Results

### Baseline characteristics

Table 1 shows the characteristics of the 990 patient-family dyads. The patients had a mean age (SD) of 59.5 (12.9)

**Table 1.** Characteristics of the 990 dyads of patients and caregivers

Patients (n = 990)	N	%	Caregivers (n = 990)	N	%
Age, mean (SD)	59.5 (12.9)		Age, mean (SD)	50.0 (14.5)	
Sex			Sex		
Male	459	46.4	Male	375	37.9
Female	531	53.6	Female	615	62.1
Marital status			Marital status		
Married	820	82.8	Married	793	80.1
Unmarried	169	17.1	Unmarried	197	19.9
Missing	1	0.1	Missing	0	0.0
Education			Education		
Less than high school (<9 years)	454	45.9	Less than high school (<9 years)	246	24.8
High school and above (≥9 years)	532	53.7	High school and above (≥9 years)	740	74.7
Missing	4	0.4	Missing	4	0.4
Monthly income			Monthly income		
<2 million KRW	574	58.0	<2 million KRW	465	47.0
≥2 million KRW	406	41.0	≥2 million KRW	520	52.5
Missing	10	1.0	Missing	5	0.5
Cancer type			Relationship with patient		
Stomach	111	11.2	Spouse	544	54.9
Lung and bronchus	108	10.9	Son/daughter	185	18.7
Liver	47	4.7	Son-/daughter-in-law	47	4.7
Colorectal	163	16.5	Parent	146	14.7
Breast	226	22.8	Sibling	42	4.2
Cervix and uterus	58	5.9	Other	14	1.4
Other	277	28.0	Missing	12	1.2
SEER cancer stage (current)			Living with patient		
<i>In situ</i> and local	279	28.2	Yes	737	74.4
Regional	295	29.8	No	253	25.6
Distant	383	38.7			
Unknown/missing	33	3.3			
Time since diagnosis, year; Mean (SD)	1.6 (2.3)				
< 1 year	594	60.0			
1–5 years	327	33.0			
>5 years	69	7.0			
Current treatment status					
Under initial treatment	562	56.8			
On regular follow-up after treatment	196	19.8			
On regular follow-up after cure	26	2.6			
Under treatment for metastasis or recurrence	198	20.0			
Not sure	4	0.4			
Other (e.g. treatment for second primary cancer)	4	0.4			

and 53.6% were female. The caregivers had a mean age (SD) of 50.0 (14.5) and 62.1% were female. Spouses accounted for 54.9% of caregivers, and 18.7% and 14.7% were children and parents of the patients, respectively.

### Distribution of and differences in responses

Most patients (76.9%) and family caregivers (61.1%) responded that the patient should be informed of his or her terminal prognosis. On the other hand, 10% of the patients and 27.8% of the family caregivers believed that it was better for patients not to be informed if families decide not to. Over half of patients responded that their physician should inform them directly (56.1%), but family caregivers most frequently answered that a physician should inform the family first, and then inform the patient if the family agreed (42.5%). Most patients (69.3%) and

family caregivers (67.0%) preferred palliative care over life-sustaining treatment. Patients preferred to be informed of their terminal status (76.9%) more than family caregivers (61.1%), and they preferred to be informed directly by their physicians (56.1 vs. 28.2%). In terms of EOL choices, more patients preferred palliative care compared with their family caregivers (69.3 vs. 67.0%); this was statistically significant. While there was no difference between PP and FCPPP on the disclosure of terminal status ( $P=0.35$ ), the FCPPP on direct disclosure and palliative care was significantly lower than the actual PP ( $P<0.001$ ; Table 2).

### Concordances among PP, FCP, and FCPPP

The concordances of PP and FCP were poor for disclosure of terminal status ( $\kappa=0.12$ ), family involvement in the disclosure process ( $\kappa=0.13$ ), and EOL choices ( $\kappa=0.08$ ).

