

Associations between accurate prognostic understanding and end-of-life care preferences and its correlates among Taiwanese terminally ill cancer patients surveyed in 2011–2012

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Abstract

Objective: Adequate knowledge of prognosis is a prerequisite for planning appropriate end-of-life (EOL) care. However, questions remain about whether the association between prognostic understanding and EOL-care intensity reflects terminally ill cancer patients' preferences for EOL care. This study investigated the associations between accurate prognostic understanding and EOL-care preferences, and identified correlates of accurate prognostic understanding.

Methods: A cross-sectional survey of 2452 terminally ill cancer patients from 23 hospitals throughout Taiwan.

Results: Nearly half the participants (49.80%) accurately understood their prognosis. These patients were significantly more likely to prefer comfort-oriented care as their goal for EOL care, but less likely to prefer life-prolonging treatments. Accurately understanding prognosis decreased the likelihood of preferring intensive care unit care, cardiac pulmonary resuscitation, cardiac massage, intubation, and mechanical ventilation support, but increased preference for hospice care. Participants were significantly more likely to accurately understand their prognosis if they were male, younger, better educated, with a stronger preference for physicians to disclose their prognosis to them, and receiving care at a hospital accredited as a medical center and in northwest Taiwan. The likelihood of accurate prognostic understanding was lower for patients recently (≤ 12 months) diagnosed with cancers with better prognosis and hematologic malignancies than for lung cancer patients.

Conclusions: Accurately understanding prognosis is associated with fewer preferences for life-sustaining treatments and is correlated with both patient and institutional characteristics. Interventions should be developed to improve accurate prognostic understanding, thus facilitating informed EOL-care decisions that may limit the use of aggressive interventions.

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Introduction

Adequate knowledge of prognosis is a prerequisite for planning appropriate end-of-life (EOL) care, thus improving quality of life at EOL [1,2]. Indeed, cancer patients with accurate prognostic understanding were more likely to question the value of further chemotherapy [3], discontinue anticancer treatments at EOL [4,5], use palliative/hospice care [6,7] with longer hospice stays [8], and die at home [9], but were less likely to use intensive care unit (ICU) care [7].

Patients' treatment preferences play an important role in determining EOL-care intensity [1,6,10,11], but only one

study investigated the relationship between prognostic understanding and preferred goals for EOL care [12]. In that study, patients who recognized they were terminally ill preferred symptom-directed EOL care over life-extending therapy [12]. Questions remain about whether the association between prognostic understanding and EOL-care intensity reflects cancer patients' EOL-care preferences. How prognostic understanding shapes preferences for EOL care warrants further investigation to facilitate providing EOL care that honors patient's wishes to achieve a good death, as suggested by the Institute of Medicine [13].

Although cancer patients' preference for prognostic disclosure has been well documented with substantial

cross-cultural unanimity [14–18], a minority of terminally ill cancer patients worldwide understood their prognosis [2,3,6,16,18–20]. Prognostic disclosure has been associated with physician factors [21,22], but few studies have explored how patient characteristics influence cancer patients' prognostic understanding. Furthermore, how health care is provided, including EOL care, is suggested to be influenced by institutional characteristics, for example, healthcare resources and hospice philosophy [11,23–25]. However, the role of institutional factors in determining terminally ill cancer patients' prognostic understanding has never been explored. Therefore, this study had two purposes: (1) to investigate the associations between accurate prognostic understanding and EOL-care preferences, and (2) to identify correlates of accurate prognostic understanding among terminally ill cancer patients. Specifically, we hypothesized that accurate prognostic understanding would predispose terminally ill cancer patients to prefer comfort-oriented care as their goal for EOL care, hospice care, and dying at home, and to be less likely to prefer life-sustaining treatments such as ICU care, cardiac pulmonary resuscitation (CPR), cardiac massage, intubation, and mechanical ventilation support at EOL. We also hypothesized that prognostic understanding would be associated with patients' demographic and disease-related characteristics as well as characteristics of the institution where they received care.

Methods

Study design and sample

For this cross-sectional study, we surveyed a convenience sample of terminally ill cancer patients at 23 hospitals throughout Taiwan from April 2011 through November 2012. Random sampling was unfeasible because no complete list was available for all prospective terminally ill patients. These 23 hospitals were selected because they predominantly provide cancer care in Taiwan. Patient eligibility criteria included: (1) diagnosed with a disease continuing to progress and judged by their oncologists as unresponsive to current curative cancer treatment and at a terminal stage, (2) cognitively competent, (3) able to communicate with data collectors, and (4) age ≥ 20 years. Eligible patients were identified by primary physicians at study hospitals and referred to data collectors without judging patients' emotional readiness to discuss their prognostic understanding and EOL-care preferences. After verifying patients' eligibility, data collectors invited them to participate without asking permission from patients' families, thus avoiding potential information biases. The study was approved by the Institutional Review Boards of the 23 hospitals. All participants signed a written informed consent.

