



# Web-Based Post-Bereavement Survey System in Specialized Palliative Care: A Feasibility Pilot Study

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Web-based post-bereavement survey systems for specialized palliative care will enable obtaining timely results on the care quality from more participants at a lower cost. The primary aim of the study was to develop a web-based post-bereavement survey system and to compare response rates for different number of items. The secondary aim was to examine response bias between web-based and mail survey in post-bereavement surveys. Between January and April 2019, two cross-sectional web-based questionnaire surveys were conducted among the bereaved families from six inpatient palliative care units in Japan. Measurements included structure and process of end-of-life (EOL) care, overall care satisfaction, achievement of a good death, depression, grief status, web survey usability, and participant and bereaved family member characteristics. The long survey included 34 items, and the short survey included 16 items. There were no significant differences in the response rates between the long and short surveys (24% and 27%, respectively,  $p = 0.376$ ). Compared with a previous nationwide post-bereavement mail survey, more children responded; however, the quality rating scores was unchanged. Despite low response rate, no apparent response bias was observed, indicating its feasibility. This survey method is low-cost, less burdensome to the institution, and allows for ongoing quality assurance.

**Keywords:** bereavement; feasibility study; online system; quality assurance

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## Introduction

Quality management of hospice and palliative care should preferably occur at national, regional, and institutional levels as well as during its planning and implementation (World Health Organization 2021). To this end, post-bereavement quality assurance surveys have been conducted in hospice and palliative care areas over the last

few decades (Addington-Hall and McCarthy 1995; Lynn et al. 1997; Teno et al. 2004; Lawson et al. 2013; Hunt et al. 2019). The main purpose of post-bereavement surveys is to assess end-of-life (EOL) care provided, identify issues, and make improvements to manage the quality of hospice and palliative care. In the Japan Hospice Palliative Care Studies (J-HOPE studies), 10,000-scale bereaved family mailed surveys have been conducted for national quality manage-

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ment of specialized palliative care services (Miyashita et al. 2008b; Aoyama et al. 2017). The J-HOPE study had three objectives: 1) to evaluate the processes, structures, and outcomes of palliative care in hospitals, palliative care units (PCUs), and home hospice services; 2) to examine bereaved family members' self-reported psychosocial conditions; and 3) to provide data to participating facilities to improve their care. However, this study had several limitations. First, most participating facilities were limited to PCUs. Second, because the survey was conducted once every four years, we could not obtain data in a timely manner. Finally, mail surveys are expensive to conduct. Recently, the Japanese government initiated a nationwide mortality follow-up survey based on death certification, allowing for a more representative survey (Nakazawa et al 2021). The J-HOPE study will be conducted only in PCUs.

To overcome the two problems of timeliness and cost, Hospice Palliative Care Japan (HPCJ) started developing a web-survey system for post-bereavement. The HPCJ is a specified nonprofit organization that aims to contribute to the quality of specialized palliative care, education, and dissemination of palliative care, with 85% of PCUs participating. The advantages of a web-based post-bereavement survey are as follows: 1) the system can be developed with 1/6 of the budget of the J-HOPE mail survey, which has a budget of approximately 16 million yen per survey, and the annual maintenance cost is meager; 2) facilities using the system can continue to conduct surveys and receive immediate feedback from the bereaved families; and 3) the number of facilities can be increased at a low cost. However, low response rates and response bias are expected for web-based post-bereavement surveys depending on the number of questions (Galesic and Bosnjak 2009).

The primary aim of the study was to develop a web-based post-bereavement survey system and to compare response rates for different number of items. We hypothesized that a smaller number of items would increase the response rate. The secondary aim was to examine response bias between web-based and mail surveys in post-bereavement survey.

## Methods

### *Web-survey system development*

A web-survey system was developed for this project. This system was created in collaboration with Hokuto Corporation, which has experience in web-based surveys. This system consists of three parts: 1) the HPCJ administrator, 2) the institutional administrator, and 3) the respondent. In the HPCJ administrator part, the following are possible: registration of the institution, creation of an ID and password for institutions to log into the system, uploading questionnaires, confirming data collected from all the participating institutions, and data download. The following are possible in the institution administrator part: registration of deceased patients, including patient demographic data, and printing out invitation letters for bereaved families, includ-

ing URL/QR code of the log on the page. In the respondent section, the participants logged in and answered questions online.