Similarly, the concordances of PP and FCPPP were poor for disclosure of terminal status ( $\kappa=0.09$ ), family involvement in the disclosure process ( $\kappa=0.17$ ), and EOL choices ( $\kappa=0.15$ ). For disclosure of terminal status, family involvement in the disclosure process, and EOL choices, the concordances of FCP and FCPPP were fair to moderate (Figure 1, Appendix 2–4 in Supporting information). Levels of concordances did not differ by disease or treatment status (Appendix 5, 6 in Supporting information).

### Factors associated with the concordances among PP, FCP, and FCPPP

There were no consistent predictors of concordances among patient and caregiver sociodemographic characteristics. Relationship to patients was a statistically significant factor associated with concordance between PP and FCP on the disclosure of terminal status (parent vs. spouse: aOR = 0.54; 95% CI = 0.33–0.88) and EOL choices (adult child vs. spouse: aOR = 0.53; 95% CI = 0.32–0.88). CCAT-PF scores indicative of family communication difficulties were significantly associated with poor concordance regarding EOL choices (aOR = 0.96; 95% CI = 0.95–0.98) and marginally with concordance regarding family involvement in disclosure process (aOR = 0.98; 95% CI = 0.97–1.00) (Table 3). Factors associated with the concordances between PP and FCPPP were largely similar to factors associated with the concordances between PP and FCP (Table 4).

### Subgroup analyses results

The characteristics of the dyads in which patients are with advanced cancer are described in Appendix 7 in Supporting information. Almost half of them responded they are caring the caregiver almost all the time. Responses to the questions (Appendix 8 in Supporting information), its concordances (Appendix 5 in Supporting information), and predictors of the concordances (Appendix 9, 10 in Supporting information) were generally similar to those of the total sample.

### Discussion

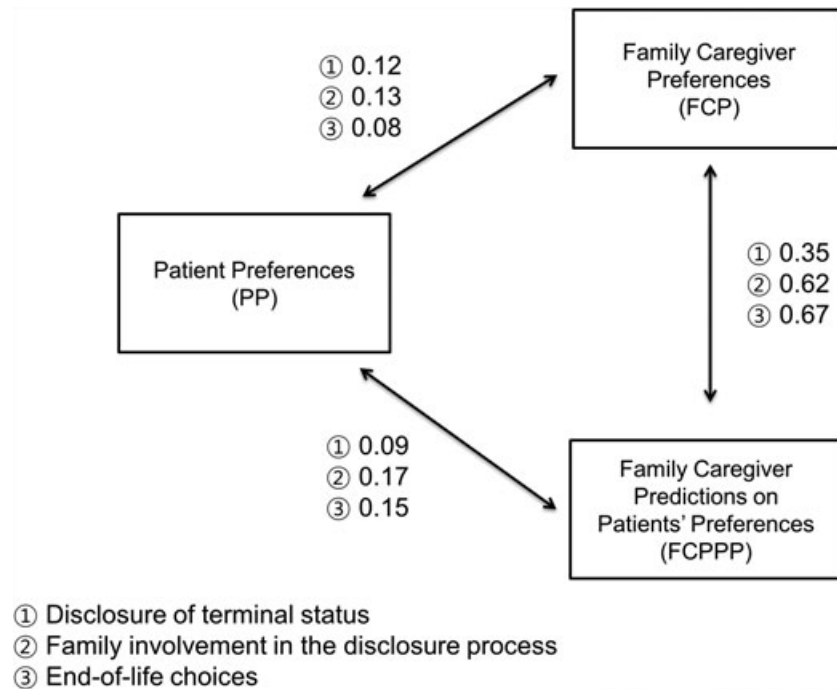
To our knowledge, this is the first study that concurrently investigated the FCP and FCPPP along with PP regarding wide range of important EOL communication issues such as disclosure of terminal status, family involvement in the disclosure process, and EOL choices in a large and representative sample of cancer patient–caregiver dyads.