Outcome measures

Prognostic understanding was evaluated by asking participants if they knew their prognosis, and if so, whether their disease was (1) curable, (2) might recur in the future, but their life was not currently in danger, and (3) cannot be cured and they would probably die in the near future [18,26]. Participants were recognized as accurately understanding their prognosis only if they indicated that their disease could not be cured and they would probably die in the near future. Regardless of their response to the first question, all participants were asked to rate their preference for physicians to disclose prognosis to them on a 5-point Likert scale (1 = strongly not preferred; 5 = strongly preferred) [18].

Preferences for EOL care were evaluated using an adapted interview protocol (Appendix A) previously developed and widely published [6,9,12,27–29]. The questions elicited preferences for (1) the EOL-care goal: life-prolonging, comfort-oriented, or other (i.e., continuing current anticancer treatment or following physician suggestions); (2) CPR when life was in danger; (3) aggressive life-sustaining treatments, including ICU care, cardiac massage, intubation, and mechanical ventilation support; (4) hospice care; and (5) preferred place of death. Of note, each life-sustaining treatment could be provided independently in Taiwan for clinical or cultural considerations [30]. For each aggressive life-sustaining treatment, patients were asked whether they: (1) wanted the treatment, (2) did not want the treatment, or (3) were undecided. Responses for each treatment were dichotomized to 'want treatment' and 'do not want treatment', with those indicating 'undecided' counted as wanting that treatment because the clinical default in most instances is to provide treatment unless specifically refused [10]. Preferred place of death was assessed by asking, 'If you were dying, would you prefer to be at home, hospital, inpatient hospice, or other at the last moment of life?' Preferred place of death was further dichotomized to home and other.

Independent variables

Demographic characteristics included gender, age, education level, and marital status. Age was divided into <45 , 45–64, 65–74, ≥ 75 years. Education level was dichotomized to \leq junior high school and \geq senior high school. Marital status was categorized as married (including cohabiting), single, divorced or separated, and widowed.

Disease-related characteristics included diagnosis, post-diagnostic survival (months), metastatic status, and comorbidity status. Post-diagnostic survival was calculated as the time between diagnosis and data collection and categorized as 1–6, 7–12, 13–24, and ≥ 25 months.

Institutional characteristics included study hospitals' status as (1) a medical center, (2) located in northwest Taiwan, and (3) having an inpatient hospice unit during

the study. Medical center status indicates an abundance of healthcare resources and more rapid adoption of new clinical practices, that is, palliative/hospice care for terminally ill patients. The location in northwest Taiwan was used to indicate greater cultural and medical sophistication because this area includes the country's capital, cities are more modern, and medical knowledge and information are highly disseminated. Having an inpatient hospice unit represented the study hospitals' intensive hospice resources when data were collected because hospice home care was limited in Taiwan and palliative consultant teams were available for all study hospitals.

Data collection

Data were gathered from patients' medical records and in-person interviews when patients were waiting for clinical visits or in their room during hospitalization. Data collectors were bachelor-prepared experienced oncology nurses. Each data collector's initial interviews were supervised by the principal investigator or a senior project manager to ensure quality of data collection.

Analysis

Associations between accurate prognostic understanding and participants' EOL-care preferences and its correlates were examined by multivariate logistic regressions using generalized estimating equations [31] to account for correlations in the error term due to clustering of individuals in the same hospital. Correlations between independent variables and outcome variables were measured by adjusted odds ratio (AOR) with 95% confidence interval (CI).

Results

Sample characteristics

From 2764 eligible cancer patients, 2467 were recruited (89.26% participation rate). The primary reasons for patients declining to participate were being too weak ($n = 191$, 64.31%) or uninterested ($n = 73$, 24.58%). The characteristics of patients who did and did not participate could not be compared because of restricted access to information about those who refused to participate in the study.

Of the 2467 patients participating in the survey, 2452 (99.39%) answered the question, 'Are you aware of your prognosis?' and comprised the study sample. For their characteristics, see Table 1.

