

## Original Article

# Talking About Death With Terminally-Ill Cancer Patients: What Contributes to the Regret of Bereaved Family Members?



Masanori Mori, MD, Saran Yoshida, PhD, Mariko Shiozaki, PhD, Mika Baba, MD, PhD, Tatsuya Morita, MD, Maho Aoyama, RN, PhD, Yoshiyuki Kizawa, MD, PhD, Satoru Tsuneto, MD, PhD, Yasuo Shima, MD, and Mitsunori Miyashita, RN, PhD

*Palliative Care Team (M.M.), Seirei Mikatahara General Hospital, Hamamatsu; Graduate School of Education (S.Y.), Tohoku University, Sendai; Department of Applied Sociology (M.S.), Kindai University, Osaka; Department of Palliative Medicine (M.B.), Suita Tokushukai Hospital, Suita; Division of Palliative and Supportive Care (T.M.), Seirei Mikatahara General Hospital, Hamamatsu; Department of Community Health (M.A., M.M.), Tohoku University Graduate School of Medicine, Sendai; Department of Palliative Medicine (Y.K.), Kobe University Graduate School of Medicine, Kobe; Department of Human Health Sciences (S.T.), Graduate School of Medicine, Kyoto University, Kyoto; Department of Palliative Medicine (Y.S.), Tsukuba Medical Center Hospital, Tsukuba, Ibaraki, Japan*

## Abstract

**Context.** Talking about death is an important issue for terminally-ill cancer patients and their families. Little is known about how often and which bereaved families regret not having talked about death with their deceased loved one.

**Objectives.** To explore the prevalence of a regret of not having talked about death with a deceased loved one among bereaved family members of adult cancer patients, and to systematically explore factors contributing to their regret.

**Methods.** We conducted a nationwide survey of 999 bereaved families of cancer patients admitted to 133 inpatient hospices in Japan and surveyed families' regret on talking about death. Exploratory analyses identified the underlying structures of process, option, and outcome subscales of factors contributing to regret.

**Results.** Among 678 bereaved families (response rate 68%), 224 (33%) regretted not having talked about death sufficiently, whereas 40 (5.9%) conversely regretted having talked about death. Three process factors ("prognostic disclosure to patient" [ $\beta = 0.082$ ,  $P = 0.039$ ], "upsetting of patient and family" [ $\beta = 0.127$ ,  $P = 0.001$ ], and "family's sense of uncertainty about when to act based on terminal awareness" [ $\beta = 0.141$ ,  $P = 0.000$ ]) and an outcome factor ("having achieved a good death" [ $\beta = -0.152$ ,  $P = 0.000$ ]) contributed to the regret of talking insufficiently.

**Conclusion.** A third of bereaved families of adult cancer patients regretted not having talked about death sufficiently. Clinicians may minimize this regret by facilitating a shared understanding of the disease and prognosis, advising families explicitly when to talk based on terminal awareness, providing continuous emotional support, and validating their decision on talking about death. *J Pain Symptom Manage* 2017;54:853–860. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

*End-of-life discussion, cancer, bereaved family, regret*

## Introduction

Achieving a good death is one of the essential goals of palliative care.<sup>1–3</sup> Critical to achieving a good death is the completion of life, which entails patients being

prepared for dying, a feeling that their life has been completed, no regrets about their own death, and family members who also have no regrets about their loved one's death.<sup>1–4</sup> Thus, minimizing the regret of

*Address correspondence to:* Masanori Mori, MD, Palliative Care Team, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Kita-ku, Hamamatsu, Shizuoka 433-8558, Japan. E-mail: [masanori.mori@sis.seirei.or.jp](mailto:masanori.mori@sis.seirei.or.jp)

*Accepted for publication:* February 20, 2017.

cancer patients' families that they did not sufficiently talk about death is an important issue for achieving a good death from the families' perspective.

