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Which Research Questions Are Important for the Bereaved Families of Palliative Care Cancer Patients? A Nationwide Survey

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Title: Which research questions are important for the bereaved families of palliative care cancer patients? A nationwide survey

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This paper is 2,674 words long and has 1 table and 19 references.

Abstract

Context: Bereaved family members are present from diagnosis to the end of life and can look

back and evaluate the experience; additionally, the family itself is also an important subject in

the care of the patient. Therefore, while it is essential to determine the priority research issues

from the viewpoint of the patients and health care workers, it is also crucial to know the

important research themes from the viewpoint of the bereaved family members.

Objectives: The purpose of this study was to identify research priorities for palliative care in

Japan, based on the viewpoint of bereaved family members.

Methods/Design: We conducted a cross-sectional, self-report questionnaire survey. Content

analysis was performed on free-text answers for research priorities. This study was carried out

as part of the third Japan HOspice and Palliative Care Evaluation (J-HOPE3) study.

Results: We extracted 1,658 codes from the transcripts and organized them into 120

subcategories on the basis of similarity. Subcategories were then organized into 8 categories

as follows: <improvement in the structure of palliative care services>, <pain relief>,

<communication>, <symptom management, other than pain>, <better care and assistance</p>

methods>, <publicizing and raising awareness of palliative care>, <cancer medical services>,

and <knowledge, skill and attitude of medical staff>.

Conclusion: The findings of this study can be used as a research agenda for palliative care,

which should take first priority in the future, and could be carried out using limited resources.

Keywords: palliative care; bereavement; evaluation; J-HOPE study; Japan

Running Title: Which theme is important for bereaved family?

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Introduction

Despite advances in cancer survival rates, palliative care remains an essential aspect of cancer care. Likewise, research in palliative care should be an important part of cancer research in Japan. To date, however, the study area for palliative care remains broad, and the available resources are limited. Therefore, it is necessary to set the research theme as the most important for the cancer patients [1,2]. Several studies to determine a priority research agenda have been conducted globally [3-13]. A wide variety of issues such as communication, delivery of care, and system management have been identified as research priorities for health care workers and cancer patients. Investigations focusing on patients are effective for revealing high priorities for palliative care research. However, in research directed at patients, the opinions of a variety of patients may be difficult to obtain as the viewpoint of survivors may be over-represented.

In contrast, the bereaved family members are present from diagnosis to the end of life and can look back and evaluate the experience; additionally, the family itself is also an important subject in the care of the patient [14-16]. Therefore, just as it is essential to determine the priority research issues from the viewpoint of the patients and health care workers, it is also crucial to know the important research themes from the viewpoint of the bereaved family members. The purpose of this study was to identify research priorities for palliative care in Japan, from the viewpoint of the bereaved family members.

Methods

Study Design

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 [17]. The detailed methodology of this survey is described elsewhere [17].

Participating Institutions

We sent letters to 396 institutions which were member of Hospice Palliative Care Japan and included 49 acute hospitals, 296 inpatient palliative care units (PCUs), and 51 home hospice services, prior to July 1, 2013. Of those approached, 175 institutions, including 20 acute hospitals, 133 PCUs, and 22 home hospice services participated in the study. We asked participating institutions to describe the treatment available, bereavement care offered for family members, and the structure of the patient care provided.

Participants

We conducted a questionnaire survey between May and July 2014. To identify potential patients, we asked each institution to identify and list up to 80 bereaved family members of patients who had died prior to October 2012. The inclusion criteria were as follows: (1) the patient died of cancer, (2) the patient was an adult, and (3) the bereaved family member was an adult. The exclusion criteria were as follows: (1) the patient received palliative care for less than 3 days; (2) the bereaved family member could not be identified; (3) treatment-associated death or death occurred in an intensive care unit; (4) the potential participant would have had serious psychological distress, as determined by the primary physician and a nurse; and (5) the potential participant was incapable of completing the self-report questionnaire because of cognitive impairment or visual disability. The questionnaire was sent to the bereaved family

members from each participating institution along with a letter explaining the survey. The return of a completed questionnaire was considered consent to participate in the study. Participants were asked to return the completed questionnaire to the secretariat office (Tohoku University) within 2 weeks. We sent a reminder to nonresponders 1 month subsequent to sending the questionnaire. If they did not wish to participate in the study, they were asked to check a "no participation" box and return the incomplete questionnaire. Ethical approval for the study was granted by the institutional review boards of Tohoku University and all participating institutions.

Data Analysis

We conducted content analysis objectively and quantitatively to analyze free-text comments.