Associations between accurate prognostic understanding and end-of-life care preferences

Among the 2452 participants, 1819 (74.18%) reported knowing their prognosis. However, only 1221 (49.80%) accurately understood that their disease could not be

Table 1. Sample characteristics ($N = 2452$)

Characteristics	<i>n</i>	%	Characteristics	<i>n</i>	%
Gender			Cancer site		
Male	1395	57.03	Colon and rectum	394	16.24
Female	1051	42.97	Lung	385	15.87
Age (years)			Liver and pancreas	372	15.33
19–64	270	11.14	Head and neck	317	13.07
65–74	1310	54.07	Breast	272	11.21
75–84	516	21.30	Stomach	182	7.50
≥85	327	13.50	Esophagus	89	3.67
Educational level			Uterus and ovaries	67	2.80
≥Senior high school	1074	44.20	Blood and lymph	46	1.90
≤Junior high school	1356	55.80	Other	301	12.41
Marital status			Post-diagnosis survival (months)		
Married	1901	78.13	≤6	771	32.42
Single	196	8.06	7–12	410	17.24
Separated/divorced	139	5.71	13–24	427	17.96
Widowed	197	8.10	>25	770	32.38
With comorbidity			Metastasis		
Yes	1395	57.72	Yes	1927	79.99
No	1022	42.28	No	482	20.01

cured, and they probably would die in the near future. After adjustment for confounders, patients with accurate prognostic understanding had significantly greater odds of preferring comfort-oriented care (AOR [95% CI]: 1.86 [1.50, 2.30]), but were less likely to prefer life-prolonging treatments (0.66 [0.52, 0.85]) as their EOL-care goal (Table 2). Accurate prognostic understanding decreased participants' likelihood of preferring to receive aggressive life-sustaining treatments at EOL, including CPR when life was in danger (0.60 [0.47, 0.77]), ICU care (0.64 [0.53, 0.78]), cardiac massage (0.62 [0.47, 0.81]), intubation (0.63 [0.45, 0.88]), and mechanical ventilation support (0.69 [0.52, 0.93]). In contrast, accurate prognostic understanding increased the preference for hospice care (1.49 [1.27, 1.74]) at EOL. However, accurate prognostic understanding was not associated with participants' choice of home as their preferred place of death.

Correlates of accurate prognostic understanding

Results of multivariate logistic regression showed that the likelihood of accurate prognostic understanding was correlated with several patient characteristics: gender, age, education level, diagnosis, post-diagnosis survival, and preferences for prognostic disclosure (Table 3). Female patients were significantly less likely to know their prognosis accurately (AOR [95% CI] = 0.72 [0.63, 0.82]). The probability of accurate prognostic understanding decreased as age increased (52.22%, 54.20%, 45.54%, and 37.00% for patients aged ≤44, 45–64, 65–74, and ≥75 years, respectively). Patients with at least a senior high school education were 1.28 times (95% CI = 1.07, 1.54) more likely to accurately know their prognosis than less educated patients. Patients diagnosed with breast, colorectal, head and neck and esophageal cancer,

Table 2. Associations between accurate prognostic understanding and end of life care preferences

EOL-care preferences	Accurate prognostic understanding		Adjusted odds ratio	95% Confidence limits		p
	Yes (n = 1221) n (%)	No ^a (n = 1231) n (%)				
EOL-care goals						
Life prolonging	113 (9.25)	156 (12.67)	0.66	0.52	0.85	0.001
Comfort oriented	685 (56.10)	487 (39.56)	1.86	1.50	2.30	<0.001
Cardiopulmonary resuscitation	275 (22.52)	421 (34.20)	0.60	0.47	0.77	<0.001
ICU admission	374 (30.63)	516 (41.92)	0.64	0.53	0.78	<0.001
Cardiac massage	273 (22.36)	407 (33.06)	0.62	0.47	0.81	0.001
Intubation	240 (19.66)	369 (29.98)	0.63	0.45	0.88	0.007
Mechanical ventilation support	276 (22.60)	387 (31.43)	0.69	0.52	0.93	0.013
Hospice care	579 (47.42)	418 (33.96)	1.49	1.27	1.74	<0.001
Home as preferred place of death	458 (37.51)	551 (44.76)	0.87	0.73	1.05	0.147

All analyses were adjusted for patients' demographic, disease-related, and institutional characteristics.

EOL, end of life; ICU, intensive care unit.

