

**Table 2.** Views on Religious Care of Families Who Have a Religion

Category	Subcategory
Instrumental care in hospitals is useful ( <i>Instrumental care</i> )	Music is useful (beautiful music, hymns, patient's favorites) Tales are useful (good tales, cheerful tales) Words are useful (encouraging words, warm words) Religious events are useful Mass is useful
Patients and family want to have freedom of choice for kind of religious care ( <i>Freedom of choice of kinds for religious care</i> )	Patients and families want to receive religious care of their choice It is useful for patients to receive religious care suitable to their physical condition It is not desirable for hospitals to offer only one form of religious care Only formal visiting by a chaplain was not good for patients
It is useful for staffs to have a religious heart ( <i>Staff involvement of religious care</i> )	It is useful for staff to have a religion It is useful for staff to be considerate regarding religion It is useful for staff to include religious care in daily care
Meeting a pastoral care worker is useful ( <i>Meeting with a pastoral care worker</i> )	Meeting pastoral care workers, having a conversation with them, or listening to them is useful
Being asked to accept religious care that is different from the patient's religion is a burden ( <i>Burden of offering a different kind of personal religion</i> )	It is burdensome for the patient to be asked about their religious view It is burdensome to receive religious care that patients do not want

analysis of the need for religious care, the sentences in each reply were analyzed line by line and content considered related to the issue of religious care was extracted. This content was classified into codes, and those with a common meaning were grouped together. Categories and subcategories were then formed and integrated (Tables 2 and 3). Several meetings of investigators were held for this purpose. Strategies for increasing the reliability of the data and analysis included interviews conducted by each investigator, and concurrent data collection and analysis until the data were confirmed. Two researchers coded and categorized the data, and the investigator obtained feedback and validation regarding the methods from research experts in nursing and qualitative methodology.

## Results

Families who had a religion (N = 28) regarded instrumental care such as music, a good tale, or a religious event held by the hospital to be useful (*Instrumental care*). They required to have freedom of choice what kind of religious care (*Freedom of choice of kind for religious care*) and they thought of religion as positive, with an indication of the importance of religious staff (*Staff involvement of religious care*) and of patients meeting a pastoral care worker (*Meeting with a pastoral care worker*). However, they regarded care offered by a religion

different from their religion as a burden (*Burden offering a different kind of personal religion*).

Families without a religion (N = 44) also regarded instrumental care as useful (*instrumental care*), and they wanted freedom whether they receive religious care (*Freedom of choice whether patients receive or not*). They indicated a requirement for palliation of anxiety for death, support for establishing relationships, and the need for a feeling of existence (*Spiritual care*). Moreover, they felt that they might not be able to accept religious care because they had not thought of this approach in usual life (*Not being able to accept religious care*). Finally, some of them felt that religious care was a burden during physical suffering, and some of them felt that religious care including preparation for death was a nuisance when patients did not think of it (*Burden of thinking of religion or nuisance*).

## Discussion

The families both with and without a religion generally regarded instrumental care such as music, hymns, tales, or religious events in the palliative care units as useful. These results are consistent with the study of Dann et al<sup>5</sup> in Western culture.

Families with a religion regarded meeting with a pastoral care worker as useful. This is in accord with the findings in Kernohan et al,<sup>8</sup> in which almost all patients viewed their interaction with the chaplaincy

**Table 3.** Views on Religious Care of Families Who do not Have a Religion

Category	Subcategory
Instrumental care in hospitals is useful ( <i>Instrumental care</i> )	Music or a hymn is useful Lecture by a well-known doctor is useful
Patients want to have freedom of choice if they receive religious care or not ( <i>Freedom of choice whether patients receive religious care or not</i> )	Patients and family want to be offered religious care when they want this care Patients and family want hospitals to let them choose religious care freely It is desirable for hospitals not to force a patient to receive religious care Forced religion is not good
Care for psycho-existential aspects of patients is needed ( <i>Spiritual care</i> )	It is the function of religion to alleviate a patient's anxiety Care such that a patient can feel their existence without limitation Religion to support the patient's mind Care such that a patient can feel their relationship with their family or mankind
Patients and families cannot accept religious care ( <i>Not being able to accept religious care</i> )	Patients and families cannot accept religious care when the religion in hospitals is different from theirs Patients and families cannot rely on care through a religion they are unaware of Patients and families have not thought about religion
It is burden and nuisance thinking of religion when a patient is suffering from physical problems ( <i>Burden of thinking about a religion and nuisance</i> )	It is a burden if a patient is told about religion during suffering Patients and families do not want to be disturbed during suffering Religious care for preparing for death is a nuisance for patients who are unaware of the seriousness of their disease

service positively. However, some families with a religion regarded religious care offered through a different kind of religion as a burden. That is, families prefer religious care that is consistent with the religious practice of the patient. Alferi et al<sup>9</sup> found that church attendance and seeking support from a priest or minister was advantageous for evangelical women but detrimental for Catholics, suggesting that the view of religious care may affect quality of life (QOL). Considering the results of Alferi et al<sup>9</sup> and the current study, it may be desirable for medical staff to offer various kinds of religious care that patients practice.

Families without a religion required "Spiritual care"; although patients did not have a particular religion, their families required the patient to receive spiritual care through religious care. The contents of spiritual care are almost in accord with the study of Kernohan et al.<sup>8</sup> These consistencies suggest that the requirement of spiritual care is similar over cultural differences.<sup>10</sup> In addition, some felt that receiving sudden religious care is difficult to accept and some saw this as a burden because they were not used to religion in their daily lives. Some even felt that care was a nuisance, such as preparation for death, though patients do not imagine it. For these people, other kinds of care rather than religious care may be suitable.<sup>11-13</sup>

## Conclusion

Bereaved families both with and without a religion evaluated "Instrumental care" such as praying or music as useful. Families with a religion required "Freedom of choice of kinds for religious care," "Staffs involvement of religious care," and "Meeting with a pastoral care worker," but some felt a "Burden of offering a different kind of religion." In contrast, families without a religion required "Freedom of choice whether patients receive religious care or not" and "Spiritual care," and some were "Not being able to accept religious care" and felt a "Burden of thinking about a religion and nuisance."