Transcripts of the free-text comments were created from the question "What kind of studies or investigations are more needed in the field of palliative care?". Data were analyzed using IBM SPSS Text Analytics for Surveys 4. Next, the content was analyzed on the basis of the method outlined by Krippendorff [18]. First, transcripts were divided into units of semantic content, and all expressions and content related to research priorities were extracted. Next, units with similar expressions and semantic content were classified into groups, summarized so that the semantic content was not lost, and codified. Codes were grouped according to similarity and subcategories were created. Subcategories were then classified and categories were created. Content analysis was conducted independently by 2 researchers (AS and MK). YK supervised confirmation of whether subcategories and categories were appropriate. Hereafter, codes are signified by "", subcategories by [], and categories by <>.

Results

We sent a questionnaire to 13,584 bereaved families, and 10,157 bereaved families returned them. A total of 9,123 participants answered the questionnaire (response rate, 67.2%). Data analysis included 2,838 participants who replied to the question "What kind of studies or investigations are more needed in the field of palliative care?". We extracted 1,658 codes from the transcripts and organized them into 120 subcategories on the basis of similarity. Subcategories were then organized into 8 categories as follows: <improvement in the structure of palliative care services>, <pain relief>, <communication>, <symptom management, other than pain>, <better care and assistance methods>, <publicizing and raising awareness of palliative care>, <cancer medical services>, and <knowledge, skill and attitude of medical staff> (Table 1).

1. < Improvement in the structure of palliative care services>

This category included 27 subcategories and 466 codes. Participants indicated that improvements to the structure of palliative care services of institutions and medical staff were important. These opinions suggested the subcategories of [What are the best ways of increasing inpatient PCUs?], and [What are the best ways of increasing the number of medical staff?]. Participants demanded the system should allow consultation with a healthcare worker regardless of the place of medical treatment, such as [How can access to the consultation system be improved for medical staff?] and [How can access to palliative care services be improved, even if patients are at home, in cases of emergency?]. Furthermore, participants indicated the need for access to palliative care services, suggesting the subcategories of [What are the best ways of a smooth referral to inpatient PCUs?] and [What are the best ways of a smooth admission to inpatient PCUs?]. [What are the best ways of providing information regarding palliative care services?] included the codes "build a system to provide information

about PCUs" and "build a system to provide information about home palliative care services".

2. <Pain relief>

This category included 8 subcategories and 342 codes. Participants requested research priorities suggesting subcategories of pain relief such as [What are the best ways of reducing sleepiness in pain relief?], [What are the best ways of treatment for pain relief?] and [What are the best ways of avoiding delirium in pain relief?]. Participant responses suggested the subcategories of developing medications, such as [What are the best ways of developing a new medication without side effects?] and [What are the best ways of developing a new analgesic?]. The subcategories of [What are the best ways of developing a new pain measurement?], [What are the best ways of treating the side effects of morphine?] and [What are the best ways of relieving neuropathic pain?] were also indicated by the participants.

3. <Communication>

This category included 10 subcategories and 288 codes. [What are the best ways of communicating between patients, families and medical staff?] included the code "communication among patients, families and physicians". Additionally, explanations from physicians were included in the subcategories of [What are the best ways of explaining imminent death to families?], [What are the best ways of explaining patients' prognoses?] and [What are the best ways of explaining the terminal stage?]. Participants showed a demand for communication with patients and their families, such as [What are the best ways of improving communication between patients and families?] and [What are the best ways of communicating with patients until death?].

4. <Symptom management, other than pain>

This category included 22 subcategories and 210 codes. Participants indicated they wanted an improvement in symptom management. These opinions suggested the subcategories of [What are the best ways of relieving fatigue?], [What are the best ways of relieving dyspnea?] and [What are the best ways of relieving constipation?]. Furthermore, participants showed a demand for palliation of psychiatric symptoms. These opinions included the subcategories of [What are the best ways of providing psychological care?], [What are the best ways of relieving insomnia?] and [What are the best ways of treating delirium?]. Other opinions included the subcategories of [What are the best ways of relieving itchiness?], [What are the best ways of relieving edema?] and [What are the best ways of relieving a dry mouth?].

5. <Better care and assistance methods>

This category included 18 subcategories and 186 codes. [What are the best ways of improving diets and assistance to eat?] included the codes "way to devise a diet" and "a diet which is more appetizing". [What are the best ways of caring for and supporting families?] included the codes "psychological care for families" and "grief counselling for families". Because of the severe pain of the patients, participants had some opinions, such as [What are the best ways of suctioning respiratory secretions?]. Other opinions suggested the subcategories of [What are the best ways of caring for elderly patients and those with dementia?] and [What are the best ways of providing palliative care for young adults?]. Some opinions associated with assistance included the subcategories of [How can we develop nursing care products?], [What are the best ways of positioning patients with less effort?] and [What are the best ways of transferring patients with less effort?].