Recent observational studies have shown beneficial effects of end-of-life (EOL) discussions with advanced cancer patients not only on patients' quality of life and quality of care, but also on bereaved families' mental health.<sup>5,6</sup> Population-based studies have also revealed that widowers who had not talked about death with their dying wife had a higher risk of feeling guilt or regret, and parents who sensed that their dying child was aware of his or her imminent death more often regretted not having talked about death with their child.<sup>7,8</sup> Although these findings suggest the importance of talking about death among cancer patients and their families to minimize bereaved families' regret, talking about death is not an easy task, leaving patients unaware of their impending death.<sup>2,3,7,8</sup> No previous study explored the prevalence of bereaved families' regret of not having talked about death sufficiently with adult cancer patients.

Regret is a painful sensation that can result from recognizing that "what is" compares unfavorably with "what might have been" (counterfactual thinking),<sup>9</sup> and a negative emotion associated with thinking about a choice one has made or is about to make.<sup>10</sup> Specifically, regret regarding cancer-related decisions can be categorized into three types according to their target: process regret (i.e., regret the decision process preceding the choice), option regret (i.e., regret the decision alternative chosen), and outcome regret (i.e., regret the outcome of a decision).<sup>10</sup> Systematically understanding what factors in these types contribute to bereaved families' regret may help clinicians support decision-making in families' talking about death. To the best of our knowledge, no study has systematically explored the factors contributing to bereaved families' regret of talking insufficiently.

Thus, the aims of the present study were: 1) to explore the prevalence of bereaved family members' regret of not having talked about death with their deceased loved one and 2) to systematically explore factors contributing to their regret.

## Methods

This study was conducted as a part of the Japan Hospice and Palliative Care Evaluation (J-HOPE)-3 study, a cross-sectional, anonymous, self-reported questionnaire survey.<sup>11</sup> The detailed methodology of this survey was described elsewhere.<sup>11</sup> In brief, the main study took place between May and July 2014, and included bereaved family members of cancer patients who had died in 133 inpatient hospice/palliative care units (PCUs).

## Participants

This study included a subpopulation of the main study: bereaved family members of cancer patients who had died in 133 PCUs. Potential subjects were bereaved family members of cancer patients who had died before January 2014 in each of the participating institutions. The inclusion criteria included: 1) the patient had died of cancer, 2) the patient was aged 20 years or older, 3) the patient had been admitted to a PCU for more than three days; and 4) the bereaved family member was aged 20 years or older. The exclusion criteria were as follows: 1) the bereaved family member could not be identified; 2) the potential participant would have suffered serious psychological distress, as determined by the primary physician and a nurse; and 3) the potential participant was incapable of completing the self-reported questionnaire because of cognitive impairment or visual disability.

## Procedure

The questionnaires for the present study were randomly sent to the bereaved family members identified by each participating institution. The return of a completed questionnaire was considered consent to participate in the study. Participants were asked to return the completed questionnaires to the study secretariat office. A reminder was sent to non-responders one month after the questionnaire had been sent out. If they did not wish to participate in the study, they were asked to check a "no participation" box and return the incomplete questionnaire. The ethical and scientific validity of the study was verified by the institutional review board of all participating institutions.

## Measurements

The questionnaire for this study was developed by the authors on the basis of a systematic literature review, interviews with 11 bereaved family members, and extensive discussions among the authors.<sup>1,3,8,10,12–16</sup> Content validity was confirmed by a pilot test with three bereaved family members and unanimous agreement of the authors. The primary endpoints were regret of not having talked about death sufficiently. Because of the lack of previously validated instruments, the endpoint parameter was developed by the authors similarly to the previous study.<sup>8</sup>

*Talk About Death and Regret.* The questionnaire asked about the family members' talking about death with the patient as follows: "Did you explicitly talk about death with the patient?"<sup>8</sup> The response categories were "never," "talked a little," "talked," and "talked a lot." In this study, regret was defined as a painful

sensation that can result from recognizing that “what is” compares unfavorably with “what might have been” (counterfactual thinking).<sup>9</sup> Thus, we subsequently asked, “How do you feel about having or not having explicitly talked about death?” The response categories were “should not have talked at all,” “should not have talked that much,” “it was just right,” “should have talked a little more,” and “should have talked much more,” which could assess the intensity of regret. The first two responses were defined as regret of having talked about death, and the latter two responses as regret of not having talked about death sufficiently. The response “it was just right” was defined as no regret.