### *Participants and procedures*

Two cross-sectional web-based surveys were conducted using convenient samples from six PCUs with experience in the J-HOPE study. The first survey was a long survey with 34 questions, conducted between January and February 2019. The second survey, a short survey with 16 items, was conducted between March and April 2019. The 16 items in the short survey were carefully selected from the 34 items in the long survey that were considered more important based on the discussion among the researchers. Both potential participants were bereaved family members of 100 consecutive patients who died between July 1, 2017, and June 30, 2018, meeting the following inclusion criteria: 1) the patient died from cancer, and 2) the bereaved were at least 20 years of age. The exclusion criteria were as follows: 1) the bereaved had psychological distress at the level that kept them from participating in the study, as determined by the primary physician, and 2) the bereaved were incapable of completing the questionnaires due to cognitive dysfunction or inability to read the Japanese language.

We asked each participating institution to divide the participants into two halves by the period of death allocated to the two surveys. The participating institutions sent invitation letters to primary caregivers by mail to the bereaved family members and asked them to respond to the questions.

This study was approved by the institutional review board in the Tokyo Women's Medical University (approval No. 4863) and by the institutional review boards in each institution.

The sample size was based on the assumption that the response rate was lower than that in the J-HOPE mail survey: 15% for long and 25% for short surveys. This assumption resulted in a sample size of 270 respondents for each survey with 80% power. Each PCU included approximately 50 respondents, for a total of approximately 300 respondents per survey.

### *Measurements*

Care Evaluation Scale version 2.0, short version (CES2.0, short version): The short version of the Care Evaluation Scale, version 2.0, is used to measure EOL care from the perspective of bereaved family members, especially focusing on the structure and process of care (Morita et al. 2004). The scale consists of 10 items scored on a 6-point Likert scale ("1 = highly disagree" to "6 = highly agree"). There is "7: N/A" if none of the other scores is applicable. In this study, we used a short version consisting of all ten items from each subscale for the long survey, and we selected five items from the short version for the short survey.

Overall care satisfaction: We asked about their overall satisfaction with care using the following question: ‘Overall, in the past month, were you satisfied with the medical care the patient received in the last place of care?’ Participants were asked to respond on a 6-point Likert scale (“1 = highly dissatisfied” to “6 = highly satisfied”) (Morita et al. 2004).

Good Death Inventory, short version (GDI, short version): The short version of the GDI evaluates EOL care from the perspective of bereaved family members (Miyashita et al. 2008a). The short version consists of 10 cores and eight optional items. Each item was answered in six stages: “1: absolutely disagree” to “6: absolutely agree.” In this study, 10 items of the shortened version were used for the long survey, and four of the ten items of the shortened version were used for the short survey.

Patient Health Questionnaire-2 (PHQ-2): The PHQ-2 is a two-item version of the nine-item Patient Health Questionnaire depression module (PHQ-9) (Kroenke et al 2003). The scale inquires about the frequency of depressed mood and anhedonia over the past two weeks, scoring each as “0: not at all” to “3: nearly every day” (Muramatsu et al 2018).

Brief Grief Questionnaire (BGQ): The BGQ was used to measure each participant’s grief (Shear et al 2006). It comprises five items rated on a three-point Likert scale (Ito et al. 2012). In this study, we administered two items to the long survey and one to the short survey.

Free comments for received care in the PCU: We asked the participants to write free comments on the care received in the PCU.

Feasibility of the web-survey: To investigate the usability of the system, we originally developed two items based on discussions among researchers, which were both

rated on 6-point Likert scales: “how was the ease of use of this web-survey system?” and “did you find something good by answering this web-survey?” For the latter item, if the answer was “very good,” “good,” or “somewhat good,” we asked for the reasons.

Participants and bereaved family member characteristics: Information on the patients’ age, sex, primary cancer site, admission date in the PCU, and date of death was collected from both surveys by inputting the information into the system by each institution. Data on family age, sex, relationship with the deceased, physical and mental health status during the caregiving period, and frequency of patient attendance were collected through a web-survey.