6. < Publicizing and raising awareness of palliative care>

This category included 13 subcategories and 115 codes. Participants indicated [What are the best ways of publicizing and raising awareness of palliative care?] and [What are the best ways of publicizing and raising awareness of home palliative care?] were important. In addition, participants indicated a need for publicizing PCUs, which included the subcategories of [What are the best ways of publicizing and raising awareness of inpatient PCUs?] and [What are the best ways of raising awareness about admission criteria for inpatient PCUs?]. Participants demanded raising awareness not only for PCUs, but also personnel training, such as [What are the best ways of educating volunteers?] and [What are the best ways of educating palliative care physicians?].

7. <Cancer medical services>

This category included 17 subcategories and 35 codes. Participants demanded the development of anticancer drugs. These opinions suggested the subcategories of [What are the best ways to manage the adverse effects of anticancer drugs?] and [What are the best ways of developing anticancer drugs?]. Furthermore, participants indicated the importance of [What are the best ways of early detection of cancer?], [What are the best ways of preventing cancer?] and [What is the cause of cancer?]. Participants had opinions about [What are the best ways of controlling infections?] and [What are the best ways of providing complementary and alternative medicines?].

8. <Knowledge, skill and attitude of medical staff>

This category included 5 subcategories and 16 codes. [How should we educate medical staff about imminent death?] consisted of "physicians' attitude to imminent death" and "the nurses' attitude to imminent death". Participants pointed out the importance of [How should we

educate physicians about attitudes and morality?], [How should we improve the professionalism of medical staff?] and [How should we educate medical staff about the value of humor?].

Discussion

The present study is the first report to clarify research priorities for the bereaved family members of cancer patients. The findings of this study can be used as a research agenda in palliative care which should be carried out as the first priority in future. Research items prioritized by bereaved family members are similar to those prioritized by health care workers and cancer patients [3-13]. These items are a wide variety of issues such as communication, process and delivery of palliative services, as well as symptom management.

The most important finding was that bereaved family members had opinions most commonly about the system in general, such as an increase in the number of medical staff and PCUs. As background for this opinion, participants found it was necessary to wait before referral to the PCU and to wait for hospitalization to the PCU. Therefore, an important research issue for us is to improve the access to palliative care services, as many believe that the interaction between PCUs and the system of general practitioners is not adequate in Japan [19].

The second important finding concerned the research of pain relief. In particular, research into ways to avoid sleepiness and delirium in cancer pain management is required. It is thought that the use of opioids inhibits communication between the patients and their families. In addition, research into the management of symptoms other than pain, such as relief of fatigue and psychological care, was demanded by bereaved family members. An improvement in communication was also important. As well as explaining the patients' condition and prognosis to the family members, it is also necessary to investigate how best to explain imminent death and the course of the disease to the family.

The present study has a number of limitations. First, this study targeted only the bereaved family members. It is unknown whether these findings are the first priority for the patients themselves. Second, we surveyed only the free-text comments and did not have an interview

with the bereaved family members. Therefore, the results may be biased and the interpretation of our findings should be carried out in conjunction with other studies. Third, the study is a questionnaire survey sent only to the bereaved family members of cancer patients who were referred to specialist palliative care services. We cannot exclude the potential for selection bias, because a previous study reported that only one-fourth of cancer patients in Japan use such services [19]. Fourth, as our study included only participants from the Japanese population, our results may not be generalizable to populations outside of Japan. Furthermore, our study excluded the bereaved family members of patients without cancer and those in intensive care units. We are uncertain whether our results can be generalized to these populations or settings.

Conclusion

The present study clarified research priorities for the bereaved family members of cancer patients. The findings of this study can be used as a research agenda in palliative care; these research areas should take first priority in the future, and could be carried out using limited resources.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

All authors contributed to the design of the protocol. YS and ST organized the study structure. MA and MM managed the project, including collecting the data of this study. TM, MM and YK managed and advised on additional studies. AS and MK performed the statistical analysis and drafted the manuscript. All authors read and approved the full manuscript.