*Factors Contributing to Regret.* We asked the family members to rate their level of agreement with 26 statements contributing to regret on a four-point Likert-type scale (1: disagree, 2: slightly disagree, 3: slightly agree, and 4: agree). The statements were classified into process, option, and outcome, based on the conceptual framework of regret.<sup>10</sup> In addition, statements regarding process and option were further divided into either situation or communication.

We performed exploratory factor analysis to identify the underlying structure of factors in process, option, and outcome. A maximum-likelihood method and promax rotated solution were used. Items with low factor loadings ( $<0.40$ ) were eliminated individually, and the exploratory factor analysis was then repeated. Then, we calculated Cronbach  $\alpha$  coefficients for each factor. The subscales of the underlying structure of the process included the following: “prognostic disclosure to patient” (two items;  $\alpha = 0.805$ ); “explanation of disease status to family” (two items;  $\alpha = 0.694$ ); “shared disease understanding between patient and family” (three items;  $\alpha = 0.693$ ); “prognostic disclosure to family” (two items;  $\alpha = 0.743$ ); “upsetting of patient and family” (two items;  $\alpha = 0.677$ ); “EOL discussions between patient and family before the diagnosis” (one item); “lack of family recognition about patient awareness of imminent death” (one item); “family’s sense of uncertainty about when to act based on terminal awareness” (one item); and “health care professional’s facilitation of patient-family communication” (one item). The subscales of the underlying structure of the option included the following: “health care professional serving as a decision coach” (four items;  $\alpha = 0.822$ ); “talk or action initiated by patient” (one item); “belief that family should not talk about death with patient” (one item); and “situations necessitating consideration of after-death matters regardless of patient preference” (one item). The subscale of the underlying structure of the outcome included “having achieved a good death” (four items;  $\alpha = 0.835$ ). For a subscale

with multiple items, we defined the score as the mean of item scores. Each subscale score, therefore, ranged from 1 to 4, with higher scores indicating higher levels of agreement for each subscale factor.

We also collected background data such as patients’ and families’ age, sex, and primary cancer site, as well as families’ relationship with the patient, education, and perceived social support. To measure family-perceived social support from people around them, we used two items derived from the Social Support Scale, a brief, reliable, and widely used scale, which was designed to assess the content of support respondents perceived.<sup>17,18</sup> The two items were “degree of supportive listening” and “degree of sympathy,” and families responded on a five-point Likert scale (“0: not at all” to “4: a great deal”), with a higher score indicating greater perceived social support. The score for perceived social support was the mean of these items.

### *Statistical Analyses*

We used descriptive statistics to summarize the participants’ background, and calculated the proportion of their responses with a 95% CI.

To explore the determinants of the family perception of prognostic disclosure, we initially screened 18 background and medical variables (patient’s age and sex, marital status, lived with family, child, region of residence, relationship with the oncologist, palliative team consulted, annual income, bereaved family member’s age, sex, relationship with the patient, education, health status during the caregiving period, availability of another person who could stay with the patient, perceived social support, religion, and religious act) and 14 factors contributing to regret by univariate analyses. Univariate analyses were carried out with Chi-squared analyses and *t*-tests for categorical and continuous variables, respectively. For the comparisons regarding regret about talking insufficiently, the participants were classified into two groups: family members who regretted not having talked about death sufficiently versus family members without regret and those who regretted having talked about death. The cut-off point was determined on the basis of clinical interpretability and the actual data distribution to divide the whole sample into approximately equal-sized comparison groups.

Next, we performed a path analysis to test the model, entering all potential predictors as independent variables. We selected potential predictors with  $P < 0.10$  on univariate analyses.

For sample size calculation, we had assumed that 30% of participants would regret not having talked sufficiently based on a previous study,<sup>8</sup> and determined that at least 559 subjects would be needed to calculate accuracy within a 10% width and 99% CI for a value of 30%.