^aReference group.

hematologic malignancies, and cancers other than those specifically coded in this study were significantly less likely than lung cancer patients to accurately understand their prognosis. The likelihood of accurate prognostic understanding was lower for patients diagnosed within 1 year of survey than those diagnosed ≥ 25 months beforehand. Patients were more likely to accurately know their prognosis if they preferred physicians to disclose their prognosis to them; with each unit increase in the preference for prognostic disclosure, the likelihood of accurate prognostic understanding increased 1.11 times (95% CI = 1.01, 1.21).

Among institutional characteristics, having an inpatient hospice unit did not increase the likelihood of participants' accurately understanding their prognosis (Table 3). Patients who received care at a medical center were significantly more likely than their counterparts to accurately know their prognosis (AOR [95% CI] = 1.67 [1.20, 2.33]). Moreover, patients who received care at a hospital in northwest Taiwan were 1.80 times (95% CI = 1.16, 2.79) more likely to accurately know their prognosis.

Discussion

Among our participants whose physicians recognized their disease as terminal, only 49.80% accurately understood their prognosis. These patients were significantly more likely to prefer comfort-oriented care as their EOL-care goal, but less likely to prefer life-prolonging treatments. Accurate prognostic understanding predisposed patients to prefer fewer life-sustaining treatments, including ICU care, CPR, cardiac massage, intubation, and mechanical ventilation support, but increased preference for hospice care and was correlated with both patient and institutional characteristics.

The prevalence of Taiwanese terminally ill cancer patients with accurate prognostic understanding was lower than those reported in the USA (68.3%) [5], Italy (58.5%)

[32] and Korea (51.0–75.0%) [3,7,16,33], comparable with those in Hong Kong (49.5%) [20], and Italy (43.5%) [19], but higher than those reported in the USA for advanced cancer patients (37.5–39%) [6,12].

In Taiwan, physicians and families believe that patients would be harmed by knowing their prognosis and therefore avoid telling patients the truth about a terminal prognosis [18]. Given the relative power of families and the cultural value of filial piety, a 'family consent for disclosure' approach [34] is commonly practiced. Despite the good intentions behind this practice to avoid emotional suffering derived from confronting one's mortality, it may deprive patients of honest information about their health status while they are coping with the dying process and making important EOL-care decisions. Indeed, prognostic understanding has improved terminally ill patients' quality of life [16,35,36], decreased anxiety, depression, and hopelessness [20,37], and enhanced spiritual well-being [38]. Furthermore, our results demonstrate that these patients' attitudes toward aggressive life-sustaining treatments were shaped by accurate prognostic knowledge because they realized that no treatments would cure their disease, decreasing the likelihood of their holding unrealistic expectations about the effectiveness of life-sustaining treatments. To avoid futile aggressive treatments for patients at EOL, families and healthcare professionals should acknowledge and honor terminally ill cancer patients' preference for prognostic information [16–18] and facilitate patients' accurate prognostic understanding.

We found that the likelihood of accurate prognostic understanding was correlated with patient and institutional characteristics. Consistent with the literature, Taiwanese cancer patients were significantly more likely to accurately understand their prognoses if they were younger [32,39], better educated [32,39,40], and strongly preferred prognostic information [16].

However, we found that accurate prognostic understanding was correlated with factors not totally consistent

Table 3. Correlates of accurate prognostic understanding among Taiwanese terminally ill cancer patients (N = 2452)