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*Original Article*

## Quality Indicators of End-of-Life Cancer Care from the Bereaved Family Members' Perspective in Japan

Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, Takayuki Ichikawa, BA, Kazuki Sato, RN, MHIthSci, Yasuo Shima, MD, and Yosuke Uchitomi, MD, PhD  
*Department of Adult Nursing/Palliative Care Nursing (M.M., T.I., K.S.), School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo; Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice (T.M.), Seirei Mikatahara Hospital, Shizuoka; Department of Palliative Medicine (Y.S.), Tsukuba Medical Center Hospital, Ibaraki; and Psycho-Oncology Division (Y.U.), Research Center for Innovative Oncology, National Cancer Center Hospital East, Chiba, Japan*

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**Abstract**

Although several studies about quality indicators (QIs) in end-of-life (EOL) cancer care have been conducted, the bereaved family members' perspective of QIs has not been investigated in Japan. The primary aim of this study was to rate QIs for EOL cancer care from the bereaved family members' perspective in Japan. A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in an inpatient palliative care unit. We mailed questionnaires to potential respondents in March 2007. Of 160 questionnaires sent, 109 responses were analyzed (effective response rate, 76%). Eighty-eight percent of participants rated the medical examination by the palliative care team or specialist positively, 80% rated the availability of emergency room (ER) services or after-hour examinations positively, and 77% agreed that medical orders to alleviate pain or suffering were documented in the chart. Only 15% of the respondents agreed that it was preferable to die at home. Additionally, 59% and 46% of participants agreed that the occurrence of a fall or pressure ulcer and death by an adverse event from surgery or chemotherapy were poor QIs, respectively. Moreover, only 17% and 14% rated the short interval from chemotherapy to dying and frequent visits to the ER or after-hour examination as poor QIs, respectively. In Japan, it would be appropriate to extract QIs from medical charts. However, many items suggested as QIs in a previous study were found to be different from the opinions expressed by bereaved family members in this study. *J Pain Symptom Manage* 2009;37:1019–1026. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Address correspondence to: Mitsunori Miyashita, RN, PhD, Department of Adult Nursing/Palliative Care

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Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan.  
E-mail: miyashita-ky@umin.net

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### Key Words

*Palliative care, end-of-life care, neoplasms, hospice, measures, quality indicators*

## Introduction

It is important to measure the quality of cancer care.<sup>1-5</sup> End-of-life (EOL) care is one of the principal components of cancer care. Therefore, measuring the quality of care for EOL cancer patients is a critical issue.<sup>6-8</sup>

In the United States, Earle et al. identified quality indicators (QIs) of EOL cancer care from an administrative database using the Delphi method.<sup>9</sup> These indicators included aggressiveness of care, hospice use, emergency room (ER) visits, and intensive care unit (ICU) admissions; they measured and validated the reliability of data extraction from the cancer registry and Medicare database.<sup>10,11</sup> In Canada, Barbera et al. measured Earle et al.'s QIs and identified factors related to poor-quality EOL care.<sup>12</sup> Furthermore, Grunfeld et al. investigated 14 QIs of EOL care from cancer registry, medical claims, and palliative care databases based on Earle et al.'s QIs, and performed an additional expert panel interview.<sup>13</sup> In other efforts to maintain quality of EOL care, the National Quality Forum presented their performance measures<sup>14</sup> and the American Society of Clinical Oncology proposed Consensus Care Standards for Palliative Care to improve delivery of palliative care in the United States.<sup>15</sup>

As an alternative method, Wenger and Shekelle developed QIs from medical chart reviews and interviews.<sup>16</sup> In the Assessing Care of Vulnerable Elders (ACOVE) project, they selected 22 conditions to develop QIs. The potential QIs were extracted from existing guidelines, systematic literature reviews, and expert opinions. For EOL care, 14 indicators were identified, including surrogate decision makers, advance directives, documentation of care preferences, life-sustaining treatment, and treatment of distress, such as pain, dyspnea, and spiritual issues.<sup>17</sup>

However, these proposed QIs were mainly based on expert opinion from health professionals. The perspectives of patients and families have rarely been taken into account. Factors considered important in EOL care

might differ among patients, families, and health professionals.<sup>18</sup> Therefore, it is important to ask patients and families to identify QIs that are important to them. The bereaved family members are generally strong surrogates for cancer patients. Because they experience the disease trajectory from diagnosis to dying, they could provide rich information about the quality of EOL cancer care. In addition, identification of QIs should consider cultural characteristics, such as those that may apply in Japan.

The Japanese Ministry of Health, Labour, and Welfare has strongly supported dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from five in 1990 to 174 in August 2007. In contrast, the growth of home-based palliative care programs has been slow, as inpatient palliative care teams were not covered by National Medical Insurance until 2002. The most common type of specialized palliative care service in Japan is the PCU. Therefore, we sampled bereaved family members in the PCU.

We surveyed bereaved family members of patients who died in the PCU on the appropriateness of QIs. The aims of this study were: 1) to rate QIs of EOL cancer care; and 2) to explore factors related to the evaluation of QIs by bereaved family members of patients who died in a PCU in Japan.

## Methods

### *Sample, Setting, and Procedure*

A cross-sectional anonymous questionnaire was administered to bereaved family members of cancer patients who had died in an inpatient PCU in Shizuoka Prefecture, Japan. To find potential participants, we identified bereaved family members of patients who had died from April 2005 to April 2006. The inclusion criteria were as follows: 1) the patient died in a PCU because of cancer; 2) the patient was aged 20 years or more; and 3) the patient

was in the hospital (not just the PCU) for at least three days. The family member who cared for the patient the longest regardless of blood relationship to the patient completed the questionnaire. The exclusion criteria were: 1) the participant was recruited for another questionnaire survey for bereaved family members; 2) the participant would have suffered serious psychological distress as determined by the primary physician (e.g., family member was treated for psychological distress after death of the patient or who was depressed at the bereaved family's meeting); 3) the cause of death was treatment-related or caused by injury; 4) there was no bereaved family member who was aged 20 years or more; 5) the participant was incapable of replying to a self-reported questionnaire; and 6) the participant was not aware of the diagnosis of malignancy.

We mailed questionnaires to potential respondents in March 2007, and a reminder was sent in April 2007 to those who did not respond. We asked the primary caregiver to complete the questionnaire. If the respondents did not want to participate in the survey, they were asked to return the questionnaire with "no participation" indicated and a reminder was not mailed to them. The ethical and scientific validity of this study was approved by the institutional review boards of Seirei Mikatahara Hospital.

#### Measurements

We asked the bereaved family members to rate the appropriateness of QIs of EOL cancer care (in the last month) using a 5-point Likert scale (1: absolutely disagree; 2: disagree; 3: unsure; 4: agree; 5: absolutely agree). The attributes were generated based on a previous literature review<sup>9-11,13,17</sup> and selected based on items suggested from previous Western studies and discussion among the authors. We asked about these items to rate their appropriateness as QIs in accordance with the experience of the bereaved families. The question was as follows: "We are investigating measurements to evaluate the quality of medical treatment. How much do you think the following attributes are important for measuring the appropriateness of good (or poor) medical treatment?"