Table 1  
Characteristics of Participants (N = 678)

Characteristics	Values	
Patients		
Age, yrs (mean ± SD)	74.2 ± 12.0	
Sex		
Male	340	50.1
Female	328	48.4
Primary cancer sites		
Lung	152	22.4
Esophagus, stomach, colon, and rectum	185	27.3
Liver, gall bladder, and pancreas	122	18.0
Breast	31	4.6
Head and neck	30	4.4
Kidney, prostate, and bladder	56	8.3
Uterus and ovary	26	3.8
Blood and lymph nodes (leukemia, myeloma, and lymphoma)	10	1.5
Other	11	1.6
Marital status		
Married	369	54.4
Unmarried	272	40.1
Lived with family		
Yes	455	67.1
No	198	29.2
Child		
Yes	39	5.8
No	607	89.5
Region of residence		
Population ≥ 300,000	270	39.8
Population < 300,000	341	50.3
Length of relationship with oncologist		
≥3 yrs	156	23.0
1–3 yrs	203	29.9
6 month–1 yr	115	17.0
3–6 months	89	13.1
<3 months	93	13.7
Palliative care team consulted		
Yes	501	73.9
No	150	22.1
Annual income, dollars		
<40,000	455	67.1
≥40,000	176	26.0
Bereaved family members		
Age, yrs (mean ± SD)	61.4 ± 12.1	
Sex		
Male	245	36.1
Female	413	60.9
Relationship with the patient		
Spouse	261	38.5
Other	396	58.4
Education		
Junior high school/high school	375	55.3
University/graduate school	283	41.7
Health status during the caregiving period		
Good	164	24.2
Not bad	335	49.4
Bad	123	18.1
Very bad	37	5.5
Availability of another person who could stay with the patient		
Yes	480	70.8
No	175	25.8
Perceived social support <sup>a</sup>	2.82 ± 0.81	
Religion		
Buddhism	382	56.3
Shintoism	13	1.7
Christianity	10	1.3

(Continued)

Table 1  
Continued

Characteristics	Values	
Other religion	15	2.0
No religion	230	30.7
Religious activities		
Routinely	145	21.4
Sometimes	314	46.3
Rarely	141	20.8
Never	56	8.3

Values are mean ± SD, or n (%).

Total percentages do not equal 100% because of missing values.

<sup>a</sup>Mean of scores of the two items (“degree of supportive listening” and “degree of sympathy”), with responses ranging from “0: not at all” to “4: a great deal,” with a higher score indicating greater perceived social support.

We conducted all statistical analyses using SPSS version 21.0 (IBM Japan Institute, Tokyo, Japan) and AMOS version 16.0 (IBM Japan Institute, Tokyo, Japan). A value of  $P < 0.05$  was considered significant in all analyses.

## Results

A total of 999 bereaved family members from 133 PCUs were included. Of them, 750 bereaved family members returned the questionnaire and 72 refused to participate. Thus, responses from 678 participants were analyzed (response rate 68%). The mean and median lengths between the day of death and the day when the first questionnaire was sent were 236 (SD 102) and 216 (range 97–788) days, respectively. The characteristics of the deceased patients and bereaved family members are summarized in Table 1.

### Talk About Death and Regret

Approximately, half of bereaved families had talked about death with their loved ones to various degrees, whereas the other half had not (Fig. 1). A third of participants regretted not having talked about death sufficiently (Fig. 2). On the other hand, 40 participants (5.9%) regretted having talked about death.

### Factors Contributing to Regret

We carried out a path analysis by first selecting six background and medical variables, and eight factors contributing to regret as independent variables in the initial model, because they were observed to be significant predictors ( $P < 0.10$ ) of regret about talking insufficiently in the univariate analysis. Next, we drew all paths according to the results of the correlation analysis. We repeated the analysis and sequentially dropped paths that were not significant until all the paths in the model became significant ( $P < 0.05$ ). Some variables were dropped from the model because none of the paths from these variables reached significance.