Accurate prognostic understanding					
Parameter	Crude rate <i>n</i> (%)	Adjusted odds ratio	95% Confidence limits		<i>p</i>
Patients' demographic characteristics					
Gender					
Female (<i>n</i> = 1051)	516 (49.10)	0.72	0.63	0.82	<0.001
Male (<i>n</i> = 1395)	704 (50.47)	Ref			
Age					
≤44 (<i>n</i> = 270)	141 (52.22)	1.96	1.29	2.99	0.002
45–64 (<i>n</i> = 1310)	710 (54.20)	2.10	1.56	2.83	<0.001
65–74 (<i>n</i> = 516)	235 (45.54)	1.42	1.04	1.95	0.029
≥75 (<i>n</i> = 327)	121 (37.00)	Ref			
Educational level					
≥Senior high school (<i>n</i> = 1074)	603 (56.15)	1.28	1.07	1.54	0.007
≤Junior high school (<i>n</i> = 1356)	607 (44.76)	Ref			
Marital status					
Married (<i>n</i> = 1901)	949 (49.92)	0.81	0.61	1.08	0.156
Single (<i>n</i> = 196)	100 (51.02)	0.80	0.50	1.28	0.350
Widowed (<i>n</i> = 197)	86 (43.65)	0.96	0.63	1.46	0.840
Divorced/separated (<i>n</i> = 139)	77 (55.40)	Ref			
Cancer site					
Lung (<i>n</i> = 385)	224 (58.18)	Ref			
Breast (<i>n</i> = 272)	141 (51.84)	0.61	0.40	0.93	0.020
Colon and rectum (<i>n</i> = 394)	178 (45.18)	0.54	0.40	0.73	<0.001
Liver and pancreas (<i>n</i> = 372)	211 (56.72)	0.93	0.75	1.16	0.525
Blood and lymph (<i>n</i> = 46)	17 (36.96)	0.51	0.27	0.96	0.036
Head and neck (<i>n</i> = 317)	129 (40.69)	0.41	0.32	0.52	<0.001
Stomach (<i>n</i> = 182)	99 (54.40)	0.81	0.60	1.08	0.151
Esophagus (<i>n</i> = 89)	36 (40.45)	0.45	0.26	0.78	0.005
Uterus and ovaries (<i>n</i> = 68)	40 (58.82)	1.09	0.62	1.95	0.758
Other (<i>n</i> = 301)	132 (43.85)	0.61	0.45	0.84	0.002
Post-diagnostic survival (months)					
≤6 (<i>n</i> = 773)	325 (42.04)	0.48	0.36	0.63	<0.001
7–12 (<i>n</i> = 410)	186 (45.37)	0.57	0.44	0.73	<0.001
13–24 (<i>n</i> = 423)	233 (55.08)	0.90	0.69	1.19	0.463
≥25 (<i>n</i> = 771)	444 (57.59)	Ref			
Metastasis					
Yes (<i>n</i> = 1927)	982 (50.96)	1.15	0.89	1.48	0.278
No (<i>n</i> = 482)	220 (45.64)	Ref			
With comorbidity					
Yes (<i>n</i> = 1395)	678 (48.60)	0.93	0.80	1.07	0.305
No (<i>n</i> = 1022)	525 (51.37)	Ref			
Preference for physician to disclose prognosis (range: 1–5)					
		1.11	1.01	1.21	0.032
Institutional characteristics					
Medical center					
Yes (<i>n</i> = 1823)	944 (51.78)	1.67	1.20	2.33	0.002
No (<i>n</i> = 629)	277 (44.04)	Ref			
Geographical area					
Northwest (<i>n</i> = 1682)	905 (53.80)	1.80	1.16	2.79	0.009
Other (<i>n</i> = 770)	316 (41.04)	Ref			
Inpatient hospice					
Yes (<i>n</i> = 2114)	1034 (48.91)	0.92	0.59	1.42	0.700
No (<i>n</i> = 338)	187 (55.33)	Ref			

Ref, reference group.

with the literature. Female Taiwanese cancer patients had a substantially lower probability of accurate prognostic understanding. In contrast, Italian [19] and Greek [39] women were more likely, and Korean [3] and British [41] women were equally as likely as men to know their

prognosis. Chinese culture commonly promotes a patriarchal ideology of male power and female subordination/inferiority [42]. Under the Confucian ethic of 'three subordinations', women should show obedience to fathers before marriage, to husbands after marriage, and

to sons after their husband's death. Because women are culturally invisible in patriarchal Chinese families, they tend to be left out of traditional family decision-making processes. Therefore, Taiwanese clinicians may choose to disclose prognostic information to male relatives rather than directly to terminally ill female cancer patients, decreasing their likelihood of accurate prognostic understanding.

Taiwanese terminally ill cancer patients' accurate prognostic understanding varied with diagnosis. However, we did not find the reported pattern [19,32,39] of patients with visible cancers (i.e., breast or head and neck cancer) more accurately perceiving their prognoses than those with more insidious cancers (e.g., gastrointestinal and esophageal cancers). We found that patients whose cancer diagnosis had a better prognosis (i.e., breast or colorectal cancers) than those with a highly fatal disease (i.e., lung or liver–pancreatic cancer) had a lower propensity to accurately understand their own prognosis. An extremely life-limiting disease, coupled with the acceptance of possible forthcoming death [43], may have predisposed physicians or families to disclose the prognosis directly to patients, increasing their likelihood of accurate prognostic understanding.

Furthermore, the likelihood of accurately understanding prognosis was approximately one-half lower for patients with hematological malignancies than for lung cancer patients—a relationship never previously explored. This result may be due to different therapeutic goals for these patients. Patients with hematological malignancies have the goal of curability or long-term survival. The potentially reversible nature of sporadic events such as infection may also lead to patients', families', and physicians' high expectations that 'everything' can be performed to promote survival for patients with hematological malignancies. These expectations may decrease the likelihood of letting 'nature take its course', recognizing disease progression, communicating about prognosis, and discussing EOL care. Indeed, patients with hematological malignancies were more likely to receive chemotherapy [44], CPR [45], and ICU care [46] at EOL, but less likely to be enrolled in hospice care [47].