*Analysis*

We calculated the descriptive statistics for all items. To examine if there was a difference between the long and short surveys, we compared the participants’ and respondents’ characteristics, CES, GDI, PHQ-2, BGQ, and feasibility of the web-survey using the chi-square test, Student’s t-test, Wilcoxon rank-sum test, or Fisher’s exact test, where appropriate. The results of J-HOPE3 mail survey are shown with the result of the long and short surveys in the table to examine bias. The J-HOPE3 mail survey consisted of a core part of 58 items and an additional part with different question content and number of items for each subject. We also conducted a theme and content analysis of these comments. We set the significance level to  $p = 0.05$  using a two-tailed test. All statistical analyses were conducted using IBM SPSS Statistics 21 or R for Windows version 4.1.2.

Table 1. Response rate.

	The long survey		The short survey		p
	N	%	N	%	
The number of bereaved families who were sent a survey invitation	268		274		
The number of bereaved families logged in the system	93	35%	101	37%	
The number of effective responses	64	24%	74	27%	0.376

Table 2. Comparison of characteristics in respondents and non-responders/refusals.

	The long survey				p	The short survey				p
	Respondents (N = 64)		Non-respondents (N = 204)			Respondents (N = 74)		Non-respondents (N = 200)		
	N/Mean	%/SD	N/Mean	%/SD		N/Mean	%/SD	N/Mean	%/SD	
Patient’s sex (female)	34	53%	74	36%	0.017	37	50%	89	45%	0.417
Patient’s age	74.5	11.5	72.6	11.7	0.252	72.6	11.7	70.8	11.7	0.252
Length of hospitalization in the PCU	26.9	31.6	22.2	27.6	0.252	33.9	39.8	19.8	21.4	0.005

SD, standard deviation; PCU, palliative care unit.

Table 3. Participants' characteristics.

		The long survey (N = 64)		The short survey (N = 74)		p	The data of PCUs in J-HOPE3 mail study (N = 6,989)	
		N	%	N	%		N	%
<b>Patient</b>								
Sex	Male	30	47%	37	50%	0.71 <sup>a</sup>	3,880	56%
	Female	34	53%	37	50%		3,109	44%
Age, y, mean ± SD, median (range)		74.5 ± 11.5	76 (28-90)	70.2 ± 13.2	71 (33-92)	0.04 <sup>b</sup>	73.9 ± 11.5	
The length of hospitalization, day, mean ± SD, median (range)		27.8 ± 31.5	22 (1-186)	33.9 ± 39.8	19 (1-208)	0.78 <sup>c</sup>	39 ± 50.4	
Cancer site	Lung	15	23%	17	23%	0.17 <sup>d</sup>	1,677	24%
	Stomach/Esophagus	6	9%	10	14%		994	14%
	Colon/Rectum	10	16%	9	12%		841	12%
	Liver/Gall bladder/Bile duct	2	3%	4	5%		218	21%
	Pancreas	5	8%	12	16%			
	Breast	2	3%	3	4%		317	4%
	Urinary	4	6%	6	8%		501	7%
	Head & neck	4	6%	6	8%		287	4%
	Uterus/Ovary	4	6%	3	4%		326	5%
	Lymphoma/Myeloma	3	5%	1	1%		164	2%
Others	9	14%	3	4%	570	8%		
<b>Bereaved family</b>								
Sex	Male	27	42%	26	37%	0.55 <sup>a</sup>	2,401	34%
	Female	37	58%	44	63%		4,635	66%
Age, y, mean±SD, median(range)		56.9 ± 10.4	57 (34-80)	59.4 ± 12.9	60(20-82)	0.22 <sup>b</sup>	61.5 ± 12.2	
Relationship to decedent	Spouse	20	31%	31	42%	0.10 <sup>c</sup>	3,113	44%
	Child	38	59%	29	39%		2,671	38%
	Child-in-low	2	3%	0	0%		431	6%
	Parent	1	2%	3	4%		148	2%
	Sibling	1	2%	5	7%		476	7%
	Others	2	3%	2	3%		234	3%
Physical health status during the caregiving period	Good	12	19%	-	-		1,501	21%
	Moderate	37	58%	-	-		3,853	55%
	Fair	13	20%	-	-		1,391	20%
	Bad	2	3%	-	-		324	5%
Mental health status during the caregiving period	Good	7	11%	-	-		715	10%
	Moderate	24	38%	-	-		3,255	46%
	Fair	26	41%	-	-		2,476	35%
	Bad	7	11%	-	-		595	8%
Frequency of attending to the patient	Every day	39	61%	-	-		4,599	65%
	4 ~ 6days/week	10	16%	-	-		1,074	15%
	1 ~ 3days/week	11	17%	-	-		1,075	15%
	Less than 1day/week	4	6%	-	-		322	5%

Some totals are not 100% due to missing values.