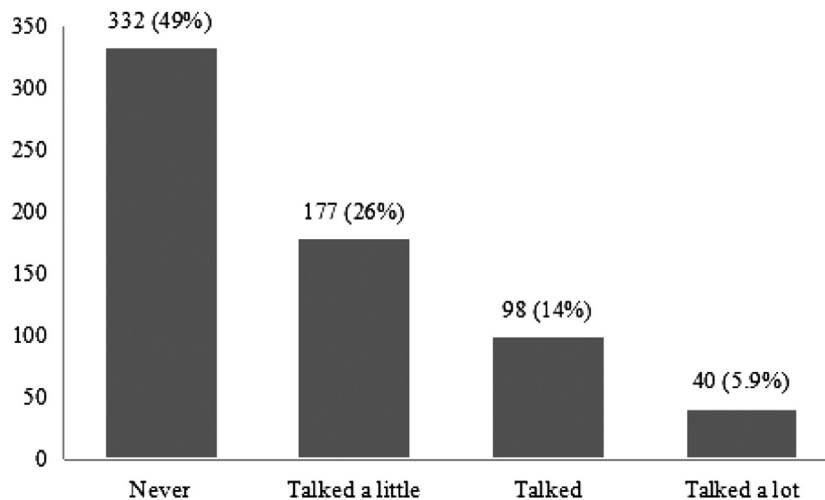


Fig. 1. Prevalence of bereaved families who had talked about death with their loved one ( $n = 678$ ).

Figure 3 represents the final model of factors contributing to regret of not having talked about death sufficiently. The fit indices for the model were the root-mean-square residual = 0.058, goodness-of-fit index = 0.977, and adjusted goodness-of-fit index = 0.934. This model accounted for 9.6% of the variance in the regret of not having talked about death sufficiently. The parameter with the highest value explaining the regret was “having achieved a good death” ( $\beta = -0.152$ ,  $P = 0.000$ ). Furthermore, “prognostic disclosure to patient” ( $\beta = 0.082$ ,  $P = 0.039$ ), “upsetting of patient and family” ( $\beta = 0.127$ ,  $P = 0.001$ ), and “family’s sense of uncertainty about when to act based on terminal awareness” ( $\beta = 0.141$ ,  $P = 0.000$ ) had significant

positive correlations with the regret. Among demographic parameters, only the patient’s age had a direct association with the regret ( $\beta = -0.098$ ,  $P = 0.017$ ).

### Discussion

The present study is, to the best of our knowledge, the first study to explore the prevalence of bereaved family members’ regret of not having talked about death with their deceased loved one (adult cancer patient), and systematically explore factors contributing to regret using the conceptual framework of regret. The present study generated several major findings.

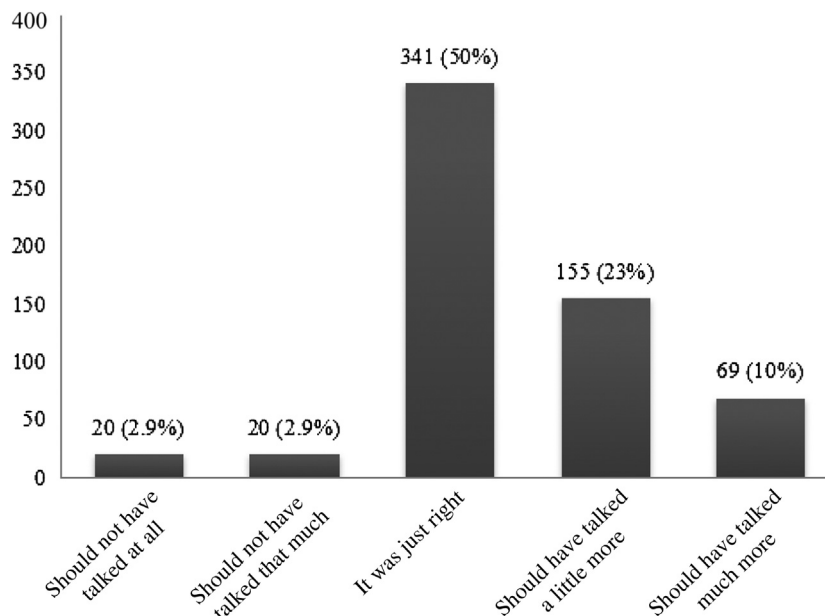


Fig. 2. Prevalence of bereaved families’ regret regarding talking about death with their deceased loved one ( $n = 678$ ).