To evaluate good QIs of EOL cancer care, we asked about 22 items from seven domains (italicized) as follows:

*Documentation of physical and emotional status in medical chart.* "Medical orders by physician for pain or suffering," "presence and level of pain and suffering," "patient's anxiety or concerns," "patient's use of the bathroom," and "family's anxiety or concerns."<sup>19</sup>

*Documentation of disease explanation in medical chart.* "Explanation of medical condition to family," "explanation of medical condition to patient," and "prognosis disclosure to the patient from the physician."

*Documentation of discussion about resuscitation in medical chart.* "Discussion about resuscitation (for example, cardiac massage) with the family" and "discussion about resuscitation (for example, cardiac massage) with the patient."

*Documentation of religion in medical chart.* "Patient's religion."

*Sufficient medical treatment.* "Medical examination by palliative care team or palliative care specialist," "availability of emergency room or after-hours examination according to patient's wishes," "medical examination by interdisciplinary team including physician, nurse, and pharmacologist," "medical examination by psycho-oncologist or psychologist (specialist in mental health care for cancer patients)," "appropriate opioid use for the treatment of pain," "frequent medical examination by physician," and "medical treatment in accordance with guidelines."

*Use of low-cost treatment.* "Use of lower cost treatment in case of equal effectiveness."

*Dying situation.* "Patient died with family present," "patient died at place of his or her choosing," and "patient died at home."

As for poor QIs of EOL cancer care, we asked about 11 items within four domains (italicized) as follows:

*Trouble with medical treatment.* "Occurrence of fall or pressure ulcer," "died by adverse event due to surgery or

chemotherapy," and "frequent change of physician-in-charge or hospital."

*ER visits and hospital stays.* "Frequent visits to ER or after-hours examinations," "long stay in the hospital," and "use of intensive care unit."

*Short interval from treatment to dying.* "Short interval from chemotherapy to dying" and "short interval from surgery to dying."

*Medical treatment during last phase.* "Short interval from admission to hospice to dying," "dying at hospital," and "cardiopulmonary resuscitation was performed."

In addition, the patient's age, sex, and number of hospital days were extracted from medical databases. We asked the bereaved family member's age, sex, relationship to the patient, and frequency of attending the patient.

### Analysis

Before the analysis, we conducted an explanatory factor analysis with an unweighted least square method to classify the items for good QIs and poor QIs. We identified six domains of good QIs and four domains of poor QIs, as mentioned earlier.

To simplify the analysis, we first calculated the total percentage of "absolutely agree" and "agree" for each item in both good QIs and poor QIs. Second, we tested related factors of good QIs and poor QIs with the Wilcoxon rank sum test with significance level of 0.05 and two-tailed tests, because several domains had a skewed distribution. All analyses were performed using the statistical package SAS version 9.1 (SAS Institute, Cary, NC, USA).

## Results

### Participant Characteristics

Of 183 questionnaires sent to bereaved family members, 23 were undeliverable and 121 were returned (response rate, 76%). Of those returned, 12 individuals refused to participate. Thus, 109 responses were analyzed (effective response rate, 68%).

Participant characteristics are shown in Table 1. Patient characteristics were as follows: The mean age  $\pm$  standard deviation (SD) was  $72 \pm 13$  years; males made up 43% of the total; and the mean number of hospital days  $\pm$  SD

Table 1  
Participant Characteristics (n = 109)

<i>Patient demographics</i>	
Age (mean $\pm$ SD, years)	72 $\pm$ 13
Gender (male), n (%)	47 (43)
Hospital days (mean $\pm$ SD)	56 $\pm$ 74
<i>Bereaved family member demographics</i>	
Age (mean $\pm$ SD, years)	61 $\pm$ 12
Gender (male), n (%)	42 (39)
Relationship	
Spouse, n (%)	47 (44)
Children, n (%)	42 (39)
Children-in-law, n (%)	8 (7)
Sibling, n (%)	4 (4)
Others, n (%)	6 (6)
Frequency of attending patient	
Every day, n (%)	80 (74)
4-6 days/week, n (%)	15 (14)
1-3 days/week, n (%)	11 (10)

Several totals do not equal 100% because of missing values.

was  $56 \pm 74$ . The length of hospitalization was longer than the national standard (about 40 days). This is because this unit is free of charge for private rooms. Japanese PCUs usually have longer hospital stays compared with Western countries. As for bereaved family members, the mean age was  $61 \pm 12$  years; 39% were males; spouses made up 44% of the total, and 39% were children; and 88% attended the patient every day or four to six days a week.

### Good Quality Indicators of End-of-Life Cancer Care

We show the evaluation of good QIs of EOL cancer care in Table 2. Agreement (absolutely agree and agree) of bereaved family members with good QI items for documentation in the medical chart were as follows: *documentation of medical condition*, 64%–78%; *documentation of disease explanation*, 42%–77%; *documentation of discussion of resuscitation*, 33–44%; and *documentation of religion*, 13%. As for *sufficient medical treatment*, 36%–83% agreed with each item. The items that received the most agreement were "medical examination by palliative care team or palliative care specialist" (83%) and "availability of emergency room or after-hours examination according to patient's wishes" (80%). Sixty-one percent agreed with the item *use of low-cost treatment*. As for the *dying situation*, 15%–65% agreed with each item, although only 15% agreed that dying at home was a good QI.

Table 2  
Appropriateness of Good QIs in EOL Cancer Care Rated by the Bereaved Family Members

	n	%
<i>Documentation of physical and emotional status in medical chart</i>		
Medical orders by physician for pain or suffering	85	78
Patient's pain and suffering	80	73
Patient's anxiety or concerns	78	72
Patient's use of the bathroom	74	68
Family's anxiety or concerns	70	64
<i>Documentation of disease explanation in medical chart</i>		
Explanation of medical condition to family	84	77
Explanation of medical condition to patient	73	67
Prognosis disclosure to the patient from physician	46	42
<i>Documentation of discussion of resuscitation in medical chart</i>		
Discussion about resuscitation with family	45	41
Discussion about resuscitation with patient	36	33
<i>Documentation of religion in medical chart</i>		
Patient's religion	14	13
<i>Sufficient medical treatment</i>		
Medical examination by palliative care team or palliative care specialist	90	83
Availability of ER or after-hour examination according to patient's wishes	87	80
Medical examination by interdisciplinary team including physician, nurse, and pharmacist	84	77
Medical examination by psycho-oncologist or psychologist	77	71
Appropriate opioid use for the treatment of pain	65	60
Frequent medical examination by physician	56	51
Medical treatment in accordance with guidelines	39	36
<i>Use of low-cost treatment</i>		
Use of low-cost treatment in case of equal effectiveness	66	61
<i>Dying situation</i>		
Patient died with family present	71	65
Patient died at place of choosing	53	49
Patient died at home	16	15

Figures are total number and percentage of "absolutely agree" and "agree."

