Brief Report

The Effects of Adding Reassurance Statements: Cancer Patients' Preferences for Phrases in End-of-Life Discussions

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Abstract

Context. When discussing end-of-life issues with cancer patients, the addition of reassurance statements is considered helpful. However, patients' preferences for such statements have not been systematically demonstrated.

Objectives. The objectives of this study were to clarify if phrases with additional reassurance statements would be more preferable to phrases without them and explore variables associated with patients' preferences.

Methods. In a cross-sectional survey, 412 cancer patients assessed their own preferences for phrases with/without additional statements using a six-point scale (1 = not at all preferable; 6 = very preferable). These included the statements of "hope for the best and prepare for the worst" ("hope/prepare") when discussing prognosis; symptom palliation when discussing code status; and specific goals, continuity of care, and nonabandonment when discussing hospice referral. We evaluated demographic data and the coping style and conducted multivariate regression analysis.

Results. Compared with the phrase of life expectancy (i.e., median + typical range) alone [mean (SD), 3.5 (1.2); 95% CI, 3.4−3.6], the phrase with the additional "hope/prepare" statement was more preferable [3.8 (1.4); 3.7−3.9]. Compared with the phrase of do-not-resuscitate alone (3.1(1.3); 3.0−3.3), the phrase with the additional statement of symptom palliation was more preferable [3.9 (1.3); 3.7−4.0]. Compared with the phrase of hospice referral alone [3.4 (1.2); 3.3−3.5], phrases with the addition of a specific goal [3.9 (1.0); 3.8−4.0], specific goal and continuity (4.4(1.0); 4.3−4.5), and specific goal, continuity, and nonabandonment [4.8 (1.2); 4.7−4.9] were more preferable. In multivariate analyses, task-oriented coping was significantly correlated with preferences for phrases including additional reassurance statements.

Conclusion. Cancer patients systematically preferred reassurance statements. In end-of-life discussions, especially with patients with task-oriented coping, clinicians may provide additional reassurance statements. J Pain Symptom Manage 2019;57:1121−1129.

Key Words

Communication, prognostic disclosure, hospice referral, do-not-resuscitate

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Accepted for publication: February 20, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.02.019

Introduction

End-of-life (EOL) discussions with advanced cancer patients are important, as they enable patients and their families to start advance care planning and make realistic decisions about the future based on individualized goals of care.[1] Several guidelines recommend effective EOL discussions with advanced cancer patients.[2–4] However, discussing EOL issues such as prognosis, code status, and hospice referral remains challenging for clinicians, and it tends to occur late in the disease trajectory.[5,6] Among clinician-related barriers to EOL discussions are the lack of training, discomfort talking about death, and fear of causing patient distress.[6–8] Better understanding of patients' preferred phrases in EOL conversations may help clinicians overcome such barriers and comfortably engage in EOL discussions.

Among the various phrases used in communication about EOL issues, the addition of reassurance statements has been proposed. EOL discussions combined with reassurance statements could potentially help advanced cancer patients maintain realistic hope while facing difficult decision making. Various reassurance statements have been suggested in different settings, which include the statement of "hope for the best and prepare for the worst" ("hope/prepare" statement),[9] optimal symptom palliation,[10] setting goals,[11,12] and ensuring the continuity of care[10] and nonabandonment.[10,13] To date, however, cancer patients' preferences for the addition of such reassurance statements on EOL discussions have not been systematically demonstrated.

This study is a planned secondary analysis of a cross-sectional survey among cancer patients who were registered in a large Web survey company in Japan. The primary aim of the present study was to clarify if phrases that add reassurance statements are preferred by cancer patients to those without such statements when discussing EOL issues including prognosis, code status, and hospice referral. Specifically, we hypothesized the following:

1. When discussing prognosis, a phrase including the "hope/prepare" statement would be preferable to that without such a statement.
2. When discussing code status, a phrase addressing symptom palliation would be preferable to that without such a statement.
3. When discussing hospice referral, phrases adding additional reassurance statements (i.e., setting specific goals, and ensuring the continuity of care and nonabandonment) would be preferable to those with fewer reassurance statements or to a phrase with a negative statement.