A wide range of preferences was noted among both patients and their family caregivers. While the majority of the patients and their family caregivers preferred the disclosure of terminal status to the patients and palliative care as an EOL care choice, there was a group of patients and family caregivers who preferred non-disclosure and life-sustaining treatment. With the family's involvement in the disclosure process, PP and FCP varied, resulting in no single preferred option. While the disclosure of terminal status has become the ethical norm and palliative

**Table 2.** Responses to the questions

	Patient preferences (PP)		Family caregiver preferences (FCP)		Family caregiver predictions of patient preferences (FCPPP)		P
	n	%	n	%	n	%	
Disclosure of terminal status							
Should be informed	761	76.9	605	61.1	780	78.8	
Better not to be informed	43	4.3	104	10.5	99	10.0	
Better not to be informed, if family decides not to	99	10.0	275	27.8	105	10.6	
Missing	87	8.8	6	0.6	6	0.6	
Difference between PP and FCP							<0.001
Difference between PP and FCPPP							0.35
Difference between FCP and FCPPP							<0.001
Family involvement in the disclosure process							
Physician should inform patient directly	555	56.1	279	28.2	404	40.8	
Physician should inform family, and let family inform the patient	142	14.3	284	28.7	235	23.7	
Physician should inform family first, and, if family agrees, inform patient	205	20.7	421	42.5	345	34.9	
Missing	88	8.9	6	0.6	6	0.6	
Difference between PP and FCP							<0.001
Difference between PP and FCPPP							<0.001
Difference between FCP and FCPPP							<0.001
EOL choices							
Life-sustaining treatment	199	20.1	319	32.2	313	31.6	
Care for maintaining quality of life	686	69.3	663	67.0	666	67.3	
Missing	105	10.6	8	0.8	11	1.1	
Difference between PP and FCP							<0.001
Difference between PP and FCPPP							<0.001
Difference between FCP and FCPPP							0.735

P-value: by the Friedman test (for terminal disclosure and family involvement in disclosure); by the McNemar test (for EOL care options).



**Figure 1.** Concordances regarding the disclosure of terminal status and end-of-life choices

care in one's EOL choices is becoming more common worldwide [22], wide variability of preferences for information and involvement in medical decision making [23,24] and for life-sustaining treatment [7] have been reported even in Anglo-American societies where patient autonomy is highly valued. As physicians are poor at perceiving patient needs related to involvement in treatment-related decision making [25], professionals should avoid stereotyping patient or family preferences regarding the

disclosure of terminal status and EOL choices and evaluate them case-by-case, considering individual situations, including family dynamics [26,27].

Consistent with previous studies, family caregivers were more likely to advocate non-disclosure of terminal status [12], involvement of families in the process of disclosure [12], and life-sustaining treatment [4,28,29]. Family caregivers may support non-disclosure because they are afraid that disclosure could cause emotional distress

**Table 3.** Factors associated with concordances between patients' preferences (PP) and family caregivers' preferences (FCP)

	Disclosure	Family involvement	EOL choices
Patient characteristics			
Age (per 10 years)	0.94 (0.81–1.10)	<b>0.84 (0.72 – 0.98)</b>	0.89 (0.75–1.04)
Female sex (vs. male)	0.94 (0.66–1.34)	1.15 (0.80–1.66)	1.40 (0.97 – 2.03)
Cancer stage, current (vs. local)			
Regional	1.13 (0.78–1.64)	1.17 (0.80–1.71)	1.16 (0.78–1.71)
Distant	1.13 (0.80–1.60)	1.42 (1.00 – 2.01)	1.07 (0.74–1.54)
Education (vs. <9 years)			
9–12 years	0.89 (0.61–1.29)	0.95 (0.66–1.38)	1.07 (0.73–1.57)
>12 years	0.92 (0.59–1.44)	0.67 (0.43–1.06)	1.08 (0.68–1.73)
Caregiver characteristics			
Age (per 10 years)	0.98 (0.83–1.16)	<b>1.31 (1.11–1.55)</b>	0.97 (0.82–1.16)
Female sex (vs. male)	1.10 (0.78–1.55)	1.09 (0.76–1.56)	1.37 (0.95–1.96)
Education (vs. <9 years)			
9–12 years	0.89 (0.51–1.20)	0.98 (0.65–1.48)	1.15 (0.75–1.76)
>12 years	0.62 (0.37–1.03)	1.08 (0.65–1.78)	1.61 (0.96 – 2.72)
Relationship (vs. spouse)			
Adult child	0.67 (0.41–1.08)	0.92 (0.56–1.50)	<b>0.53 (0.32–0.88)</b>
Parent	<b>0.54 (0.33–0.88)</b>	1.20 (0.73–1.97)	0.89 (0.52–1.50)
Others	1.43 (0.76–2.68)	0.92 (0.51–1.67)	1.41 (0.71–2.83)
Communication characteristics			
CCAT_PF (per point)	0.99 (0.98–1.01)	0.98 (0.97–1.00)	<b>0.96 (0.95–0.98)</b>

Disclosure: disclosure of terminal status; family involvement: family involvement in disclosure process; EOL: end-of-life.