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Table 1. List of Research Questions

Category	Subcategory	No. of codes	%
Total Number		n = 1658	100.0%
Improvement in the			
structure of palliative		466	28.1%
care services			
	What are the best ways of increasing inpatient palliative care units?	125	7.5%
	What are the best ways of increasing the number of medical staff?	59	3.69
	How can access to the consultation system be improved for medical staff?	57	3.49
	How can access to palliative care services be improved, even if patients are at home, in cases of emergency?	35	2.1
	What are the best ways of a smooth admission to inpatient palliative care units?	33	2.0
	What are the best ways of providing information regarding palliative care services?	22	1.3
	What are the best ways of a smooth referral to inpatient palliative care units?	22	1.3
	What are the best ways of improving physicians' duty systems in inpatient palliative care units?	18	1.1
	What are the best ways of building a system for home palliative care services?	16	1.0
	What are the best ways of building a system for inpatient palliative care units in case of emergency at night?	12	0.7
	How can home care be maintained as long as possible?	9	0.5
	What are the best ways of supporting patients when going back home and staying away from inpatient palliative care units?	8	0.5
	What are the best ways of improving the environment of inpatient palliative care units?	7	0.4
	What are the best ways of cooperation between care managers and hospital staff?	7	0.4
	What are the best ways of improving the system of palliative care provision for patients on anticancer treatment?	5	0.3
	What are the best ways of cooperation between the home	5	0.3

	doctor and inpatient palliative care units?		
	What are the best ways of cooperation between hospitals and	5	0.20/
	inpatient palliative care units?	5	0.3%
	What are the best ways of shortening the time taken for	4	0.2%
	admission to inpatient palliative care units?	4	0.270
	What are the best ways of preparing inpatient palliative care	4	0.2%
	units with less hospital expense?	7	0.270
	How we can set up inpatient palliative care units in general	3	0.2%
	hospitals?	3	0.270
	What are the best ways of cooperation between psychiatrists	2	0.1%
	and palliative care services?	_	0.1.7.0
	What are the best ways of coordinating transition from	2	0.1%
	inpatient palliative care units?		
	What are the best ways of gathering information regarding	2	0.1%
	palliative care resources in the area?		
	What are the best ways of organizing religious staff?	1	0.1%
	What are the best ways of cooperation between urologists and	1	0.1%
	palliative care services?		
	What are the best ways of setting up outpatient palliative care?	1	0.1%
	What are the best ways of setting up palliative care centers?	1	0.1%
Pain relief		342	20.6%
	What are the best ways of reducing sleepiness in pain relief?	195	11.8%
	What are the best ways of treatment for pain relief?	86	5.2%
	What are the best ways of avoiding delirium in pain relief?	29	1.7%
	What are the best ways of developing a new medication without side effects?	17	1.0%
	What are the best ways of developing a new pain	5	0.3%
	measurement?	3	0.5%
	What are the best ways of treating the side effects of morphine?	5	0.3%
	What are the best ways of developing a new analgesic?	4	0.2%
	What are the best ways of relieving neuropathic pain?	1	0.1%
Communication		288	17.4%
	What are the best ways of communicating between patients,	102	6.2%
	families and medical staff?	102	0.270
	What are the best ways of explaining imminent death to	35	2.1%
	families?		
	families? What are the best ways of explaining patients' prognoses?	32	1.9%

	patients and families?		
	What are the best ways of explaining the course of the disease?	25	1.5%
	What are the best ways of explaining the terminal stage?	17	1.0%
	What are the best ways of communicating with patients until death?	15	0.9%
	What are the best ways of explaining patients' medical conditions to families?	13	0.8%
	What are the best ways of explaining possible symptoms?	10	0.6%
	What are the best ways of communicating among medical staff?	7	0.4%
Symptom management,		210	12.7%
other than pain			
	What are the best ways of relieving fatigue?	40	2.4%
	What are the best ways of providing psychological care?	35	2.19
	What are the best ways of relieving dyspnea?	16	1.09
	What are the best ways of relieving constipation?	16	1.09
	What are the best ways of relieving insomnia?	13	0.89
	What are the best ways of treating delirium?	11	0.79
	What are the best ways of relieving distension caused by ascites?	11	0.79
	What are the best ways of relieving nausea?	10	0.69
	What are the best ways of relieving itchiness?	9	0.59
	What are the best ways of relieving edema?	9	0.59
	What are the best ways of relieving a dry mouth?	9	0.59
	What are the best ways of relieving sleepiness?	5	0.39
	What are the best ways of lessening respiratory secretions?	5	0.39
	What are the best ways of relieving stomatitis?	4	0.29
	What are the best ways of sedation for symptom management?	4	0.29
	What are the best ways of caring for patients with fever?	3	0.29
	What are the best ways of dealing with dysgeusia?	3	0.29
	What are the best ways of improving appetite loss?	2	0.19
	What are the best ways of relieving a cough?	2	0.19
	What are the best ways of dealing with nose bleeding?	1	0.19
	What are the best ways of relieving hiccups?	1	0.19
	What are the best ways of treating akathisia?	1	0.19
Better care and		186	11.2%
assistance methods			/
	What are the best ways of improving diets and assistance to	61	3.7%

