

Original Article

Communication Disparity Between the Bereaved and Others: What Hurts Them and What Is Unhelpful? A Nationwide Study of the Cancer Bereaved



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Abstract

Context. The importance of communication between the cancer bereaved and others has been emphasized, but little is known about the more problematic aspects of this communication such as “unhelpful communication.”

Objectives. The aim of this study was to establish which types of communication are perceived by the bereaved to be unhelpful.

Methods. We conducted a cross-sectional, anonymous, nationwide survey at 103 certified hospice facilities/palliative care units in Japan.

Results. A total of 630 (63%) bereaved responded. Over 60% of the bereaved experiencing such communication considered it to be unhelpful, with the most unhelpful communication being “They emphasized the positive aspects of death.” Thirteen items related to communication were separated into two factors (“advice for recovery” and “comments on cancer”) by factor analysis. “Comments on cancer” were more unhelpful to them and were more often provided by those around them. With regard to “advice for recovery,” losing a spouse was a stronger predictor with a higher odds ratio for communication distress than losing a parent (odds ratio, 5.34; 95% CI, 1.63–17.57).

Conclusion. A number of the bereaved have experienced unhelpful communication regarding advice on dealing with bereavement and cancer. To prevent putting an unnecessary burden on the bereaved with such unhelpful communication, it is essential to understand problematic aspects. Even when people have no intention of hurting the bereaved, some communication may do so. Communication with the bereaved is also a core clinical skill required by health professionals, and further efforts are required to support the grieving process. *J Pain Symptom Manage* 2018;55:1061–1067. © 2018 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Cancer bereaved, communication, unhelpful, distress, nationwide study, J-HOPE study

Introduction

The number of cancer patients and mortality due to cancer are increasing despite advancements in its treatment.¹

The death of a close family member is one of the most stressful events in life.² Bereaved individuals face various types of distress: physical,^{3,4} psychiatric, psychological,^{5–8} and behavioral,^{3,9} for which

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different types of support are necessary. Therefore, the World Health Organization and some previous studies have emphasized the importance of bereavement counseling for family and friends.^{10–12}

Effective social support can provide great benefits, especially when received from sources such as family, friends, and acquaintances and when there is good or helpful communication with the bereaved.¹³ However, some reports have indicated that the bereaved can be adversely affected through communication with others,¹⁴ which may be causally related to their distress as “unhelpful support.”^{15–17} In the case of cancer, over 60% of the bereaved have received secondary harm through communication with others, resulting in additional hardships beyond the pain of bereavement.^{8,18}

Some studies have demonstrated that social support has both positive and negative aspects; therefore, we need to consider the importance of providing appropriate support.^{19,20} However, to our knowledge, little is known about problems such as unhelpful communication in a cancer support setting.

In this study, we therefore investigated communication between the cancer bereaved and others. The primary aims were 1) to establish which types of communication are perceived by the bereaved to be unhelpful; 2) to determine the proportion of the bereaved who have experienced such communication, as well as its frequency; and 3) to determine the statistical relationships with their background and perceived distress.

Methods

Participants and Procedures

We conducted a cross-sectional, anonymous, nationwide survey at 195 certified hospice facilities/palliative care units for Hospice Palliative Care in Japan, with 103 palliative care units agreeing to participate in this study. Between October 2010 and April 2011, we mailed the questionnaires from the participating institutions to the bereaved who had lost a loved one to cancer more than one year but less than two years previously. Primary care physicians identified bereaved families that fulfilled the inclusion criteria: 1) primary caregiver of an adult cancer patient, 2) aged 20 years or more, 3) capable of replying to a self-reported questionnaire, 4) without serious psychological distress as determined by the physician. The last criterion was adopted in the same way as in our previous surveys^{21,22} on the assumption that primary palliative care physicians could identify families who would suffer serious psychological distress from this survey. A sheet explaining the aims and methods of this survey was included along with the questionnaire, and its return was regarded as consent to participate in the study.

Questionnaire

Bereaved Family Members' Perceived Distress. First, with no specific measurement tool available to evaluate the experience of the bereaved regarding communication with people around them, we developed a questionnaire based on a systematic literature review^{8,23,24} and discussion among the authors. The questionnaire included 13 items that may be regarded as unhelpful and/or distressing in the context of communication between the bereaved and others. No items other than the aforementioned 13 items were extracted from the results of an interview survey conducted for the 20 cancer bereaved in conjunction with the aforementioned survey. Furthermore, content validity of the survey items was confirmed by medical specialists (the authors), and face validity was also confirmed in a pilot survey involving another 20 cancer bereaved.