The secondary aim was to explore factors contributing to patients' preferences for phrases.

Methods

Participants and Procedures

The methods were reported in detail previously.[14] Briefly, eligible patients were those with cancer followed in an outpatient clinic for their cancer care and aged 20 years or older. The survey company (Macromill, Ltd.) recruited potential participants across Japan by convenient sampling and sent questionnaires to them online in February 2018. Potential participants first read introductory statements that summarized the contents of the questionnaire and explained they could feel free to withdraw at any time if they wished so. Responses were considered consent to participate. Responses to the questionnaire were voluntary, and confidentiality was maintained throughout all investigations and analyses. The main paper specifically focused on cancer patients' preferences for 13 different phrases conveying prognostic information only (e.g., various phrases with or without explicit and nonexplicit disclosure, those conveying uncertainty, and those with "hope/prepare" statement). The current study expands to other important topics of EOL discussions (i.e., code status and hospice referral) and specifically explores cancer patients' preferences for phrases with reassurance statements. The ethical validity of the study was approved by the institutional review board of Seirei Mikatahara General Hospital.

Measurement

Patients' Preferences for Phrases of EOL Discussions. We first explained participants about situations where a doctor asks questions about prognostic disclosure, code status, and hospice referral as follows:

Phrases on disclosure or prognosis: "Imagine that you want to know your life expectancy, and you asked your doctor. If your doctor predicts that your life expectancy is approximately 2 years and he/she starts the conversation by saying 'That is a difficult question', to what level would you prefer the following statements as a follow-up?"

Phrases on code status: "If patients' cancer-related symptoms have worsened, they have become bedridden, and they develop cardiac or respiratory arrest, it has been shown that they rarely recover to a point that they are able to walk after undergoing cardiopulmonary resuscitation. In a situation where your cancer-related symptoms have worsened and you have become bedridden, how much explanation would you like to be given from a doctor about resuscitation if you should go into cardiac or respiratory arrest? Imagine that your doctor is explaining the measures that will be taken if you should go into cardiac or respiratory arrest. Assume that the doctor believes that 'Resuscitation, such as

cardiac massage, is not beneficial for you, so it should not be performed. However, it can be performed if you really wish for them to do so. If by any chance you are about to go into cardiac or respiratory arrest, resuscitation is unlikely to help recover your cardiac function and respiration, but will likely increase distress.' If your doctor starts the conversation by saying 'if you should go into cardiac or respiratory arrest', to what level would you consider the following statements preferable as a follow-up?"

Phrases on hospice referral: "If cancer symptoms worsen and anticancer therapy has to be terminated, doctors may recommend that patients transfer from a hospital that focuses on treatment to a place where they can receive care centered on reducing symptoms (inpatient hospice or home hospice care). How much explanation would you like to be given from a doctor when he/she discusses the possible transfer to an inpatient hospice or home hospice care for the first time? Imagine that you are hospitalized and had your cancer treatment terminated. The doctor is explaining to you about the possible transfer to an inpatient hospice or home hospice care service. Assume that the doctor believes that 'it is better to refer you to an inpatient hospice or home hospice care because additional hospitalization is unlikely to help'. Your doctor starts the conversation by saying 'In your current state, I think that it would be better for you to receive care centered on reducing symptoms rather than focusing on treatment at the hospital'. To what level would you consider the following statements preferable as a follow-up?"