By the same token, treatment goals for patients with a newly diagnosed disease (≤ 1 year) tend to be curative, which may hinder clinicians from discussing prognosis with these patients. In contrast, patients who have lived longer with cancer may have had more time to adjust psychologically to having a fatal illness. They may be more likely to prefer knowing their prognosis, and physicians may be more likely to disclose the prognosis, increasing the likelihood of these patients accurately understanding their prognosis.

Institutional characteristics have been suggested as powerful indicators of how health care is provided, including EOL care [11,23–25]. Thus, institutional factors

might also influence terminally ill patients' prognostic understanding. To address this possibility, we investigated the never-explored association of institutional characteristics with these patients' prognostic understanding. Taiwanese terminally ill cancer patients who received care at a medical center had 1.67 times higher probability of accurately understanding their prognosis than those who received care at a nonmedical center hospital. In Taiwan, the hospice movement was initiated by healthcare professionals at accredited medical centers, where it was rapidly integrated into cancer care. Thus, physicians affiliated with medical centers may be predisposed to adopt hospice philosophy when caring for terminally ill cancer patients, including appropriately informing patients of their prognosis to facilitate EOL-care planning, therefore increasing patients' likelihood of acknowledging themselves as terminally ill. Furthermore, participants who received care at a hospital in northwest Taiwan were significantly more likely to accurately understand their prognosis than those who received care in other areas of Taiwan. In northwest Taiwan, medical knowledge and information are highly disseminated. Patients receiving care in this area may be more empowered to assert their rights in healthcare decision-making. Therefore, terminally ill cancer patients receiving care in northwest Taiwan may be more likely to seek their prognosis to make EOL-care decisions that reflect their own values and preferences. However, our data did not support our hypothesis that accurate prognostic understanding is more likely for patients receiving care in a hospital with an inpatient hospice unit due to abundant hospice resources and diffusion of palliative care philosophy and practices.

This study was limited by using a convenience sample, which may not adequately represent the targeted population. Nevertheless, participants' gender, age, and disease categories had similar distributions as for cancer patients who died in Taiwan in 2011 [48], except patients with colorectal cancer were overrepresented. Our cross-sectional design might not have captured fluctuations in patients' prognostic understanding and EOL-care preferences as patient death approaches. Furthermore, our observational study precludes inferring a cause–effect relationship for our finding that accurate prognostic understanding was associated with fewer preferences for aggressive EOL treatments. Despite using rigorous statistical methods and including a broad range of potential influencing factors, we cannot exclude the possibility of unmeasured residuals, such as patients' symptom distress [41], anxiety, and depressive symptoms [40], as well as attitudes and previous experiences with death, family attitudes toward patient prognostic understanding, and physicians' attitudes toward practice of prognostic disclosure. Our participants' characteristics and data collection methods for prognostic understanding and EOL-care preferences may not correspond to those used in the studies we compared

with our findings. To facilitate cross-cultural comparisons, we suggest international studies using the same methodology (i.e., same definition of terminally ill, same interview guide to elicit prognostic understanding and EOL-care preferences). Finally, although we adopted measures for prognostic understanding and EOL-care preferences from widely published studies [6,9,12,26–29], their psychometrics needs formal validation.

In conclusion, our results indicate that terminally ill cancer patients' accurate prognostic understanding is associated with a greater preference for hospice care but fewer preferences for aggressive life-sustaining treatments, extending previously reported associations between accurate prognostic information and avoidance of futile aggressive EOL treatments [3–5,7]. Previous observations [3–5,7] that cancer patients who accurately understood their terminal status avoided futile aggressive EOL treatments may reflect patients' preferences, thereby affirming and preserving their autonomy and integrity. Terminally ill cancer patients' accurate prognostic understanding was correlated with both patient and institutional characteristics.