Second, the subjects were each asked to respond to 13 questions about whether they had experienced such communication, and questions to which the subjects answered “yes” were then rated on a five-point scale. The level of distress as perceived by the bereaved family members was evaluated as follows: 5: “very helpful,” 4: “helpful,” 3: “neither helpful nor unhelpful,” 2: “unhelpful and distressing,” or 1: “very unhelpful and distressing” (Fig. 1).

Good Death Inventory. The Good Death Inventory (GDI) evaluates end-of-life care from the perspective of a bereaved family member. The GDI short version consists of 18 items in 10 core domains and eight optional domains. Each item is scored on a seven-point Likert scale. High scores indicate a good death.²⁵

Demographic Data. The primary palliative care physicians recorded background demographic data for all patients (deceased). In addition, the bereaved reported their relationship with the patient and the interval between the death of the patient and the completion of the questionnaire.

Statistical Analysis

First, descriptive statistics were used to analyze the background information of the patients and the bereaved. For the patients, the analysis included age, gender, primary tumor site, and admission period. For the bereaved, the analysis included age, gender, relationship with the deceased, and total score for the short version of the GDI.²⁵

Second, the proportions of the bereaved who had experienced each item related to communication with others were calculated.

Third, to categorize the items for experiences of the bereaved in terms of communication with others into

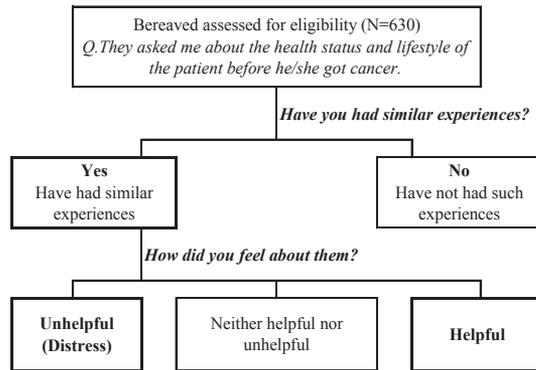


Fig. 1. Flow diagram of this questionnaire.

similar groups, a factor analysis with principal component extraction was performed. The minimum eigenvalue for extraction was set at 1. Scree plots, factor loadings, percent of variance explained by factors, and cumulative percent of variance explained were examined. Items with a minimum loading of 0.4 were considered relevant.

Fourth, we devised scores for each factor extracted from items for experiences related to others by the bereaved. We considered the evaluation bias associated with the recall of and responses regarding distressing experiences, and item responses were classified into two categories based on the occurrence of distressing experiences. The binary scores for items for the same factor were summed. A score of more than or equal to one distressing experience was categorized as 1, and a score of no distressing experience was categorized as 0.

We next performed binomial logistic regression analyses using those binary scores for distressing experiences for each factor as outcome variables and demographic characteristics as independent variables. Odds ratios and 95% CIs were calculated. Hosmer-Lemeshow goodness of fit was tested using chi-squared values and *P*-values to validate the adequacy of the logistic regression model. A *P*-value greater than 0.05 suggested a good fit of the model. For all the remaining analyses, the significance level was set at 5%. IBM-SPSS (Statistical Package for the Social Sciences; IBM Corp., Armonk, NY) for Windows version 23 was used for data analysis.

Results

Of the 1003 questionnaires sent to the bereaved family members, 630 were completed and returned (response rate 63%).

Participant Characteristics

Table 1 summarizes the characteristics of the patients and their bereaved. Regarding the patients, the lung was the most common primary tumor site

(24.4%). The median period of hospitalization was less than one month (27 days). Regarding the bereaved, spouse was the most common relationship with the deceased (39.7%). The mean and median durations from the patient's death to the survey were 17.2 and 16 months, respectively. The mean total GDI (short version) score was 84.03.

Experiences of the Bereaved in Communicating With Others

Figure 2 shows the proportion of experiences for each of the 13 items regarding communication experienced by the cancer bereaved.

From the binary scores, taking into consideration the distress bias of the bereaved, the most unhelpful communication received was "They emphasized the positive aspects of the death." Based on the Likert Scale scores, the most unhelpful communication received was "They asked me why I did not notice it earlier" (mean \pm SD: 2.62 \pm 0.91) followed by "They emphasized the positive aspects of the death" (mean \pm SD: 2.65 \pm 0.82).