#### Poor Quality Indicators of End-of-Life Cancer Care

We show the evaluation of poor QIs of EOL cancer care in Table 3. As for the occurrence of *adverse events*, 47%–59% agreed with each item. Agreement (absolutely agree and agree) with the following items was considerably less: *ER visits and hospital stays*, 2%–14%; *short*

Table 3  
Appropriateness of Poor QIs in EOL Cancer Care Rated by the Bereaved Family Members

	n	%
<i>Adverse events</i>		
Occurrence of fall or pressure ulcer	64	59
Died by adverse event from surgery or chemotherapy	50	46
Frequent change of physician-in-charge or hospital	51	47
<i>ER visits and hospital stays</i>		
Frequent visits to ER or after-hour examinations	15	14
Long stay in the hospital	3	3
Use of ICU	2	2
<i>Short interval from treatment to dying</i>		
Short interval from chemotherapy to dying	18	17
Short interval from surgery to dying	12	11
<i>Medical treatment of last phase</i>		
Short interval from admission to hospice to dying	6	6
Dying at hospital	0	0
Cardiopulmonary resuscitation was performed	0	0

Figures are total number and percentage of "absolutely agree" and "agree."

*interval from treatment to dying*, 11%–17%; and *medical treatment of last phase*, 0%–6%.

#### Factors Related to Evaluation of Good and Poor Quality Indicators

Table 4 shows factors that were significantly different between good QIs and poor QIs. Bereaved family members of patients with a long hospital stay were more likely to rate documentation of the medical condition in the chart positively. Older bereaved family members ( $\geq 65$  years) were also more likely to agree that disease explanation was documented in the chart. In addition, women rated the sufficiency of medical care and the dying situation more positively. Bereaved family members of patients who had long hospital stays and younger family members were more likely to indicate the occurrence of adverse events (a poor QI).

#### Discussion

Most participants did not consider ER visits or ICU use, a short interval from treatment to dying, or medical treatment in the last phase of life to be poor QIs. In addition,



most bereaved family members rated death at a hospital positively in this sample.

In previous studies, aggressive treatment in EOL settings was regarded as a poor QI.<sup>9,10,13</sup> However, in our study, only 17% rated a short interval from chemotherapy to dying as a poor QI. In a Japanese good death study, fighting against cancer was an important issue for achieving a good death for some people.<sup>20</sup> In addition, Japanese bereaved families of patients in PCUs were distressed by the cessation of anticancer treatment and transition to palliative care.<sup>21</sup> Usually, family members were not able to abandon disease-modifying therapy and wished to prolong the loved one's life. Therefore, treatment availability is an important issue for family members. Similarly, ER visits or use of the ICU was not rated as a poor QI, in contrast to previous studies.<sup>9,12,13</sup> From the bereaved family member's perspective, it is important to be able to use the ER or ICU. These results do not conflict with previous studies in Western countries. The negative attitude toward aggressive treatment would include reaction to the high cost and distress of life-prolonging treatment, including chemotherapy, in the last phase of life.

Although the patient dying in a PCU did not usually experience aggressive treatments, the families desired life-prolonging medical treatment for the patient and were afraid that care would be insufficient. The availability of medical treatment is an important issue from the Japanese bereaved family members' perspective. Therefore, aggressive treatment and ER/ICU visits are not included as poor QIs for all cancer patients in Japan. We need to conduct further research to explore the relationship between aggressive treatment, ER/ICU visits, and the achievement of a good death in Japan.

The second finding of our study is the positive attitude toward dying in a hospital. Although 49% rated dying at a favorite place as preferable, only 15% rated dying at home as the preferred place. In addition, only 3% rated a long stay in the hospital and none considered dying at a hospital to be a poor QI. However, we should be careful in interpreting these results. The participants are the bereaved family members who lost a loved one in a PCU. In Japan, only 6% of cancer patients died at

home in 2004. These results suggest that it is currently difficult to die at home in our country because of the lack of home palliative care specialists and the care burden on the family. Therefore, the role of inpatient facilities is important if the patient or family desire inpatient care. Most Japanese prefer "not being a burden to others" as an important component of a good death.<sup>20</sup> Therefore, although a nationwide Japanese study revealed that almost half the general public wanted to die at home,<sup>22</sup> dying at a hospital is not considered a poor QI of EOL cancer care. Although some patients prefer to die at home, the medical system in Japan may not make it practical. In addition, 65% of participants considered the patient dying in the presence of family members to be a positive QI. This shows that the place of death is not as important as the environment of care at the time of death. The medical practitioner should support an intimate relationship between the patient and family in EOL cancer care.

The documentation of medical conditions and disease explanation was rated as a good QI by bereaved family members. This is in agreement with the results of previous Western studies.<sup>16,17</sup> These results would suggest that documentation and communication among physician, patient, and family were recognized as important from the bereaved family members' view. However, only 42% of participants agreed that prognosis disclosure to the patient from the physician was documented in the chart. In Japan, not all patients want to know their prognosis. Careful communication between physician and patient about prognosis is necessary.<sup>22</sup> In addition, the occurrence of adverse events, which could be determined from a medical chart review, was rated as a poor QI. An audit of the documentation of QIs would be appropriate and feasible in Japan.

Most participants agreed that there was medical treatment, including medical examination by the palliative care team or palliative care specialist; medical examination by an interdisciplinary team including a physician, a nurse, and a pharmacologist; and medical examination by a psycho-oncologist or psychologist. Although care by an interdisciplinary team is necessary for EOL care, it is inadequate in Japan.<sup>23</sup> In addition, the number of palliative care professionals is insufficient.

Table 4  
Factors Related to Good QIs and Poor QIs

	n	Mean ± SD	P-value <sup>a</sup>
<i>Domains of good QIs and variables</i>			
Documentation of physical and emotional status in medical chart			
Hospital days			
<30	54	3.8 ± 0.6	0.016
≥30	48	4.1 ± 0.7	
Documentation of disease explanation in medical chart			
Age (years)			
<65	67	3.7 ± 0.6	0.007
≥65	35	4.1 ± 0.7	
Sufficient medical treatment			
Gender			
Male	41	3.7 ± 0.5	0.030
Female	62	3.9 ± 0.6	
Dying situation			
Gender			
Male	41	3.4 ± 0.7	0.023
Female	62	3.7 ± 0.6	
<i>Domains of poor QIs and variables</i>			
Adverse events			
Hospital days			
<30	52	3.3 ± 0.9	0.002
≥30	49	3.7 ± 0.9	
Age (years)			
<65	66	3.7 ± 0.7	0.002
≥65	35	3.1 ± 1.0	

<sup>a</sup>Wilcoxon rank sum test.