Clinicians should be aware that accurate prognostic understanding is commonly lacking among terminally ill cancer patients as shown in our and worldwide studies [2,3,6,12,16,18–20]. To identify these patients, clinicians should pay particular attention to those who are more likely to inaccurately understand their prognosis, that is,

those who are female, older, less educated, recently diagnosed with cancers having a relatively good prognosis and with hematologic malignancies, and receiving care at a nonmedical center or at hospitals in areas where knowledge and information are poorly disseminated. Effective interventions facilitating prognostic communication and improving accurate prognostic knowledge [5] must be developed and transferred to real-life healthcare practices. Equipped with and empowered by accurate prognostic understanding, terminally ill cancer patients may be better prepared to make truly informed EOL-care decisions that limit 'futile' aggressive EOL care in accord with their wishes and in their best interests.

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Conflict of interest

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References

- Weeks JC, Cook EF, O'Day SJ, et al. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA* 1998;**279**:1709–1714.
- Ray A, Block SD, Friedlander RJ, et al. Peaceful awareness in patients with advanced cancer. *J Palliat Med* 2006;**9**:1359–1368.
- Baek SK, Kim SY, Heo DS, et al. Effect of advanced cancer patients' awareness of disease status on treatment decisional conflicts and satisfaction during palliative chemotherapy: a Korean prospective cohort study. *Support Care Cancer* 2012;**20**:1309–1316.
- Hui D, Con A, Christie G, et al. Goals of care and end-of-life decision making for hospitalized patients at a Canadian tertiary care cancer center. *J Pain Symptom Manage* 2009;**38**:871–881.
- Temel JS, Greer JA, Admane S, et al. Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non small-cell lung cancer: results of a randomized study of early palliative care. *J Clin Oncol* 2011;**29**:2319–2326.
- Wright AA, Mack JW, Kritek PA, et al. Influence of patients' preferences and treatment site on cancer patients' end-of-life care. *Cancer* 2010;**116**:4656–4663.
- Yun YH, Lee MK, Kim SY, et al. Impact of awareness of terminal illness and use of palliative care or intensive care unit on the survival of terminally ill patients with cancer. *J Clin Oncol* 2011;**29**:2474–2480.
- Cherlin E, Fried T, Prigerson HG, et al. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? *J Palliat Med* 2005;**8**:1176–1185.
- Wright AA, Keating NL, Balboni TA, et al. Place of death: correlations with quality of life of patients with cancer and predictors of bereaved caregivers' mental health. *J Clin Oncol* 2011;**28**:4457–4464.
- Rose JH, O'Toole EE, Dawson NV, et al. Perspectives, preferences, care practices, and outcomes among older and middle-aged patients with late-stage cancer. *J Clin Oncol* 2004;**22**:4907–4917.
- Kelley AS, Morrison RS, Wenger NS, et al. Determinants of treatment intensity for patients with serious illness: a new conceptual framework. *J Palliat Med* 2010;**13**:807–813.
- Mack JW, Weeks JC, Wright AA, et al. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* 2010;**28**:1203–1208.
- Institute of Medicine, Field MJ, Cassell C (eds). *Approach Death: Improving Care at the End of Life*. National Academy Press: Washington, DC, 1997; 4.
- Trice ED, Prigerson HG. Communication in end-stage cancer: review of the literature and future research. *J Health Commun* 2009;**14**:95–108.
- Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 2009;**23**:29–39.
- Yun YH, Kwon YC, Lee MK, et al. Experiences and attitudes of patients with terminal cancer and their family caregivers toward the disclosure of terminal illness. *J Clin Oncol* 2010;**28**:1950–1957.
- Fujimori M, Akechi T, Morita T, et al. Preferences of cancer patients regarding the disclosure of bad news. *Psycho-Oncology* 2007;**16**:573–581.
- Tang ST, Liu TW, Lai MS, et al. Congruence of knowledge, experiences and preferences for disclosure of diagnosis and prognosis between terminally ill cancer patients and their family caregivers in Taiwan. *Cancer Invest* 2006;**24**:360–366.
- Bracci R, Zanon E, Cellerino R, et al. Information to cancer patients: a questionnaire survey in three different geographical areas in Italy. *Support Care Cancer* 2008;**16**:869–877.