For almost all the 13 items, over 60% of the bereaved who had experienced such communication considered it to be unhelpful. Most highly experienced unhelpful communication was "They said that time will take care of the rest" (59.12%), followed by "They asked me about the health status and lifestyle of the patient before he/she got cancer" (58.71%) and "They asked me about the course of cancer" (57.79%). Moreover, six of the 13 items were experienced by more than half of the bereaved.

Factorial Validity of the Experiences of the Bereaved

Table 2 summarizes factor loadings from principal factor extraction with promax rotation. Two factors were extracted, which we designated as advice for recovery (consisting of eight items) and comments on cancer (five items). These two factors explained 68% of the total variance.

Predictors of Distressing Experiences

Table 3 summarizes the predictors of distressing experiences extracted from the binomial logistic regression analyses. Loss of a spouse was a stronger predictor and had a higher odds of communication distress than did loss of parent (relationship with the deceased is child) with regard to "advice for recovery" (odds ratio, 5.34; 95% CI, 1.63–17.57).

Discussion

This study investigated communication between the bereaved who have lost a loved one to cancer and the people involved with them. This is, to the best of our knowledge, the first systematic study to explore the

Table 1
Background of Patients and the Bereaved Families

	Subjects	
	No.	%
Patients		
Age, yrs		
Mean \pm SD	72 \pm 12	
Range	30–96	
Gender		
Male	347	55.1
Female	282	44.8
Primary tumor site		
Lung	153	24.4
Stomach	88	14.0
Colon, rectum	78	12.4
Pancreas, bile duct	71	11.3
Uterus, ovary	42	6.7
Bladder, kidney, prostate	36	5.7
Liver	33	5.3
Breast	31	4.9
Head and neck	23	3.7
Esophagus	22	3.5
Unknown	2	0.3
Others	51	8.1
Admission period (days)		
Mean \pm SD	46.5 \pm 64.5	
Median	27	
Bereaved families		
Age, yrs		
Mean \pm SD	61 \pm 12	
Range	27–92	
Gender		
Male	185	29.4
Female	358	56.8
Relation to the deceased		
Spouse	250	39.7
Child	193	30.6
Sibling	41	6.5
Son-in-law/daughter-in-law	33	5.2
Parent	14	2.2
Interval from patient death to study (months)		
Mean \pm SD	17.2 \pm 4.5	
Median	16	
Good Death Inventory (short version, total score)		
Mean \pm SD	84.03 \pm 14.81	
Median	84.5	

Percentages do not add up to 100% due to missing values.

experience of the cancer bereaved regarding communication with others, what they were told, and how they perceived such communication with others, and the major findings of this study can be summarized as shown in the following.

First, we identified that unhelpful communication with the bereaved can be classified into two categories: 1) advice for recovery and 2) comments on cancer. Advice on how the bereaved should recover from grief was found to be perceived as unhelpful. Some may want the bereaved to get over their grief and offer advice on how they should recover as observing someone's distress is also distressing. In recovery from grief, a gap may remain between the actual recovery and that perceived by others.

“Comments on cancer” are specific to the cancer bereaved. Over 50% of the bereaved had been asked

about the patient's “cause” and “course” of cancer by others out of curiosity. Such insensitive questions about cancer may be asked owing to a lack of knowledge about the disease. Reported misconceptions regarding palliative care service, delirium, and opioids²⁶ may also be related to such inquisitive and invasive questions.

All five of the “comments on cancer” items in this evaluation rated more highly than five of the seven “advice for recovery” items in the unhelpful evaluation rating. Unfortunately, “comments on cancer” were more unhelpful for the bereaved and were more often provided by others than was “advice for recovery.”

Second, “spouse” was the most common background characteristic of those who tended to perceive certain types of communication as unhelpful. “Losing a spouse” has been reported as a notable background factor affecting quality of life and impaired mental health.^{24,27} Those who have lost their spouses not only experience grief but also face significant changes in their daily lives and roles. Bereaved spouses may also be burdened by having to conduct a funeral or several memorial services and, in some cases, undergo civil procedures related to property and assets. Advice for recovery provided for bereaved spouses can be perceived as unhelpful communication as it may be regarded as instructions to the bereaved and, subsequently, increase their psychological burden.

The results of this study suggested that advice related to recovery for the bereaved does not meet their needs. Support that does not accommodate the bereaved family's needs is nothing but unhelpful for them, even if others regard it as helpful, which is similar to the case of cancer patients and their families.²⁸ Their need is, perhaps, for support in their daily lives, rather than that for recovery from grief.