The education and development of specialized palliative care providers is an urgent need.<sup>24</sup>

In Japan, also, most patients favor dying at home. We think that patients receiving home hospice care would not object to treatment in the ER or ICU. The sense of "safety" is important for EOL cancer patients. Family caregiver's time off and equipment at home vary among individuals. Overall, Japanese home hospice is less advanced than in the United States and United Kingdom. The status of home palliative care patients and caregivers is still unclear.

#### Limitations and Future Perspectives

This study has some limitations. First, the study was conducted at a PCU. The Japanese PCU usually does not provide aggressive treatment in the last phase of life.<sup>25</sup> If bereaved family members had experienced aggressive treatment in the EOL stage, their evaluation might have changed. In addition, the patient and family expressed a desire to be admitted to a PCU. Moreover, most Japanese bereaved families are satisfied with the care in the

PCU.<sup>26</sup> Therefore, participants rated inpatient care positively. For these reasons, the results of this study might not be generalizable to other settings. Second, in Japan, the progress of home hospice care is slower than in the United States and United Kingdom, and therefore, hospital stays are longer than in Western countries. This study might not be generalizable to Western countries. Third, the participants were surveyed one to two years after their family member's death; hence, there is a potential for recall bias. Finally, we investigated the evaluation of ACOVE's attributes from bereaved family members. However, the ACOVE project is aimed at the ambulatory elderly, not cancer patients. Although we believe that the concept of the ACOVE project is applicable to measuring the quality of cancer care in Japan, it might become a worldwide standard. It is necessary to evaluate QIs from medical charts targeting EOL cancer care.

In future studies, we should examine a broader range of bereaved families, including those with loved ones dying on general hospital wards and at home. Most of our results differed from previous studies in Western countries. It is still unclear whether these results are unique to Asian countries, including Japan. Further research comparing the Japanese experience with Western countries is needed. In addition, we need to clarify the relationship between the QIs examined and consequences of care, such as a good death.

#### Conclusions

In conclusion, we asked bereaved family members to evaluate QIs in EOL cancer care. Most participants did not consider ER visits or ICU use, a short interval from treatment to dying, and medical treatment in the last phase to be poor QIs. In addition, most bereaved family members rated death at a hospital positively. The documentation of medical conditions and disease explanation was rated as a good QI, and the occurrence of adverse events was rated as a poor QI. An audit of documentation would be appropriate. However, many QIs suggested in the previous study were different from those of the bereaved family members in this survey. We need further research regarding development of QIs in Japan.

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# The Long-Term Effect of a Population-Based Educational Intervention Focusing on End-of-Life Home Care, Life-Prolongation Treatment, and Knowledge about Palliative Care

KAZUKI SATO, and MITSUNORI MIYASHITA, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo, Japan; TATSUYA MORITA, Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara General Hospital, Shizuoka, Japan; MASAO SUZUKI, Fukushima Division, Soshukai Okabe Clinic, Fukushima, Japan

**Abstract** / Misconceptions and a lack of knowledge are barriers to providing palliative care. This study examined the long-term effect of an educational intervention with the general public focusing on end-of-life home care, life-prolongation treatment, and knowledge about palliative care. We offered a one-hour educational lecture for community residents in 11 districts in Fukushima, Japan. Lecture attendees were asked to complete pre- and post-questionnaires and a six-month postal follow-up questionnaire. A total of 424 respondents completed and returned the follow-up questionnaire. Beliefs about the feasibility of home death did not significantly change. In addition, many of the other significant changes that occurred immediately after the intervention reverted to initial opinions six months later. This population-based educational intervention was not effective for the long term, except that it had a partial influence on certain misconceptions about palliative care. Therefore, other approaches are needed to achieve substantial long-term effects.

**Résumé** / Les préjugés et le manque de connaissances sur ce que sont les soins palliatifs sont deux des éléments qui nuisent à sa mise en place. Cette étude voulait étudier les effets à long terme d'un programme d'information et d'éducation auprès du grand public et qui parlerait surtout sur les soins de fin de vie à la maison, les traitements de prolongation de vie et sur des notions générales sur les soins palliatifs. Nous avons tenu des conférences éducatives d'une heure auprès des résidents de 11 districts de Fukushima au Japon. Les personnes qui assistaient à la conférence ont complété un questionnaire avant et un questionnaire après le conférence. Six mois plus tard un questionnaire de suivi leur a été envoyé par la poste. Un total de 424 personnes ont complété et retourné le dernier questionnaire postal. Les croyances au sujet de la possibilité de mourir à la maison n'avaient pas

changées de façon significative. De plus, plusieurs autres changements plus significatifs qui s'étaient produits immédiatement après l'intervention retournaient aux positions initiales six mois plus tard. Cette intervention éducative de nature démographique n'a pas été efficace à long terme, mais elle a cependant eu une influence à tout le moins partielle sur certaines idées erronées au sujet des soins palliatifs. Il faudra utiliser d'autres approches pour atteindre des objectifs à long terme.

## INTRODUCTION

Misconceptions and a lack of knowledge about palliative care are barriers to providing palliative care for end-of-life cancer patients (1-10). Actually, a significant proportion of the Japanese general public has incorrect beliefs about pain medication and communication with physicians (11). Educational intervention is needed to overcome these barriers (1, 7).

In addition, reports have shown that only 6 percent of cancer patients die at home (12), although 55 percent of the general public in Japan prefer home as the place of death (13). A systematic review revealed that the most important factors linked to dying at home are low functional status, patient preference, use and intensity of home care, living arrangements, and extended family support (14). Based on these findings, the authors proposed that public education was one of the actions that would enable people to die at home.

Several educational intervention studies focusing on cancer pain management have been con-

ducted for patients (15-19); and others focusing on knowledge of delirium (20), advanced directives (21), and coping strategies (22-25) have been conducted for caregivers of terminally ill patients. One study examined the general public's reaction to the topic of palliative care using a video on cardiopulmonary resuscitation (CPR), and it demonstrated effective improvement in knowledge immediately after the intervention (26). However, there is limited evidence of the effectiveness of public education on palliative care and no evidence of its long-term effects.

We had previously conducted a prospective educational intervention for the general public focusing on end-of-life home care, life-prolongation treatment, and knowledge about palliative care, and we reported that there were many significant changes in belief before and after the intervention (27). Specifically, belief in the feasibility of home death increased from 9 percent to 34 percent. Furthermore, preference for life-prolongation treatment and attitudes toward end-of-life care, including symptom management at home, misconceptions about opioids, artificial hydration, and communication issues between patients and medical practitioners, significantly improved.