Participants rated their preferences for various phrases of EOL discussions. In this study, we report two phrases on disclosure of a prognosis of 2 years, two phrases on code status including do-not-resuscitate, and five phrases on hospice referral with or without additional reassurance statements (Table 1). We had decided to test various reassurance statements on hospice referral, as discussions on hospice referral, if poorly done, could particularly cause a sense of abandonment.[13] In preparation for the questionnaire development, these phrases were generated with specific attention to their underlying concepts based on in-depth focus group interviews with 10 oncologists/palliative care physicians, a systematic literature review,[9–13,15–18] and discussions among the researchers. The instrument was piloted on four cancer patients, who provided feedback on the content, clarity, and format of the items. They also confirmed that the survey questions were self-explanatory and would not cause anxiety. Minor revisions were made in response to their feedback. Participants were asked to choose the responses that best reflected how they would like to be informed of their prognosis (scored on a six-point Likert scale from 1 ["not at all preferable"] to 6 ["very preferable"]).

Variables

Demographic data such as the age, sex, employment status, annual household income, marital status, family situation (e.g., living with family, children younger than 20 years of age, and/or parents requiring care), education level, and religion were assessed. Medical data such as the cancer site, duration since cancer diagnosis, presence of recurrence/metastasis, and performance status were also obtained. We also assessed participants' coping styles with the Coping Inventory for Stressful Situations (CISS).[19,20] The CISS is a validated 48-item instrument that distinguishes three basic coping strategies with 16 items per scale: task-oriented, emotion-oriented, and avoidance. The score for each item ranges from 1 = "not at all" to 5 = "very much," and scores for all items per scale are summed to obtain scale scores (16–80), with a higher score signifying a greater use of that particular coping strategy (i.e., task-oriented, emotion-oriented, and avoidance). These variables either have been shown to contribute to patients' preferences for EOL discussions previously[10,16,21–31] or are deemed clinically important.

Statistical Analyses

We used descriptive statistics and calculated means, SDs, and 95% CIs of preference scores. Then, we conducted multivariate linear regression analyses to identify variables contributing to patients' preferences for each phrase of prognostic information. Demographic and medical data and CISS scores were entered as independent variables. A backward, stepwise selection method was used to remove nonsignificant variables from the models, with $P < 0.05$ considered significant.

Assuming that 50%–75% of participants would prefer each phrase, 288–384 subjects would be sufficient to calculate the accuracy to within a 10% width with 95% CIs. Thus, assuming missing data, 400 subjects would be sufficient. In all statistical evaluations, $P < 0.05$ was considered significant. All analyses were performed using the Statistical Package for the Social Sciences, version 24.0 (IBM Japan Institute, Tokyo, Japan).

Results

In total, 412 cancer patients participated from all eight regions of Japan. Their baseline characteristics are summarized in Table 2.

Preferences for Phrases Conveying EOL Information

Figure 1 shows the mean scores, SDs, and 95% CIs of preferences for phrases with or without additional