20. Chan WC. Being aware of the prognosis: How does it relate to palliative care patients' anxiety and communication difficulty with family members in the Hong Kong? *J Palliat Med* 2011;**14**:997–1003.
21. Fine E, Reid MC, Shengelia R, *et al*. Directly observed patient-physician discussions in palliative and end-of-life care: a systematic review of the literature. *J Palliat Med* 2010;**13**:595–603.
22. Cherny NI. Factors influencing the attitudes and behaviors of oncologists regarding the truthful disclosure of information to patients with advanced cancer. *Psycho-Oncology* 2011;**20**:1269–1284.
23. Barnato AE, Herndon MB, Anthony DL, *et al*. Are regional variations in end-of-life care intensity explained by patient preferences? *Med Care* 2007;**45**:386–393.
24. Barnato AE, Bost JE, Farrell MH, *et al*. Relationship between staff perceptions of hospital norms and hospital-level end-of-life treatment intensity. *J Palliat Med* 2007;**10**:1093–1100.
25. Thorne SE, Bultz BD, Baile WF. Is there a cost to poor communication in cancer care?: a critical review of the literature. *Psycho-Oncology* 2005;**14**:875–884.
26. Kaplowitz SA, Campo S, Chiu WT. Cancer patients' desires for communication of prognosis information. *Health Commun* 2002;**14**:221–241.
27. Carmel S, Mutran EJ. Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments. *Soc Sci Med* 1999;**49**:303–311.
28. Zhang B, Wright AA, Huskamp HA, *et al*. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009;**169**:480–488.
29. Stapleton RD, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Association of depression and life-sustaining treatment preferences in patients with COPD. *Chest* 2005;**127**:328–334.
30. Huang YC, Huang SJ, Ko WJ. Going home to die from surgical intensive care units. *Intensive Care Med* 2009;**35**:810–815.
31. Twisk JWR. Longitudinal data analysis. A comparison between generalized estimating equations and random coefficient analysis. *Eur J Epidemiol* 2004;**19**:769–776.
32. Corli O, Apolone G, Pizzuto M, *et al*. Illness awareness in terminal cancer patients: an Italian study. *Palliat Med* 2009;**23**:354–359.
33. Yun YH, You CH, Lee JS, *et al*. Understanding disparities in aggressive care preferences between patients with terminal illness and their family members. *J Pain Symptom Manage* 2006;**31**:513–521.
34. Akabayshi A, Feters MD, Elwyn T. Family consent, communication, and advance directives for cancer disclosure: A Japanese case and discussion. *J Med Ethics* 1999;**25**:296–301.
35. Tchen N, Bedard P, Yi QL, *et al*. Quality of life and understanding of disease status among cancer patients of different ethnic origin. *Br J Cancer* 2003;**89**:641–647.
36. Tang ST, Liu TW, Tsai CM, *et al*. Patient awareness of prognosis, patient-family caregiver congruence on the preferred place of death, and caregiving burden of families contribute to the quality of life for terminally ill cancer patients in Taiwan. *Psycho-Oncology* 2008;**17**:1202–1209.
37. Thompson GN, Chochinov HM, Wilson KG, *et al*. Prognostic acceptance and the well-being of patients receiving palliative care for cancer. *J Clin Oncol* 2007;**25**:5757–5762.
38. Leung KK, Chiu TY, Chen CY. The influence of awareness of terminal condition on spiritual well-being in terminal cancer patients. *J Pain Symptom Manage* 2006;**31**:449–456.
39. Papadopoulos A, Vrettos I, Kamposioras K, *et al*. Impact of cancer patients' disease awareness on their family members' health-related quality of life: a cross-sectional survey. *Psycho-Oncology* 2011;**20**:294–301.
40. Hagerty RG, Butow PN, Ellis PM, *et al*. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol* 2005;**16**:1005–1053.
41. Hinton J. The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliat Med* 1999;**13**:19–35.
42. Gates H. The commoditization of Chinese women. *Signs* 1989;**14**:799–832.
43. Wagner GJ, Riopelle D, Steckart J, *et al*. Provider communication and patient understanding of life-limiting illness and their relationship to patient communication of treatment preferences. *Pain Symptom Manage* 2010;**39**:527–534.
44. Earle CC, Landrum MB, Souza JM, *et al*. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol* 2008;**26**:3860–3866.
45. Wallace SK, Ewer MS, Price KJ, *et al*. Outcome and cost implications of cardiopulmonary resuscitation in the medical intensive care unit of a comprehensive cancer center. *Eur J Cancer Care* 2002;**10**:425–429.
46. Barbera L, Paszat L, Chartier C. Indicators of poor quality end-of-life cancer care in Ontario. *J Palliat Care* 2006;**22**:12–17.
47. Manitta VJ, Philip JA, Cole-Sinclair MF. Palliative care and the hemato-oncological patient: can we live together? A review of the literature. *J Palliat Med* 2010;**13**:1021–1025.
48. Department of Health. Statistics of causes of death, volume I. 2011. <http://www.doh.gov.tw/ufile/doc/2011%20statistics%20of%20causes%20of%20death.pdf>. Accessed on June 15, 2013.

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