The results of J-HOPE3 are shown so that the difference between the results of this web survey and the mail survey can be seen.

<sup>a</sup>Chi-square test, <sup>b</sup>Student's t-t test, <sup>c</sup>Wilcoxon rank-sum test, <sup>d</sup>Fisher's exact test.

SD, standard deviation; PCU, palliative care unit; J-HOPE3, Japan Hospice and Palliative Care Evaluation Study 3.

Table 4. The distributions of outcomes.

		The long survey (N = 64)		The short survey (N = 74)		p	The data of PCUs in J-HOPE3 mail study (N = 6,989)	
		Mean	SD	Mean	SD		Mean	SD
CES	Physicians endeavored to relieve physical discomfort of the patient	5.1	1.0	5.3	0.7	0.433	5.2	0.8
	Nurses have adequate knowledge and skills to alleviate physical symptoms of the patient	5.1	1.1	5.0	1.0	0.515	5.3	0.7
	Physicians have adequate knowledge and skills to alleviate physical symptoms of the patient	5.1	1.0	-	-		5.2	0.8
	Physicians, nurses and staff endeavored so that the patient's hope would be accomplished	5.1	1.1	-	-		4.9	1.0
	Physician gave sufficient explanation to the family about condition and the medical treatment	4.7	1.2	-	-		5.0	1.0
	Hospital or room was convenient and comfortable	5.2	1.1	5.3	0.8	0.823	5.1	0.9
	Consideration was given to the health of family	4.9	1.1	4.8	1.0	0.839	4.7	1.1
	The total cost is reasonable	4.8	1.0	4.8	1.3	0.767	4.9	0.9
	Admission (use) is possible when necessary without waiting	4.9	1.3	-	-		4.9	1.2
	There is good cooperation among staff members such as physicians and nurses	5.0	1.0	-	-		5.0	1.0
Overall satisfaction	Overall satisfaction for received care during the hospitalization	5.1	1.0	5.0	1.0	0.700	5.0	1.0
GDI	Being free from pain	5.1	1.8	5.4	1.4	0.288	5.3	1.4
	Being free from physical distress	5.0	1.8	-	-		5.2	1.4
	Spending time with peace	5.2	1.7	-	-		5.2	1.4
	Being able to stay at one's favorite place	4.9	1.7	-	-		4.8	1.6
	Having some pleasure in daily life	4.3	1.8	4.4	1.8	0.686	4.2	1.6
	Trusting physician	5.7	1.4	-	-		5.5	1.3
	Making trouble for others	4.2	1.8	-	-		4.5	1.6
	Spending enough time with one's family	5.1	1.5	5.2	1.6	0.653	4.9	1.4
	Being dependent in daily activities	3.0	1.9	-	-		3.0	1.9
	Living in calm circumstances	5.6	1.4	-	-		5.4	1.2
	Being valued as a person	6.2	1.1	6.1	1.2	0.596	6.0	1.0
Feeling that life is complete	4.3	2.0	-	-		4.6	1.8	
PHQ-9	Little interest or pleasure in doing things	0.7	0.9	-	-		0.7	0.9
	Feeling down, depressed, or hopeless	0.8	0.9	1.0	1.0	0.596	0.7	0.8
BGQ	Having trouble accepting the death	1.1	0.6	-	-		1.4	0.7
	Thoughts that bother you	1.2	0.6	1.3	0.7	0.445	1.0	0.6

The results of J-HOPE3 are shown so that the difference between the results of this web survey and the mail survey can be seen.

CES, Care Evaluation Scale ver.2. The scores range from 0 to 6, with a higher score representing a higher level of agreement.