Table 1
Underlying Concept and Actual Phrases Conveying Prognostic Information

Concept	Phrases
Prognosis	
Life expectancy (i.e., median + typical range)	"Considering an average patient in the same situation as you, I think it is approximately 2 years, but it may vary from 1 to 4 years for the average patient. However, this is just an estimate based on the average, so it does not tell us what will happen to you exactly." (Gives predicted life expectancy.)
Life expectancy + **'hope/prepare'**	"Considering an average patient in the same situation as you, I think it is approximately 2 years, but it may vary from 1 to 4 years for the average patient. However, this is just an estimate based on the average, so it does not tell us what will happen to you exactly. **We will do our best to make sure that you have a better-than-average outcome. On the other hand, if you do progress faster than average, I think it is a good idea to prepare yourself for the unexpected.**" (Gives predicted life expectancy with the addition of 'hope for the best and prepare for the worst' statement.)
Code status	
Do-not-resuscitate (DNR)	"I would suggest it is best not to perform resuscitation such as cardiac massage. Is that ok with you?" (Suggests what he/she believes is the best option.)
DNR + **symptom palliation**	"I would suggest it is best not to perform resuscitation, such as cardiac massage, **but to make sure you are free from symptoms.** Is that ok with you?" (Suggests what he/she believes is the best option, and adds the explanation that he/she intends to palliate symptoms.)
Hospice referral	
Hospice + nothing can be done	"I would like to refer you to an inpatient hospice or home hospice care. This hospital focuses on treatment, and I do not think there is anything that can be done here for you." (Tells you where you will be referred to, and that nothing can be done at the hospital. Does not mention the specific goal or seamless transition of care.)
Hospice	"I would like to refer you to an inpatient hospice or home hospice care." (Tells you where you will be referred to, but does not mention the specific goal or seamless transition of care.)
Hospice + **specific goal** (referring to what hospice does)	"I would like to refer you to an inpatient hospice or home hospice care. **They will take appropriate measures to manage any symptoms and changes in your physical conditions.**" (Tells you where you will be referred to, as well as the specific goal of the transfer. Does not mention the seamless transition of care.)
Hospice + **specific goal + continuity**	"I would like to refer you to an inpatient hospice or home hospice care. **They will take appropriate measures to manage any symptoms and changes in your physical conditions. I will make sure that the doctor I refer you to is up-to-date on your treatment as well as your current state.**" (Tells you where you will be referred to, and about the specific goal of the transfer and the seamless transition of care.)
Hospice + **specific goal + continuity + nonabandonment**	"I would like to refer you to an inpatient hospice or home hospice care. **They will take appropriate measures to manage any symptoms and changes in your physical conditions." I will make sure that the doctor I refer you to is up-to-date on your treatment as well as your current state. Please feel free to contact me any time should you have any questions or problems.**" (Tells you where you will be referred to, and about the specific goal of the transfer and the seamless transition of care. Adds that the relationship with your doctor will continue.)

The concepts and phrases of reassurance statements are bolded (these reassurance statements were not highlighted in the actual questionnaire).

phrases. There were no missing data. Overall, the participants preferred phrases more when more reassurance statements were added.

Compared with the phrase of life expectancy alone [mean (SD), 3.5 (1.2); 95% CI, 3.4−3.6], the phrase with the additional "hope/prepare" statement was more preferable [3.8 (1.4); 3.7−3.9]. Similarly, compared with the phrase of do-not-resuscitate alone [3.1 (1.3); 3.0−3.3], the phrase with the additional statement of symptom palliation was more preferable [3.9 (1.3); 3.7−4.0]. Finally, compared with the phrase of hospice referral alone [3.4 (1.2); 3.3−3.5], phrases with the addition of more reassurance statements were more preferable: the phrase of hospice referral with the addition of a specific goal [3.9 (1.0); 3.8−4.0]; the phrase of hospice referral with the addition of a specific goal and continuity [4.4 (1.0); 4.3−4.5]; the phrase of hospice referral with the addition of a specific goal, continuity, and nonabandonment [4.8 (1.2); 4.7−4.9]. By contrast, the phrase with the addition of "nothing can be done" was the least preferable [2.8 (1.2); 2.7−2.9].

Table 2
Baseline Characteristics of Participants ($N = 412$)

Characteristics	*n* (%)
Age, mean (SD)	61 (13)
Sex	
Male	256 (62)
Female	156 (38)
Marital status	
Yes	315 (77)
No	97 (24)
Living with family	
Yes	349 (85)
No	63 (15)
Religion	
Yes	198 (48)
None	214 (52)
Employment	
Employed	222 (58)
Unemployed	161 (42)
Highest education	
Vocational school/university/graduate school	252 (61)
Junior high school/high school	161 (39)
Having a child	
Yes	77 (19)
No	336 (81)
Having a parent requiring care	
Yes	47 (11)
No	366 (89)
Family history of cancer death	
Yes	209 (51)
No	204 (49)
ECOG PS	
0	268 (65)
≥1	144 (35)
Cancer site	
Kidney, bladder, prostate, and testis	116 (23)
Breast	96 (19)
Gastrointestinal tract	72 (14)
Blood and lymph node	52 (10)
Lung	42 (8.2)
Head and neck	41 (8.0)
Liver, biliary tract, and pancreas	36 (7.0)
Uterus, ovary	31 (6.0)
Other	29 (5.6)
Annual household income	
<4,000,000 yen	142 (40)
≥4,000,000 yen	210 (60)
Duration since cancer diagnosis	
≤2 years	100 (24)
2 to 5 years	149 (36)
≥5 years	163 (40)
Chemotherapy experience	
Yes (current)	74 (18)
Yes (completed)	113 (27)
Never	224 (54)
Recurrence or metastasis	
Yes	99 (24)
No	309 (75)
CISS, mean score (SD)	
CISS task-oriented (range: 16–80)	51 (9.3)
CISS emotion-oriented (range: 16–80)	42 (11)
CISS avoidance (range: 16–80)	46 (8.9)