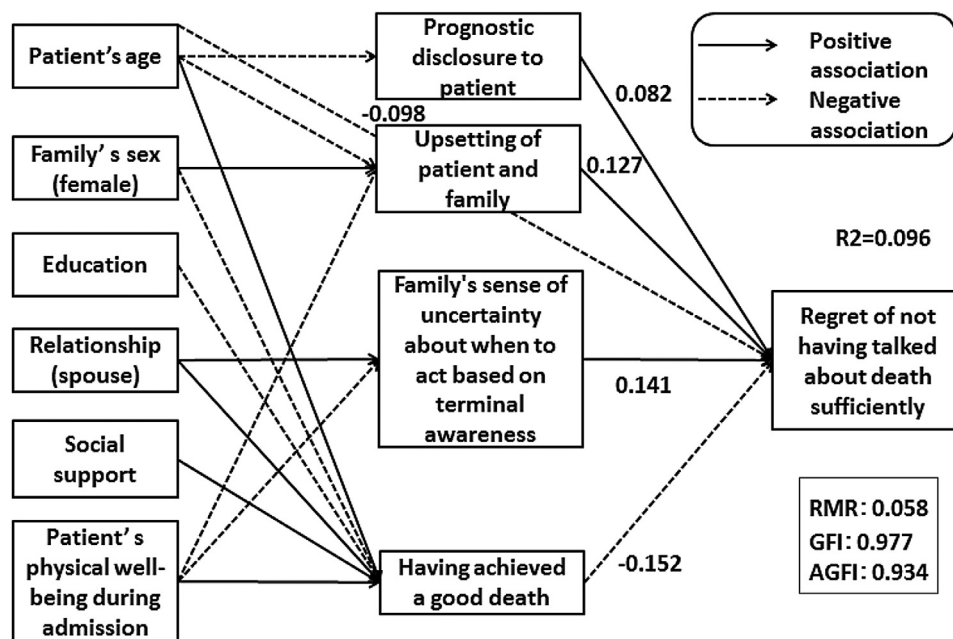


Fig. 3. Factors contributing to regret of not having talked about death sufficiently. RMR = root-mean-square residual; GFI = goodness-of-fit index; AGFI = adjusted goodness-of-fit index.

The first and most important finding is that up to a third of the bereaved family members regretted not having talked about death. This is consistent with a previous survey that showed 27% of parents regretted not having talked about death with their child dying of cancer.<sup>8</sup> As regret is in part correlated with overall care satisfaction and the health-related quality of life among bereaved family members, future studies will be urgently needed to develop care strategies to help patients and families talk about death.<sup>4</sup> On the other hand, only <6% of participants regretted having talked about death in our cohort. This is similar to a previous study revealing that no parent regretted having talked about death with their dying child. These findings may partly be explained by the observation that “inaction” (e.g., not having talked about death) can evoke more regret in the long-term than “action” (e.g., having talked about death).<sup>19</sup> As families who had talked about death could recognize both the positive and negative outcomes of the actual conversation, they might find it easier to cognitively cope with and psychologically justify the consequences. On the other hand, families who had not talked could not evidently see the outcomes as a result of “inaction,” and in retrospect might not clearly remember the reasons why they had not talked, which may lead to more regret. These findings indicate that, if families of advanced cancer patients are unsure whether or not they should talk with their loved one about death, they may benefit from knowing that very few families of adult patients regretted having done so. At the same time, given the sensitivity of the topic and its potentially variable bereavement outcomes,

clinicians are strongly encouraged to fully explore perceptions, values, goals, and challenges at admission or initial contact with the patient and the family.