Overall satisfaction ranges from 0 to 6, with a higher score representing a higher level of satisfaction.

GDI, Good Death Inventory. The scores range from 0 to 7, with a higher score representing a higher level of agreement.

PHQ-9, the Patient Health Questionnaire-9. The score ranges from 0 to 4, with a higher score representing a higher level of trouble.

BGQ, the Brief Grief Questionnaire. The score ranges from 0 to 3, with a higher score representing a higher level of grief.

SD, standard deviation; PCU, palliative care unit; J-HOPE3, Japan Hospice and Palliative Care Evaluation Study 3.

## Results

### *Response rates of the long and the short surveys*

For the long survey, 268 invitation letters were mailed, and 64 participants responded to the web-survey (24%). For the short survey, 274 invitation letters were mailed, and

74 participants responded to the web-survey (27%). There were no significant differences in the response rates between the long and short surveys ( $p = 0.376$ ) (Table 1).

Comparison of respondents' and non-respondents/refusals' characteristics revealed that the response rate was not significant except more female in the long survey ( $p =$

Table 5. Recognitions of using the web-survey.

	The long survey (N = 64)		The short survey (N = 74)		P
How was the ease of use of this web-survey system?					
Very easy to use	4	6%	9	2%	0.50
Easy to use	32	50%	27	5%	
Somewhat easy to use	5	8%	5	1%	
Somewhat difficult to use	15	23%	9	2%	
Difficult to use	5	8%	3	1%	
Very difficult to use	3	5%	1	0%	
Did you find something good for you by answering this web-survey?					
Very good	2	3%	3	2%	0.27
Good	19	30%	24	16%	
A little good	27	42%	19	13%	
Not very good	12	19%	4	3%	
Not good	3	5%	1	1%	
Not good at all	1	2%	1	1%	
The reasons of “very good”, “good” and “a little good” (multiple answer) choices					
It would be good if it would be useful for the future development of medical care by communicating the opinions of my family	48	75%	45	61%	
It was an opportunity to express gratitude to the hospital and staff	45	70%	40	54%	
It was an opportunity to convey requests to hospitals and staff	34	53%	43	58%	
It was an opportunity to look back at that time	34	53%	36	49%	
It was an opportunity to tell the hospital what was difficult to say directly	19	30%	23	31%	
It was an opportunity to organize my feelings	17	27%	14	19%	

Fisher’s exact test was used for all tests.

0.017) and longer hospital stays in the short survey ( $p = 0.005$ ) (Table 2).

#### Participants characteristics

No differences in patient characteristics were observed between the long and short surveys, except for patient age (74.5 vs. 70.2 years,  $p = 0.04$ ) (Table 3). In this survey, more children answered than in the J-HOPE3 mail survey (long survey, 59%; short survey, 39%; and J-HOPE3, 38%).

#### Outcomes of the long and short survey

There were no significant differences between the long and short surveys in CES, overall care satisfaction, GDI, PHQ-9, and BGQ scores (Table 4). Comparing the web long survey and J-HOPE3 mail survey, ranges of mean CES scores (SD) were 4.7-5.2 (1.0-1.3) and 4.7-5.3 (0.7-1.2), respectively. Mean Overall care satisfaction scores were 5.1 (1.0) and 5.0 (1.0), respectively. Ranges of mean GDI scores were 3.0-6.2 (1.1-2.0) and 3.0-6.0 (1.0-1.9), respectively. Mean PHQ-9 scores were 0.7-0.8 (0.9) and 0.7 (0.8-0.9), respectively. Mean BGQ scores were 1.1-1.2 (0.6) and 1.0-1.4 (0.6-0.7), respectively (Table 4).

#### Feasibility of using the web-survey

Regarding the ease of using this web-based survey system, most respondents answered from “very easy to use”

to “somewhat easy to use” (64% vs. 76%,  $p = 0.50$ ). For the question of benefits answering this web-survey, most respondents answered from “very good” to “a little good” (75% vs. 89%,  $p = 0.27$ ) (Table 5).

#### Number and contents of comments

Of the 46 comments, 67% and 70% were thankful words, and 45% and 22% were opinions/complaints in the long and short surveys, respectively. The median number (range) of written words was 103 (7-723) words and 92 (9-616) words, respectively.