ECOG PS = Eastern Cooperative Oncology Group Performance Status; CISS = Coping Inventory for Stressful Situations.

Variables Associated With Patient Preferences

Table 3 lists the variables associated with patients' preferences for all the phrases. R^2 of each model was low, indicating that the contribution of the variables explaining patients' preferences is small, although a significant tendency was noted. Overall, women and patients with task-oriented coping were significantly more likely to prefer phrases with additional reassurance statements, and those with emotion-oriented and avoidance coping were significantly less likely to prefer phrases with such statements.

Discussion

To the best of our knowledge, this is the first study to empirically demonstrate that the addition of more reassurance statements is associated with greater patients' preferences when communicating EOL issues. As EOL discussions between clinicians and cancer patients still occur infrequently in Japan as compared with the Western countries such as the U.S., this study may provide clinicians with some useful strategies consistent with patients' preferences.[6,32] The first and most important finding was that greater preferences were noted for phrases of hospice referral with the addition of reassurance statements. This preference is not explained by the length of phrases themselves, as the addition of a negative statement (i.e., "nothing can be done") was the least preferable, consistent with prior survey findings.[11,12] Previous studies showed patients' preferences for each component of additional statements, such as setting specific goals including optimal symptom palliation,[10–12] the continuity of care,[10,18] and nonabandonment,[10,13] but none has shown their incremental benefit. A similar tendency was also noted on discussion of prognosis with an additional "hope/prepare" statement, and that of the code status with the additional statement of symptom palliation, which is consistent with the prior literature.[9,10] The potential interpretation is that reassurance statements may convey not only information but also compassion, reassurance, and a personalized message consistent with patients' wishes, which may help them maintain hope in the context of patient-centered care.[1] Another interpretation regarding the "hope/prepare" statement is that it also contains a promise that the patient will obtain a "better than average outcome." The participants might have preferred the phrase including this statement because of this promise, not because of a suggestion to prepare for the worst. These need to be confirmed in future studies. Overall, clinicians may be advised to add reassurance statements when discussing EOL issues such as prognosis, code status, and hospice referral with cancer patients.

The second important finding was that certain variables, particularly patients' preexisting coping styles, were associated with patient preferences. Notably, patients with task-oriented coping and those with emotion-oriented/avoidance coping tended to