Within this study, we conducted a six-month prospective follow-up study to determine the actual effect of the intervention over time. The aim of the study was to examine the long-term effects of an educational intervention with the general public on the topic of palliative care.

## METHOD

### Participants and Procedures

Potential participants were those who attended educational community lectures. The researcher explained the aim of the study and spoke about privacy protection and voluntary participation. Self-administered questionnaires were completed before and after the intervention. Demographic characteristics were covered in the pre-questionnaire. A total of 607 people attended the lectures (17 to 188 per lecture), and 595 people completed the pre- and post-questionnaires.

We mailed follow-up questionnaires to those who completed the pre- and post-questionnaires six months after the intervention. Of the 595 participants, 26 were excluded due to previous participation ( $n=8$ ) or unknown name and address ( $n=18$ ). We re-sent questionnaires to those who did not respond within one month. We received 425 questionnaires, one of which was excluded because of a difference in the respondent's name between the pre- and follow-up questionnaires. Finally, 424 participants were included in the analysis (the response rate was 75 percent).

This study was approved by the institutional review board of the Fukushima Medical University.

### Intervention

One-hour educational lectures were held for community residents from April 2006 to March 2007. Simple pamphlets about the lectures were distributed; no special invitations were issued. The lectures were free and offered during periodic regional community meetings in the 11 districts of Fukushima City. Fukushima City is the capital of Fukushima Prefecture; it is located about 250 kilometres north of Tokyo, and it has a population of 288,000.

The topics of the lectures were: the limitations of cancer treatment, life-prolongation treatment for end-of-life cancer patients, opioids, artificial hydration, communication between patients and physicians, the feasibility of home care for end-of-life cancer patients, and district health resources for terminally ill cancer patients. A physician gave all of the lectures.

### Measures

To examine the effect of the educational intervention, our main outcome criterion was change of belief about the feasibility of home death. The feasibility of home death was rated as "possible," "impossible," or "unsure." We also investigated beliefs about barriers to end-of-life home care, preferences for life-prolongation treatment, and attitudes toward end-of-life care using pre- and follow-up questionnaires. We did not ask facilitators of home death for their preferred place of end-of-life care because this information did not suit the purpose of our intervention.

Barriers to end-of-life home care included: absence of a visiting physician, absence of a visiting nurse, absence of 24-hour consultation, absence of family caring, care burden on the family, anxiety about worsening physical condition, anxiety about arranging immediate hospital admission when physical condition worsened, inadequate living environment, economic burden, and inability to relieve suffering at home. Participants were asked to agree or disagree that these barriers were relevant to their home care situation.

We investigated the preference for life-prolongation treatment if participants were terminally ill cancer patients. We asked about their preference for artificial hydration, artificial nutrition, vasopressors, mechanical ventilation, and CPR using a 4-point Likert scale: want to receive, probably want to receive, probably do not want to receive, and do not want to receive.

We investigated attitudes toward end-of-life care in five areas: four questions for pain, two questions for hydration/nutrition, three questions for communication, two questions for cancer treatment, and five questions for home care (see Table 5). The questions were identical to those we used in our previous study (11), and they employed a 5-point Likert scale: strongly agree, agree, unsure, disagree, and strongly disagree.

### Analyses

Initially, we examined the characteristic differences between respondents and non-respondents in the follow-up questionnaires using the Wilcoxon test or Fisher's exact test, as appropriate. Then we compared the responses to follow-up questionnaires with those to the pre-questionnaires in order to examine the long-term effects of the educational intervention using the Wilcoxon signed-rank test. Regarding the feasibility of home death, we identified the proportion of "possible" responses. In addition, the responses to the post-questionnaire underscored the short-term effect of the educational intervention on these participants. For all analyses, the significance level was set at  $p < 0.05$ , and the two-sided test was used. All statistical analyses were performed with SAS 9.1 for Windows.

## RESULTS

The characteristics of the 424 participants who completed pre- and follow-up questionnaires are shown in Table 1. The mean age  $\pm$ SD was 66  $\pm$ 10 years, 64 percent were female, 88 percent were living with someone, and 67 percent experienced bereavement within 10 years. There were no significant differences between the 424 respondents and the 171 non-respondents in the follow-up questionnaires, except that the non-response group included more females (77 percent,  $p < 0.001$ ).

### Feasibility of Home Death

The feasibility of home death is shown in Table 2. While 41 participants (10 percent) agreed that home death was feasible before the educational

**Table 1 / Participant Characteristics (n=424)**

	n	(%) <sup>a</sup>
<b>Age</b>		
50 years and under	28	(6.6)
51-60 years	72	(17)
61-70 years	179	(42)
71 years and over	145	(34)
<b>Gender</b>		
male	153	(36)
female	270	(64)
<b>Education</b>		
junior high school	99	(23)
high school	220	(52)
college	55	(13)
university	47	(11)
<b>Health status</b>		
good	177	(42)
moderate	185	(44)
fair	56	(13)
bad	2	(0.5)
<b>Experience of hospital admission</b>		
yes	246	(58)
no	176	(41)
<b>Family members living with participant</b>		
none	50	(12)
one	128	(30)
two or three	128	(30)
four or more	117	(28)
<b>Experience of bereavement within 10 year</b>		
yes	283	(67)
no	136	(32)

<sup>a</sup>Percentages were not summed up 100 percent due to missing values.

intervention, significantly more agreed immediately after the intervention (n=158, 37 percent,  $p < 0.001$ ); however, no significant difference was seen between the pre- and six-month-follow-up responses (n=52, 12 percent,  $p = 0.117$ ).

### Barriers to End-of-Life Home Care

Barriers to end-of-life home care are shown in Table 3. In the post-questionnaire, 8 of 10 barriers showed significant improvement as a result of the intervention. In contrast, there were no significant differences between the pre- and follow-up responses, except for "absence of 24-hour consultation" (pre, 20 percent; follow-up, 27 percent;  $p = 0.004$ ) and "anxiety about worsening physical condition" (62 percent, 57 percent,  $p = 0.049$ ).