## Discussion

A significant finding of this pilot study is the identification of response rates for the web-based bereavement survey. The response rate for both surveys was approximately 30%. They were higher than expected but lower than the J-HOPE’s response rate of about 70% for the self-administered questionnaire mail survey (Miyashita et al. 2008b, 2015; Aoyama et al. 2017). A possible reason is that the potential survey participants were older and less familiar with the web-survey. The response rate for this survey was lower than that of Zhao’s survey (43.6%) (Zhao et al. 2021). As Zhao’s survey was administered only to those who responded to the preliminary survey, we did not know what the response rate would have been if the preliminary survey



had not been conducted.

Differences in the number of items did not affect the response rate or the respondents' background. This rejects our hypothesis that a smaller number of items would increase the response rate. This might be because numbers 34 and 16 were not significantly different from the response, especially in the online survey. If the response rate did not change, it would be reasonable to use a longer survey to obtain more information.

In both surveys, more than 60% of respondents offered a positive evaluation of the usability of the web-based survey system. In the free description, 70% of the responses were words of gratitude to the facility. It would be encouraging for the staff to receive direct gratitude from the bereaved family in a setting where the patient will eventually die. These results show that the web-based survey system was satisfactory. If the response rate did not change, it would be reasonable to use a longer survey to obtain more information.

In this survey, more children answered than in the J-HOPE3 mail survey (long survey, 59%; short survey, 39%; and J-HOPE3, 38%). The child might have input the data because the parent (husband/wife of the deceased) cannot use the Internet and ask the child to input data with the parent. The distributions of the CES, GDI, PHQ, and BGQ items were similar between the web-based surveys and the J-HOPE3. In a comparison between respondents and non-respondents, the shorter the length of hospital stay, the lower the response rate. This was similar to the J-HOPE mail survey (Miyashita 2016). These results indicate no specific biases in the responses because this was a web-based survey.

This study had some limitations. First, the number of participating facilities and participants was small and may have been biased. Second, in the interviews with each participating facility, after the survey was completed, opinions on system improvement were provided, although all were minor points. In addition to improving them, the challenge is to improve and evaluate the system so that it will be more accessible and more beneficial for the facilities, such as setting evaluation items for each facility and setting the aggregation period.

In conclusion, we developed a web-based post-bereavement survey system for EOL care evaluation and examined its feasibility in a pilot study. Although the response rate of this survey was low, no apparent response bias was observed, indicating its feasibility. This survey method is low cost, less burdensome to the institution, and allows for ongoing quality assurance. In the future, improving the system, expanding the number of targets and settings, and evaluating the system by the facility will be an issue.

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### Author Contributions

T.S. substantially contributed to the study conceptualization and drafted the original manuscript. K.S. significantly contributed to the interpretation of the results. A.H., A.S., S.O., Y.S., Y.S. and T.H. substantially contributed to the data collection and interpretation. Y.S. supervised the conduct of this study. M.M. supervised the conduct of this study and secured funding. All authors critically reviewed and revised the manuscript draft and approved the final version for submission.

### Conflicts of Interest

The authors declare no conflict of interest.