**Table 4.** Factors associated with concordances between patients' preferences (PP) and family caregivers' prediction on patients' preferences (FCPPP)

	Disclosure	Family involvement	EOL choices
Patient characteristics			
Age (per 10 years)	1.06 (0.90–1.25)	0.88 (0.75–1.03)	0.92 (0.78–1.09)
Female sex (vs. male)	0.86 (0.59–1.25)	1.07 (0.76–1.53)	1.17 (0.81–1.70)
Cancer stage, current (vs. local)			
Regional	1.00 (0.67–1.49)	0.85 (0.60–1.22)	0.96 (0.65–1.44)
Distant	1.13 (0.67–1.42)	0.97 (0.69–1.37)	0.83 (0.57–1.20)
Education (vs. <9 years)			
9–12 years	1.17 (0.78–1.75)	1.05 (0.73–1.51)	1.30 (0.89–1.92)
>12 years	1.10 (0.68–1.78)	1.10 (0.71–1.70)	1.36 (0.85–2.19)
Caregiver characteristics			
Age (per 10 years)	0.85 (0.71–1.01)	1.04 (0.89–1.23)	0.90 (0.75–1.07)
Female sex (vs. male)	0.94 (0.65–1.37)	1.03 (0.73–1.45)	1.15 (0.80–1.65)
Education (vs. <9 years)			
9–12 years	0.67 (0.42–1.06)	0.82 (0.55–1.23)	1.06 (0.69–1.64)
>12 years	0.68 (0.39–1.17)	0.67 (0.41–1.09)	1.28 (0.76–2.18)
Relationship (vs. spouse)			
Adult child	<b>0.59 (0.36–0.99)</b>	0.79 (0.49–1.27)	<b>0.53 (0.32–0.89)</b>
Parent	<b>0.58 (0.35–0.98)</b>	1.03 (0.63–1.69)	0.78 (0.46–1.34)
Others	0.92 (0.48–1.75)	0.82 (0.46–1.46)	1.22 (0.61–2.47)
Communication characteristics			
CCAT_PF (per point)	0.98 (0.97–1.00)	0.99 (0.97–1.00)	<b>0.97 (0.95–0.98)</b>

Disclosure: disclosure of terminal status; family involvement: family involvement in disclosure process.

and loss of hope in the patients, and may prefer indirect disclosure because they think that they know the patients' emotional condition and can provide more comfort and hope for the future when they disclose the terminal status to the patients. Family caregivers may oppose palliative care as they can regard the discontinuation of life-sustaining treatment as a passive form of euthanasia [4]. While such attitudes can be explained partly by the Oriental philosophy of filial piety [13,30], a similar sense of duty, labeled 'role obligation,' can be found in Western cultures [31].

Consistent with previous studies [4,7,28,29], we showed much poorer concordance in the preferences toward EOL issues among the patient–caregiver dyads. While it seems natural that two independent persons would have differing values and attitudes toward certain issues [4], the discordant preferences between patient and family, often not even recognized in practice because of a lack of communication, could present a significant dilemma for health professionals.

Considerable inaccuracy in FCPPP has been widely documented [9–11,32], and our results are consistent with those previous studies. Interestingly, our study showed that FCPPP was more concordant with FCP than with PP. This suggests that advance directives should be encouraged in the best interest of all patients. However, surrogate decision making is a common reality, because relatively few patients prepare advance directives or have spoken to their surrogates about their wishes [33].