The second important and novel finding is that factors in process and outcome contributed to regret of not having talked about death sufficiently. In the path analysis, three factors in process (“prognostic disclosure to patient,” “upsetting of patient and family,” and “family’s sense of uncertainty about when to act based on terminal awareness”) had positive, and one unified outcome factor (“having achieved a good death”) had negative associations with regret. The identification of the initial factor is consistent with a previous study showing that parents who sensed that their child was aware of his or her imminent death were more likely to regret not having talked about it.<sup>8</sup> Insufficient conversations about death after the disclosure of imminent death to the patients may leave them with fearful thoughts, alone or without optimal emotional support.<sup>8</sup> The association of the outcome factor as a result of talking about death with less regret makes clinical sense, as achieving a good death is a major component of a “good death.”<sup>1–3</sup> These findings may indicate the importance of explaining the potential future trajectory at least to families; facilitating shared understanding of prognosis either explicitly or implicitly among patients and families; advising families explicitly when to talk based on terminal awareness; providing continuous emotional support even after the prognostic disclosure; and validating patients’ and families’ decision on talking about death.

Of note is that the patient's age was negatively associated with regret, in addition to its negative association with prognostic disclosure to the patient, upsetting of the patient and family, and positive association with having achieved a good death. These findings are consistent with the growing body of evidence that younger patients and their families tend to have lower preparedness and greater psychosocial distress despite their higher tendency to be informed of their imminent death.<sup>20–22</sup> Furthermore, the Japanese traditionally valued “non-disclosure” of bad news to patients, and considered unawareness of death important.<sup>3</sup> However, the increasing number of Japanese people has preferred knowing their terminal prognosis, and the predominant majority of oncologists have recently reported having EOL discussions with advanced cancer patients at some point in the disease trajectory.<sup>23,24</sup> Nonetheless, preference for non-disclosure of imminent death might still prevail among older Japanese patients, which may have lessened the families' later regret of not having talked about death sufficiently. Clinicians should bear in mind that younger patients and their families may benefit from extra support before and after talking about death.

Interestingly, neither religion nor religious activity was associated with regret of not having talked about death sufficiently. This is in contrast to the previous study in which more religious parents had higher likelihood of feeling regret not having talked about death with their dying child.<sup>8</sup> The potential interpretation may be that religiosity and/or spirituality is not predominantly considered important for a good death in Japan, whereas it is considered essential by most patients in the western culture.<sup>1–3</sup> Future research is warranted to clarify the roles of religiosity and/or spirituality in the development of later regret among bereaved families.

Despite the strengths of the nationwide survey and utilization of the conceptual framework about regret, our study has several limitations. First, this was an after-death survey among bereaved family members with a moderate response rate (68%) and variable lengths between the patient's death and survey administration, which may have introduced recall and selection biases. However, our primary endpoint, bereaved families' regret about talking insufficiently, is by definition a negative emotion on recall associated with thinking about a choice they had made, and we had extracted potential factors contributing to regret essentially from interviews with bereaved family members. Previous national surveys from the U.S. and Japan involving bereaved family members also reported similar response rates.<sup>1,25</sup> Thus, we believe that this limitation is justifiable. Second, we performed no formal testing of the validity and reliability of the question asking about regret with its intensity, as

well as factors contributing to regret. We believe that this limitation does not severely limit the quality of our study, because our question responses could capture counterfactual thinking, which is the key component of regret<sup>9</sup>; established tools to measure factors contributing to regret of not having talked about death were not available; we performed exploratory analyses and calculated the Cronbach  $\alpha$ ; and our findings were highly interpretable. Third, because of the nature of the cross-sectional study, we could not control for pre-existing psychological features leading to a proneness to regret among the family members. Furthermore, quality in-depth interviews might have elucidated much more relevant factors contributing to regret. These limitations may be the reason why our models of parameters leading to regret explained only approximately 10% of the variation (Fig. 3). We would strongly encourage future studies including in-depth interviews to capture more extensive factors associated with regret; mixed-method studies to clarify underlying mechanisms that cause later regret; and prospective cohort studies that control for families' pre-existing features leading to a proneness to regret.