### References

- Addington-Hall, J. & McCarthy, M. (1995) Regional Study of Care for the Dying: methods and sample characteristics. *Palliat. Med.*, **9**, 27-35.
- Aoyama, M., Morita, T., Kizawa, Y., Tsuneto, S., Shima, Y. & Miyashita, M. (2017) The Japan Hospice and Palliative Care Evaluation Study 3: study design, characteristics of participants and participating institutions, and response rates. *Am. J. Hosp. Palliat. Care*, **34**, 654-664.
- Galesic, M. & Bosnjak, M. (2009) Effects of questionnaire length on participation and indicators of response quality in a web survey. *Public Opin. Q.*, **73**, 349-360.
- Hunt, K.J., Richardson, A., Darlington, A.E. & Addington-Hall, J.M. (2019) Developing the methods and questionnaire (VOICES-SF) for a national retrospective mortality follow-back survey of palliative and end-of-life care in England. *BMJ Support. Palliat. Care*, **9**, e5.
- Ito, M., Nakajima, S., Fujisawa, D., Miyashita, M., Kim, Y., Shear, M.K., Ghesquiere, A. & Wall, M.M. (2012) Brief measure for screening complicated grief: reliability and discriminant validity. *PLoS One*, **7**, e31209.
- Kroenke, K., Spitzer, R.L. & Williams, J.B. (2003) The Patient Health Questionnaire-2: validity of a two-item depression screener. *Med. Care*, **41**, 1284-1292.
- Lawson, B., Van Aarsen, K. & Burge, F. (2013) Challenges and strategies in the administration of a population based mortality follow-back survey design. *BMC Palliat. Care*, **12**, 28.
- Lynn, J., Teno, J.M., Phillips, R.S., Wu, A.W., Desbiens, N., Harrold, J., Claessens, M.T., Wenger, N., Kreling, B. & Connors, A.F. Jr. (1997) Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatments. *Ann. Intern. Med.*, **126**, 97-106.
- Miyashita, M. (2016) Research on methodology of research on bereaved families. In *The Japan Hospice and Palliative Care Evaluation Study 3 (J-HOPE3)*, edited by Miyashita, M., Tsuneto, S. & Shima, Y., Japan Hospice/Palliative Care Foundation Committee of The Japan Hospice and Palliative Care Evaluation Study, Osaka, pp. 70-79.
- Miyashita, M., Morita, T., Sato, K., Hirai, K., Shima, Y., Uchitomi, Y. (2008a) Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J. Pain Symptom Manag.*, **35**, 486-498.
- Miyashita, M., Morita, T., Sato, K., Tsuneto, S. & Shima, Y. (2015) A nationwide survey of quality of end-of-life cancer care in designated cancer centers, inpatient palliative care units, and

- home hospices in Japan: the J-HOPE study. *J. Pain Symptom Manage.*, **50**, 38-47 e33.
- Miyashita, M., Morita, T., Tsuneto, S., Sato, K. & Shima, Y. (2008b) The Japan HOspice and Palliative Care Evaluation study (J-HOPE study): study design and characteristics of participating institutions. *Am. J. Hosp. Palliat. Care*, **25**, 223-232.
- Morita, T., Hirai, K., Sakaguchi, Y., Maeyama, E., Tsuneto, S. & Shima, Y.; Quality Assurance Committee; Japanese Association of Hospice Palliative Care Unit (2004) Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J. Pain Symptom Manage.*, **27**, 492-501.
- Muramatsu, K., Miyaoka, H., Kamijima, K., Muramatsu, Y., Tanaka, Y., Hosaka, M., Miwa, Y., Fuse, K., Yoshimine, F., Mashima, I., Shimizu, N., Ito, H. & Shimizu, E. (2018) Performance of the Japanese version of the Patient Health Questionnaire-9 (J-PHQ-9) for depression in primary care. *Gen. Hosp. Psychiatry*, **52**, 64-69.
- Nakazawa, Y., Takeuchi, E., Miyashita, M., Sato, K., Ogawa, A., Kinoshita, H., Kizawa, Y., Morita, T. & Kato, M. (2021) A population-based mortality follow-back survey evaluating good death for cancer and noncancer patients: a randomized feasibility study. *J. Pain Symptom Manage.*, **61**, 42-53 e42.
- Shear, K.M., Jackson, C.T., Essock, S.M., Donahue, S.A. & Felton, C.J. (2006) Screening for complicated grief among Project Liberty service recipients 18 months after September 11, 2001. *Psychiatr. Serv.*, **57**, 1291-1297.
- Teno, J.M., Clarridge, B.R., Casey, V., Welch, L.C., Wetle, T., Shield, R. & Mor, V. (2004) Family perspectives on end-of-life care at the last place of care. *JAMA*, **291**, 88-93.
- World Health Organization (2021) Quality health services and palliative care: practical approaches and resources to support policy, strategy and practice. <https://www.who.int/publications/i/item/9789240035164> [Accessed: June 25, 2023].
- Zhao, J., You, L., Tao, H. & Wong, F.K.Y. (2021) Validation of the Chinese version of the Care Evaluation Scale for measuring the quality of structure and process of end-of-life care from the perspective of bereaved family. *BMC Palliat. Care*, **20**, 85.
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