	eat?		
	What are the best ways of caring for and supporting families?	40	2.4%
	What are the best ways of suctioning respiratory secretions?	26	1.6%
	What are the best ways of caring for excretion?	9	0.5%
	What are the best ways of caring for elderly patients and those with dementia?	7	0.4%
	How can we develop nursing care products?	7	0.4%
	What are the best ways of grief counselling for bereaved families?	6	0.4%
	What are the best ways of caring for decubitus ulcers?	5	0.3%
	What are the best ways of drinking for patients with dysphagia?	5	0.3%
	What are the best ways of caring for patients with oxygen inhalation?	4	0.2%
	What are the best ways of positioning patients with less effort?	3	0.2%
	What are the best ways of transferring patients with less effort?	2	0.1%
	What are the best ways of caring for patients with stoma?	2	0.1%
	What are the best ways of lessening aspiration?	2	0.1%
	What are the best ways of providing palliative care for young adults?	2	0.1%
	What are the best ways of preventing stroke?	2	0.1%
	What are the best ways of making personal hygiene procedures easier for patients?	2	0.1%
	What are the best ways of treating patients who do not know their diagnosis?	1	0.1%
Publicizing and raising			
awareness of		115	6.9%
palliative care			
	What are the best ways of publicizing and raising awareness of palliative care?	41	2.5%
	What are the best ways of publicizing and raising awareness of home palliative care?	19	1.1%
	What are the best ways of educating medical staff in palliative care?	13	0.8%
	What are the best ways of publicizing and raising awareness of inpatient palliative care units?	12	0.7%
	What are the best ways of raising awareness about admission	7	0.4%

1			
	What are the best ways of educating volunteers?	5	0.3%
	What are the best ways of educating palliative care physicians?	5	0.3%
	What are the best ways of educating about euthanasia and	3	0.2%
	dying with dignity?	J	U.270
	What are the best ways of educating about death?	3	0.2%
	What are the best ways of equalizing quality in inpatient	2	0.1%
	palliative care services?	2	0.170
	What are the best ways of cardiopulmonary resuscitation in	2	0.10/
	case of emergency?	2	0.1%
	What are the best ways of caring for dying patients in general	2	0.10/
	wards?	2	0.1%
	What are the best ways of caring for dying patients in nursing	1	0.10/
	homes?	1	0.1%
Cancer medical services		35	2.1%
	What are the best ways of managing the adverse effects of	0	0.50/
	anticancer drugs?	9	0.5%
	What are the best ways of early detection of cancer?	3	0.2%
	What are the best ways of developing anticancer drugs?	3	0.2%
	How can we reduce the burden of costly medication?	3	0.2%
	What are the best ways of supporting decision-making in	•	0.404
	cancer treatment?	2	0.1%
	What are the indications for rehabilitation?	2	0.1%
	What is the cause of cancer?	2	0.1%
	What are the best ways of carrying out clinical research?	2	0.1%
	What are the best ways of preventing cancer?	1	0.1%
	What are the best ways of reducing the quantity of unused		
	drugs left in the home?	1	0.1%
	What are the best ways of using medication not covered by		
	health insurance?	1	0.1%
	What are the best ways of developing medication without drug		
	eruption?	1	0.1%
	What are the best ways of evaluating medication?	1	0.1%
	What are the best ways of relieving suffering in physical		
	examinations?	1	0.1%
	What are the best ways of controlling infections?	1	0.1%
	What are the best ways of providing cell-free and concentrated		
	ascites reinfusion therapy?	1	0.1%
		1	0.1%
	What are the best ways of providing complementary and	1	0.1%

	alternative medicines?		
Knowledge, skill and		16	1.0%
attitude of medical staff		10	1.0 /0
	How should we educate medical staff about imminent death?	10	0.6%
	What are the best ways of lessening pain with indwelling venous lines?	2	0.1%
	How should we educate physicians about attitudes and morality?	2	0.1%
	How should we improve the professionalism of medical staff?	1	0.1%
	How should we educate medical staff about the value of humor?	1	0.1%