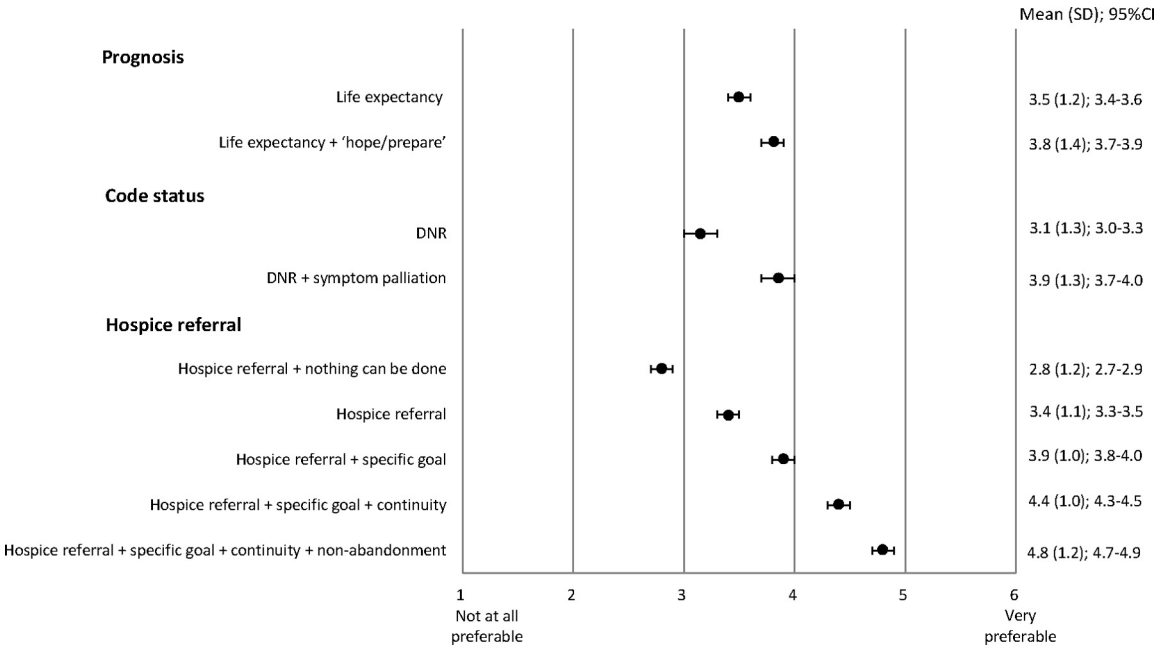

Fig. 1. The effects of adding reassurance statements when discussing prognosis, code status, and hospice referral. DNR = do-not-resuscitate; "hope/prepare" = "hope for the best and prepare for the worst."

have opposite preferences: the former preferred phrases with additional reassurance statements while the latter did not. Our main study exploring patients' preferences for various phrases of prognostic disclosure also indicated that patients with task-oriented coping were more likely to prefer explicit prognostic disclosure, while those with emotion-oriented/avoidance coping were more likely to prefer vague or no disclosure.[14] One potential interpretation may be that the additional statements, even if they sounded reassuring, and in hypothetical scenarios, might make patients face serious situations associated with their EOL, leading to a weaker preference among those with latter coping styles. These findings suggest that clinicians may need to ask patients and/or families about their typical ways of coping during prior stressful life events and take these coping styles into consideration when discussing EOL issues.[27] At the same time, the identification of a single coping style of advanced cancer patients may not always be easy. Thus, it is essential to ask permission for EOL discussions; assess their understanding, current coping, and information preferences; and carefully consider information that should be given to them and respond to emotion.[7] Future research is warranted to identify the most practical and effective strategies to explore patients' underlying coping styles and clarify if EOL communication tailored to these coping styles results in more favorable short- and long-term patient-reported outcomes.

The strengths of our study were a relatively large sample size of patients with various cancer types from all eight regions of Japan, the use of a validated tool to assess coping styles, no missing data regarding outcomes, and systematic comparison of previously proposed phrases with concrete concepts. However, our study has limitations. First, as we applied convenient sampling via the Internet using a private Web-based company and analyzed the first 412 responders, we could not extract a response rate. This sampling method might have introduced a selection bias and contributed to the high proportion of men and patients with higher education, greater household income, and specific cancer types. Second, the participants who were registered in the Web-survey company may not represent actual patients, and their preferences were based on a hypothetical situation and lengthy questions. EOL communication may require several encounters and should take individual and cultural differences in the real world into account. Third, although the phrases were generated based on in-depth focus group interview, a systematic literature review, and extensive discussions among the authors, they have not been validated.