Spouse caregivers showed higher concordances with PP and more accurate predictions of PP regarding the

disclosure of terminal status and EOL choices. This is consistent with the result of previous study in which spouse showed higher elder-proxy accuracy regarding EOL decisions than adult children [9]. In addition, higher concordance regarding family involvement in cancer treatment decision making was found with patient–spouse dyads than adult child dyads [34]. While this might reflect the cohort effect, it might due to that couples would have similar values and experiences throughout their marital life. Although more evidence is necessary, spouses could be more reliable surrogate decision makers than other family members.

Of note, family communication dysfunction reflected in CCAT-PF scores was associated with discrepancy between PP and FCP, as well as PP and FCPPP. Similarly, proxies reporting higher family conflict had lower elder-proxy accuracy regarding EOL decisions in previous studies [9]. Indeed, open dialogue between patient and family caregivers has been suggested as a potential solution to maintain patient autonomy [4,28] and to ensure surrogate accuracy [11,33]. However, some studies found that discussions between patients with family caregivers about treatment preferences did not result in agreement about life-sustaining treatment [7], and a systematic review found that such prior discussion generally did not improve surrogate accuracy [32]. Further studies are warranted to determine if interventions to facilitate patient–caregiver communication would lead to more patient–caregiver agreement in EOL care.

One significant limitation of this study is that we used hypothetical scenarios to examine preferences on the

disclosure of terminal status and EOL choices. Since many of patients in our study had 'in situ' or very early cancer, there would be a concern about the validity and relevance of the study; patients with earlier stage who can expect cure or have good progression would have different preference on the disclosure of terminal status and EOL compared to patients with advanced stages. However, fear of cancer recurrence is the most common distressing factors for all patients, even for disease-free cancer survivors [35], suggesting that most of our study subjects also would have thought about possible recurrence or death during their illness trajectory and they could be also relevant subjects for hypothetical questions about EOL issues. In addition, similar patterns were observed with the subgroup analyses confined to subjects with advanced cancer compared to the results of the overall sample supporting that subject selection did not affect that validity of the study. Furthermore, from the clinical perspective, all advance care planning is done with hypothetical scenarios [9], and preferences have been suggested to be generally stable throughout the illness [36]. Actually, the hypothetical scenario approach has been widely used for EOL preference research [3,16] and is often the only method to investigate these kinds of research questions [33].

This study also has other limitations. First, we enrolled patients who were accompanied by their family caregivers at hospitals, and their preferences might differ from patients who did not have accompanying family members. Similarly, we were limited in not obtaining preferences from other family caregivers who could not be with the patients. However, the accompanying family member would likely be the closest primary caregiver who shared the disease experience and had more opportunities to discuss their views. Thus, we think that such possible bias could even strengthen our conclusion of low concordances in their preferences or inaccurate surrogate predictions. Second, of note is the higher missing rate in patients. They might be those who did not want to think about a terminal prognosis, even though it was given as a hypothetical scenario. So, the missing cannot be assumed to be missing at random and could be a source of bias. Finally, our study results might not be directly applicable to other countries.

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However, the EOL issues addressed in our study can happen to families of any cultural background [26] and ought to be meaningful in most developed countries with ever increasing multiculturalism.

Effective communication with family caregivers, as well as patients, is critical to optimal EOL care [37]. However, our study clearly shows that family caregivers neither generally concur with patients in their preferences, nor do they reliably predict PP. Interestingly, FCPPP were rather similar to their *own* preferences. EOL discussions within the family context are far from simply advocating self-determination versus palliative care. Patient and family caregivers often find it difficult to raise such topics themselves [7,38]. It is the responsibility of healthcare professionals to lead the discussion, based on need [37]. Healthcare professionals should be aware of the relational aspects in EOL communication [27] and adopt a careful communication strategy that allows the satisfaction of family caregivers as well as the patient [26,30]. Running a family meeting is one useful way for information sharing and goal clarification in cancer care [37,39]. However, appropriate guidance is rare [31,37], and most healthcare professionals do not receive sufficient training to conduct this type of therapeutic communication [37]. More emphasis on incorporating family caregivers in EOL communication is needed from clinical, research, and training perspectives.

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## Conflict of interest

None disclosed.

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