Providing assistance to the bereaved in different situations without consideration of whether they need such assistance is not beneficial and may occasionally even be harmful.^{15,29,30}

Some limitations of this study should be noted. First, the population was limited to the bereaved who have experienced bereavement in palliative care wards and thus represents only 8.4% of all patients who die of cancer in Japan.³¹ However, we do not believe that this limitation undermined the importance of our findings as our results are not directly related to the place of death but to the cause of death. Second, this study has mainly demonstrated the negative side of communication as “unhelpful communication” from the recipient's perspective. Bereaved reported their worst experience, and this may have impact on the results. This study confirmed the existence of “unhelpful communication,” but the reason

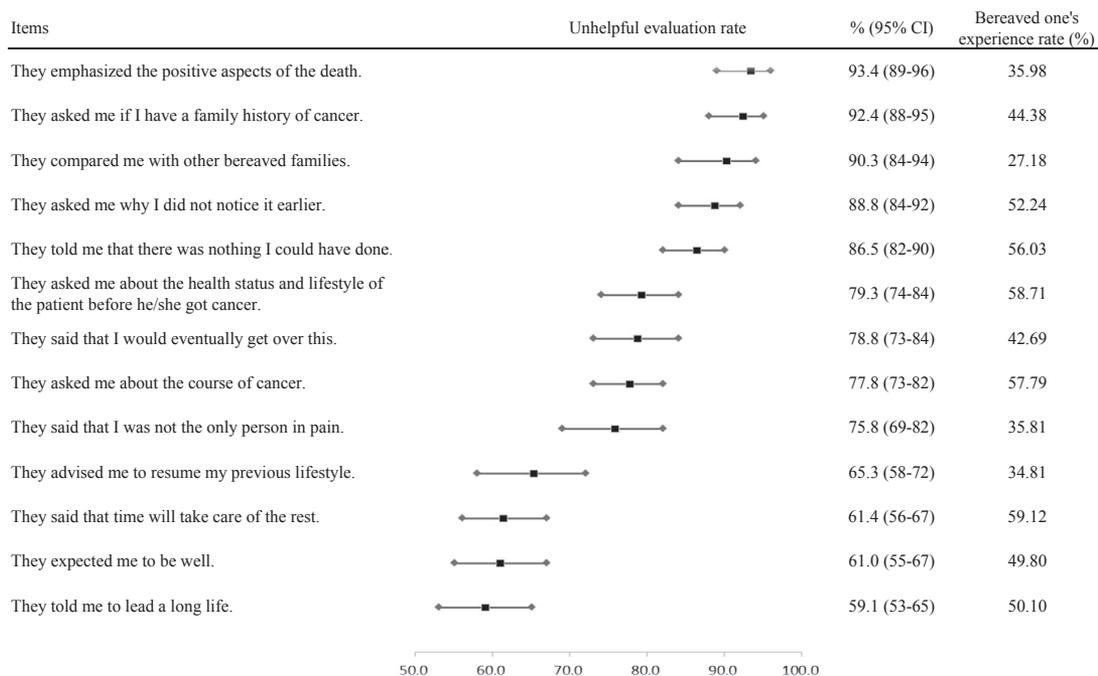


Fig. 2. Unhelpful communication items and their evaluation and experience rates.

why the communication was “unhelpful” was not clear. We will continue to study unhelpful communication in the future and seek to clarify the reason why such communication is offered and why it is “unhelpful” for the bereaved family, while further studies are also needed for “helpful communication.” Third, the use of a cross-sectional design limits the ability to follow up the bereaved and determine the impact on health outcome or whether perceptions of communication fluctuate over time. Although additional studies are needed to resolve these limitations and to incorporate communication with the bereaved

into communication skills training, these results indicated that tactful communication is obviously needed for the bereaved. Fourth, this study is a nationwide quantitative research project based on qualitative research conducted on bereaved families in Japan, and there is a possibility that the Japanese cultural background influences the results. This study did not reflect the cultural and religious background in Japan in the national survey items; however, there are items that need to be considered when undertaking studies in different cultures and religious spheres in future. For example, bereavement clinics deal with

Table 2
Factor Loading From Explanatory Factor Analysis of Items Related to Painful Experiences