**Table 2 / Feasibility of Home Death**

	Pre		Post (vs Pre)			Follow-up (vs Pre)		
	N	(%)	N	(%)	P	N	(%)	P
Possible	41	(10)	158	(37)	<0.001***	52	(12)	0.12
Impossible	240	(57)	107	(25)		226	(53)	
Unsure	132	(31)	141	(33)		144	(34)	
Missing	11	(2.6)	18	(4.0)		2	(0.5)	

$p < 0.001$

Table 3 / Barriers to End-of-Life Home Care

	Pre %	Post %	(vs Pre) P	Follow-up %	(vs Pre) P
Absence of visiting physician	31	27	0.04*	35	0.12
Absence of visiting nurse	23	17	0.009**	25	0.33
Absence of 24-hour consultation	20	21	0.83	27	0.004**
Absence of family caring	19	20	0.81	22	0.18
Burden for family to care	78	68	<0.001***	82	0.09
Anxiety about worsening physical condition	62	52	<0.001***	57	0.05*
Anxiety about immediate admission to hospital when physical condition worsens	43	34	<0.001***	42	0.55
Insufficient living environment	18	14	0.02*	20	0.40
Economic burden	44	24	<0.001***	44	1.00
Suffering not relieved at home	43	19	<0.001***	41	0.45

p<0.05, \*\* p<0.01, \*\*\* p<0.001

Table 4 / Preference for Life-Prolongation Treatment<sup>a</sup>

	Pre %	Post %	(vs Pre) P	Follow-up %	(vs Pre) P
Artificial hydration	61	51	0.006**	61	0.69
Artificial nutrition	48	37	0.008**	38	0.06
Vasopressor	37	32	0.26	30	0.21
Mechanical ventilation	21	20	0.87	15	0.02*
CPR	25	21	0.37	16	0.02*

<sup>a</sup> Figures are total percentages of "want to receive" and "probably want to receive."  
p<0.05, \*\* p<0.01

### Preferences for Life-Prolongation Treatment

Preferences for life-prolongation treatment are shown in Table 4. As a result of the intervention, the preferences for artificial hydration and nutrition were significantly decreased for the short term, while significantly fewer participants preferred mechanical ventilation (pre, 21 percent; follow-up, 15 percent;  $p=0.015$ ) and CPR (25 percent, 16 percent,  $p=0.023$ ) for the long term.

### Attitudes toward End-of-Life Care

Attitudes toward end-of-life care are shown in Table 5. All of the first four questions regarding pain-related beliefs improved for the short term, and responses to three of the questions remained significantly improved, although to a lesser extent, six months after the intervention: "cancer pain is sufficiently relieved if treatment is adequate" (pre, 67 percent; follow-up, 74 percent;  $p=0.016$ ), "opioids shorten life" (31 percent, 23 percent,  $p=0.039$ ), and "opioids cause addiction" (23 percent, 21 percent,  $p=0.020$ ).

Belief that "artificial hydration and nutrition relieve symptoms" was significantly improved for the short term and remained partially improved after six months (pre, 34 percent; follow-up, 28 percent;  $p<0.001$ ). In contrast, the change that

occurred for "artificial hydration and nutrition should be continued as the minimum standard until death" was not sustained for the long term (47 percent, 50 percent,  $p=0.407$ ).

Regarding communication-related beliefs and cancer-treatment-related beliefs, the following significantly improved after the intervention: "physicians are generally poor at communicating bad news," "physicians are uncomfortable discussing death," "it would be intolerable if I were told that I had incurable cancer," and "cancer treatment has only limited effectiveness." But there were no significant differences between responses in the pre- and follow-up questionnaires.

All of the last five questions regarding home-care-related beliefs improved for the short-term, and responses to three of the questions remained significantly improved six months after the intervention: "death at home suggests to relatives that family cannot provide sufficient medical care for patient" (pre, 15 percent; follow-up, 8 percent;  $p<0.001$ ), "death at home suggests to neighbours that family cannot provide sufficient medical care for patient" (16 percent, 12 percent,  $p<0.001$ ), and "a large hospital provides better-quality medical treatment than a clinic before death" (53 percent, 40 percent,  $p<0.001$ ).

Table 5 / Attitudes toward End-of-Life Care<sup>a</sup>

	Pre %	Post %	(vs Pre) P	Follow-up %	(vs Pre) P
Cancer pain is sufficiently relieved if treatment is adequate	67	82	<0.001**	74	0.02*
Opioids shorten life	31	7	<0.001**	23	0.04*
Opioids cause addiction	23	3	<0.001**	21	0.02*
Consciousness is clear if pain medication is not used	29	29	0.03*	29	0.97
Artificial hydration and nutrition should be continued as the minimum standard until death	47	29	<0.001**	50	0.41
Artificial hydration and nutrition relieve symptoms	34	23	<0.001**	28	<0.001**
Physicians are generally poor at communicating bad news	29	21	<0.001**	31	0.35
Physicians are uncomfortable discussing death	17	9	<0.001**	17	0.51
It would be intolerable if I were told that I had incurable cancer	40	26	<0.001**	32	0.06
Cancer treatment has only limited effectiveness	67	63	0.02*	65	0.84
I want to receive cancer treatment as long as possible	44	47	0.17	45	0.34
Medical systems are insufficient for treatment or care at home	60	30	<0.001**	57	0.33
In my circumstance, it is difficult to be cared for at home	61	30	<0.001**	57	0.10
Death at home suggests to relatives that family cannot provide sufficient medical care for patient	15	8	<0.001**	8	<0.001**
Death at home suggests to neighbours that family cannot provide sufficient medical care for patient	16	11	<0.001**	12	<0.001**
A large hospital provides better-quality medical treatment than a clinic before death	53	11	<0.001**	40	<0.001**

<sup>a</sup>Figures are total percentages of "strongly agree" and "agree."

\* p<0.05, \*\* p<0.001

## DISCUSSION

In our previous study, we delivered one-hour educational lectures on palliative care to a public audience and reported a large number of significant changes in belief immediately after the intervention (27). In this six-month follow-up survey, we learned that many of the changes had reverted to initial beliefs. However, there was improvement in the misconception of opioids, artificial hydration, and home death — although to a lesser extent.

This was the first study to examine the long-term effects of an educational intervention regarding palliative care for the general public. Although lack of knowledge and misconceptions were barriers to appropriate palliative care (1-10), only a few studies have examined the effect of a population-based educational intervention (26). Further-

more, no studies have systematically used pre-, post-, and follow-up questionnaires. Therefore, our findings provide some useful information concerning the development of educational interventions to help the general public overcome the barriers to palliative care.

We propose several possible reasons to organize educational interventions and offer suggestions for how to conduct interventions that will be effective in the long term. First, our intervention was conducted only once for each participant, with the intention of minimizing the burden of participating. Our results, however, suggest the need for repeated education sessions in order to sustain long-term effects. However, it is also necessary to develop other approaches to eliciting participants' internal motivation to learn (28). As didactic lectures may be unmemorable and there-



fore ineffective, experience-based education and small-group discussions should be considered instead. In addition, we should take into account the fact that exposure to palliative care and home death — which may be gained through the media or from the experiences of relatives or friends — may change beliefs, because experience provides a basis for learning (28). Finally, among our participants were many elders, and some were illiterate and hard of hearing; a 60-minute lecture might have exceeded the limits of their ability to concentrate. Different approaches will be necessary for various age groups.