In conclusion, we demonstrated that cancer patients, especially those with task-oriented coping, prefer clinicians adding reassurance statements when discussing EOL issues. Clinicians may be advised to add reassurance statements when discussing prognosis, code status, and hospice referral with cancer patients. Future studies are warranted if EOL

Table 3

Variables Associated With Patients' Preferences for Phrases Conveying Prognostic Information

Variables	Life Expectancy ($R^2 = 0.03$)		Life Expectancy + Hope/Prepare[a] ($R^2 = 0.08$)		DNR (R^2=0.05)		DNR + Symptom Palliation[a] (R^2=0.07)		Hospice + Nothing Can Be Done (R^2=0.10)		Hospice (R^2=0.00)		Hospice + Specific Goal[a] (R^2=0.05)		Hospice + Specific Goal[a] + Continuity[a] (R^2=0.01)		Hospice + Specific Goal[a] + Continuity[a] + Nonabandonment[a] (R^2=0.02)	
	β	t	β	t	β	t	β	t	β	t	β	t	β	t	β	t	β	T
Age	—	—	**0.18**	**2.85**	**0.17**	**3.42**	**0.31**	**4.88**	**0.20**	**3.25**	—	—	—	—	—	—	—	—
Sex (Ref: male)	**0.13**	**2.50**	**0.19**	**3.08**	—	—	0.11	1.82	**−0.13**	**−2.04**			0.09	1.66	**0.17**	**3.30**	**0.19**	**3.02**
Employment (Ref: unemployed)	**0.11**	**2.08**	—	—	—	—	—	—	—	—			—	—	0.10	1.95	0.09	1.86
Marital status (Ref: no)	**0.13**	**2.21**	—	—	—	—	−0.09	−1.81	—	—	—	—	—	—	—	—	—	—
Household income (Ref: <4,000,000 yen)	**−0.12**	**−1.99**	—	—	—	—	—	—			—	—	—	—	—	—	—	—
Education (Ref: ≤high school)	—	—	—	—	—	—	—	—	**−0.11**	**−2.14**	—	—	**−0.13**	**−2.49**	—	—	—	—
ECOG PS (Ref: 0)	—	—	—	—	**0.12**	**2.42**	0.09	1.84	—	—	—	—	—	—	—	—	—	—
CISS task-oriented	0.09	1.81	**0.22**	**4.35**	**−0.10**	**−1.99**	—	—	**−0.14**	**−2.49**	—	—	**0.13**	**2.44**	**0.33**	**5.91**	**0.42**	**7.74**
CISS emotion-oriented	—	—	—	—	—	—	—	—	—	—	—	—	**−0.16**	**−3.01**	**−0.17**	**−3.24**	**−0.18**	**−3.54**
CISS avoidance	—	—	—	—	—	—	—	—	—	—	**0.15**	**2.52**	—	—	**−0.16**	**−2.79**	**−0.19**	**−3.41**

DNR = do-not-resuscitate; ECOG PS = Eastern Cooperative Oncology Group Performance Status; CISS = Coping Inventory for Stressful Situations.

Backward elimination method was used for all multiple regression analyses, and only variables that remained in each model are listed in the table. References are provided for categorical variables. The others are continuous variables.

Significant values based on $P < 0.05$ are bolded.

[a]Concepts of reassurance statements.

communication with additional reassurance statements has long-term effects on the decision making of advanced cancer patients.

Disclosures and Acknowledgments

The authors would like to thank Dr. Kengo Imai, Dr. Isseki Maeda, Dr. Takashi Yamaguchi, and Dr. Naosuke Yokomichi for their participation in their focus group discussions. The authors would also like to thank staff members of Cancer Solutions, Inc. (Ms. Naomi Sakurai, Ms. Chizuko Komagata, Ms. Wakana Shirahama, and Ms. Midori Takahashi) for their valuable input during pilot testing. This study was supported by a Health, Labour, and Welfare Sciences Research Grant: Research for Promotion of Cancer Control Programmes (H29-Cancer Control-general-017).

The authors declare no conflicts of interest with respect to the research, authorship, and publication of this article.

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