Factor Name	Items	Factor 1	Factor 2
Advice for recovery	They told me to lead a long life.	0.88	-0.09
	They said that I was not the only person in pain.	0.85	-0.04
	They advised me to resume my previous lifestyle.	0.84	-0.23
	They expected me to be well.	0.81	0.01
	They said that time will take care of the rest.	0.79	0.10
	They compared me with other bereaved families.	0.67	0.16
	They emphasized the positive aspects of the death.	0.56	0.22
Comments on cancer	They said that I would eventually get over this.	0.46	0.26
	They asked me about the course of cancer.	-0.11	0.94
	They asked me about the health status and lifestyle of the patient before he/she got cancer.	-0.16	0.89
	They asked me if I have a family history of cancer.	0.07	0.80
	They asked me why I did not notice it earlier.	0.05	0.79
	They told me that there was nothing I could have done.	0.24	0.59
	Eigenvalue	6.41	1.78
% of variance explained	49.28	13.68	
Cumulative % of variance explained	49.28	62.95	

Extraction method: principal component analysis. Rotation method: promax. Values in bold indicate factor loading >0.40.

Table 3
Predictors of Two Factors for Distressful Communication

	Advice for Recovery (<i>n</i> = 395)		Comments on Cancer (<i>n</i> = 419)	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Age of patient	1.02	0.98–1.07	1.00	0.96–1.04
Gender of patient				
Male	1		1	
Female	1.33	0.76–2.34	1.00	0.55–1.83
Age of respondent	0.98	0.94–1.03	1.04	1.00–1.08
Gender of respondent				
Male	1		1	
Female	1.39	0.81–2.39	0.72	0.40–1.28
Period of hospitalization of patient	1.00	1.00–1.00	1.00	1.00–1.01
Period of time after bereavement				
Within one year	1		1	
One year or longer	1.70	0.81–3.59	1.25	0.52–3.00
Relationship with the deceased				
Child	1		1	
Spouse	5.34	1.63–17.57	0.58	1.88–1.77
Hosmer-Lemeshow goodness of fit: chi-square and <i>P</i> -value	15.12	0.06	4.02	0.86

more than a few bereaved families living in a religious context who experience comments such as “be glad as your loved one was called to God” or “your loved one was a believer and has been called to God, so you shouldn’t feel sorrow.”

In conclusion, this study revealed the characteristics of communication experienced by the bereaved families of cancer patients and the background of the vulnerable bereaved. Instead of giving advice and making comments without careful consideration, attentive listening to the bereaved is the most important approach to preventing unhelpful communication. Communication is a multifaceted process. Understanding the problematic aspects, in addition to the supportive aspects, is necessary for effective communication with the bereaved. Further research on unhelpful and helpful communication between the bereaved and others is crucial. Communication with the cancer bereaved is also needed as a core clinical skill for health professionals, and further efforts are required to support the grieving process.

Disclosures and Acknowledgments

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The authors declare that they have no competing interests.

Ethical approval: The ethical and scientific validity of this study was approved by the institutional review boards of Saitama Medical University International Medical Center (08-031) and all participating institutions. This study was conducted in accordance with the ethical guidelines for epidemiological research of the Ministry of Education, Culture, Sports, Science

and Technology, and the Ministry of Health, Labor and Welfare of Japan.

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Appendix

Questionnaire

Please let us know about your experience as a member of a bereaved family. This questionnaire is designed so that we can learn from your experience regarding how we should communicate with bereaved families and what their intentions are. The questions cover the words of other people (family members, relatives, and friends).

If you have had similar experience, please encircle the number of the response that best describes your feelings.

If you have not had such an experience, simply choose "I have not had such an experience."

Item	No. I Have Not Had Such an Experience	If You Have Had Similar Experience, "How Did You Feel About Them?"				
		Very Unhelpful and Distressing	Unhelpful and Distressing	Neither Helpful nor Unhelpful	Helpful	Very Helpful
They asked me about the health status and lifestyle of the patient before he/she got cancer.	0	1	2	3	4	5
They asked me why I did not notice it earlier.	0	1	2	3	4	5
They asked me if I have a family history of cancer.	0	1	2	3	4	5
They asked me about the course of cancer.	0	1	2	3	4	5
They told me that there was nothing I could have done.	0	1	2	3	4	5
They emphasized the positive aspects of the death.	0	1	2	3	4	5
They advised me to resume my previous lifestyle.	0	1	2	3	4	5
They compared me with other bereaved families.	0	1	2	3	4	5
They expected me to be well.	0	1	2	3	4	5
They said that time will take care of the rest.	0	1	2	3	4	5
They said that I would eventually get over this.	0	1	2	3	4	5
They said that I was not the only person in pain.	0	1	2	3	4	5
They told me to lead a long life.	0	1	2	3	4	5