In conclusion, this nationwide survey revealed that a third of bereaved family members of adult cancer patients regretted not having talked about death sufficiently with their deceased loved one. Both the process of decision-making on whether or not to talk as well as its positive outcome (i.e., having achieved a good death) were associated with bereaved family members' regret. Clinicians may minimize family members' later regret of having talked insufficiently by explaining the potential future trajectory at least to families; facilitating shared understanding of the disease and prognosis either explicitly or implicitly among patients and families; advising families explicitly when to talk based on terminal awareness; providing continuous emotional support even after the prognostic disclosure; and validating patients' and families' decision on talking about death.

### *Disclosures and Acknowledgments*

This study was conducted with the cooperation of Hospice Palliative Care Japan (HPCJ). The authors would like to thank all participants and participating institutions for taking part in this study. This study was part of The Japan Hospice and Palliative Care Evaluation Study, funded by Japan Hospice Palliative Care Foundation, and in part supported by Japan Society for the Promotion of Science KAKENHI Grant Number JP16K15418.

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

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## *Appendix*

■ We will ask you how you and your loved one (patient) communicated after it became clear that the patient's illness was incurable. Please circle only one number that is the most applicable to you.

Did you explicitly talk about death with the patient?

1. Never	2. Talked a little	3. Talked	4. Talked a lot
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How do you feel about having or not having explicitly talked about death?

1. Should not have talked at all	2. Should not have talked that much	3. It was just right	4. Should have talked a little more	5. Should have talked much more
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■ After it became clear that the patient's illness was incurable, there may have been various communications with patients and health care professionals. We will ask you about your experiences and beliefs. Please circle only one number that is the most applicable to you.

If there is discrepancy of experiences and beliefs among the family, please answer your own.

	Disagree	Slightly disagree	Slightly agree	Agree
<b>Situations or communications between the patient and family</b>				
Patient and family discussed preferred EOL care before the diagnosis.	1	2	3	4
Patient was aware of the imminent death.	1	2	3	4
Family was aware of the imminent death.	1	2	3	4
Awareness of imminent death was explicitly or implicitly shared between patient and family.	1	2	3	4
Family was unsure if patient was aware of the imminent death.	1	2	3	4
Family did not even think of talking about death with patient.	1	2	3	4
Family wanted to do something for patient, but was not sure when would be the high time.	1	2	3	4
Patient initiated conversation about death and/or action based on terminal awareness.	1	2	3	4
Family had to discuss issues related to death (e.g., money, family, job) or act based on terminal awareness regardless of patient preference.	1	2	3	4
Patient was upset about the imminent death.	1	2	3	4
Family was upset about the imminent death.	1	2	3	4
<b>Communications with the health care professionals</b>				
Family was explicitly informed of the patient's disease status (e.g., sites of metastases).	1	2	3	4
Family was explicitly informed of the influences of the patient's disease on future activities of daily life.	1	2	3	4
Patient was explicitly informed that the disease was incurable.	1	2	3	4
Patient was explicitly informed of the estimated prognosis.	1	2	3	4
Family was explicitly informed that the disease was incurable.	1	2	3	4
Family was explicitly informed of the estimated prognosis.	1	2	3	4
Health care professional facilitated communication between patient and family.	1	2	3	4
Family was able to talk to health care professional any time when there was subtle change in patient's or family's situation.	1	2	3	4
Health care professional advised from the medical perspective whether the goal of patient and family was appropriate (e.g., advised to do certain things a little earlier).	1	2	3	4
Health care professional facilitated conversation about death between patient and family.	1	2	3	4
Health care professional facilitated planning on how to spend time with patient and family.	1	2	3	4
<b>Family's perceptions</b>				
Patient was able to spend time according to his or her wishes.	1	2	3	4
Patient and family shared same perspective in dealing with the disease.	1	2	3	4
Patient was able to spend time while maintaining hope.	1	2	3	4
Family's roles were fulfilled.	1	2	3	4