Misconception about opioids is a common barrier to optimal pain management (6-10). In fact, educational intervention produced improvement in pain outcomes and pain-related knowledge among cancer patients (15-18). In a population-based survey, 24 to 33 percent of the Japanese general public said that they believed that opioids shortened life and caused addiction (11). Our one-hour educational lecture dramatically improved the degree of misconception about opioids immediately after the intervention, and the improvement remained significant, although to a lesser extent, at the six-month follow-up.

Beliefs about most barriers to home care were not sustained, and beliefs about the feasibility of home death reverted to initial opinions. It may be difficult to change beliefs about barriers using educational intervention, because some barriers are related to an actual lack of resources, such as a family caregiver or home care; there are significant factors associated with home death (14). However, hospital access is relatively free for end-of-life care in Japan; more than 90 percent of cancer patients have died in hospital over the last decade (29). This accessibility may actually contribute to misconceptions about end-of-life home care. Our educational intervention helped to dispel the negative image of death at home as opposed to end-of-life care at a large hospital, although this improvement was somewhat reduced after six months.

This study had several limitations. First, participants were community residents who volunteered to participate; they therefore represented one geographic community and tended to be health-conscious. Second, our participants were mostly elderly; they therefore did not represent all age groups in the general population. Third, our outcomes were subjective. Further study should be devoted to examining objective factors, such as the number of home deaths. Finally, our educational intervention was not based on adult education theory. By incorporating an appropriate theoretical framework, a more effective and applicable intervention could be developed.

## CONCLUSION

This population-based educational intervention was not effective in the long term. Many of the significant changes in belief that occurred immediately after the intervention reverted to initial opinion six months later, although there was some remaining effect on certain misconceptions related to palliative care. Other approaches are needed to achieve more substantial and long-lasting effects: for example, repeated education sessions; experience-based education and small-group discussions; exposure to palliative care and home death; and different strategies for different age groups. Further study is needed to develop and evaluate more effective educational intervention.

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**Original Article**

## Late Referrals to Palliative Care Units in Japan: Nationwide Follow-Up Survey and Effects of Palliative Care Team Involvement After the Cancer Control Act

Tatsuya Morita, MD, Mitsunori Miyashita, RN, PhD, Satoru Tsuneto, MD, PhD, Kazuki Sato, RN, MHlthSci, and Yasuo Shima, MD

*Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice (T.M.), Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka; Department of Adult Nursing/Palliative Care Nursing (M.M., K.S.), School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo; Department of Palliative Medicine (S.T.), Osaka University Graduate School of Medicine, Osaka; and Department of Palliative Medicine (Y.S.), Tsukuba Medical Center Hospital, Ibaraki, Japan*

**Abstract**

*Referral to palliative care units tends to be delayed. In Japan, the Cancer Control Act was established in 2006 to improve the quality of life of cancer patients by facilitating greater access to specialized palliative care services. The primary aims of this study were to clarify the family-perceived appropriateness of the timing of referral to palliative care units after the Cancer Control Act, and to determine the effects of the involvement of the palliative care team on the family-perceived referral timing. An additional aim of this study was to clarify the family-perceived usefulness of the palliative care team. A multicenter questionnaire survey was conducted on a sample of 661 bereaved family members of cancer patients who were admitted to palliative care units in Japan. A total of 451 responses were analyzed (response rate: 68%). Half of the bereaved family members regarded the timing of referrals to palliative care units as late or too late: too late (25%, n = 114), late (22%, n = 97), appropriate (47%, n = 212), early (2.4%, n = 11), and very early (1.8%, n = 8). Among 228 families who reported that patients had commented on the timing of referrals, about half reported that the patients said the timing of referral was late or too late: too late (23%, n = 52), late (21%, n = 49), appropriate (48%, n = 110), early (4.4%, n = 10), and very early (3.1%, n = 7). The families of patients with a palliative care team (n = 191) tended to report less frequently that they believed the referral timing to be late or too late (43% vs. 51%, P = 0.073); they also reported significantly less frequently that the patients said that the referral timing was late or too late (36% vs. 52%, P = 0.037). The percentages of families who evaluated the palliative care team as useful or very useful were: 93% (symptom control), 90% (emotional support), 92% (family support), and 87% (care coordination).*

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Address correspondence to: Tatsuya Morita, MD, Department of Palliative and Supportive Care, Palliative Care Team, and Seirei Hospice, Seirei Mikatahara

General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan. E-mail: [tmorita@sis.seirei.or.jp](mailto:tmorita@sis.seirei.or.jp)

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*Half of the Japanese bereaved families of patients admitted to palliative care units regarded the timing of referrals as late or too late, and the rates identified in the survey were similar to those recorded before the Cancer Control Act. Involvement of the palliative care team, however, significantly correlated with lower family- and patient-perceived late referrals, and palliative care team activity was generally perceived as useful by the bereaved family members. Further dissemination of palliative care teams could contribute to better access to palliative care units and quality palliative care throughout the country.* J Pain Symptom Manage 2009;38:191–196. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

#### **Key Words**

*Referral, family, palliative care team, palliative care, cancer*

### **Introduction**

The World Health Organization defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness,” and states that this is achieved “through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment.”<sup>1</sup> Although palliative care is rooted in compassionate care for dying patients, the primary aim of palliative care is to minimize patient and family suffering at all stages of life-threatening illness.<sup>1</sup> Early referrals to specialized palliative care services, that is, immediate referrals to palliative care specialists when patient and family require specialized care for adequate symptom relief, could be useful in achieving symptom control and in promoting systematic detection of unmet needs, prevention of symptoms, and strengthening emotional connections between patients and families.<sup>2</sup>

Several empirical studies, however, have revealed that physicians usually refer patients to specialized palliative care programs at very late stages of cancer.<sup>3–9</sup> In the United States, Italy, and Japan, the median survival from the initial referral to patient death ranges from three to six weeks, and about 15% of the patients die within a week after initial referrals.<sup>4–9</sup> From the bereaved family perspective, multiple surveys have identified family-perceived late referrals to palliative care units or hospice-care programs.<sup>6–9</sup> A Japanese survey in 2002 revealed that more than half of the family members and patients reported that the timing of referral to a palliative care unit was late or too late.<sup>9</sup>

From 2003 to 2006, in Japan, the Cancer Control Act was established to improve the quality of life of all cancer patients throughout the country, and disseminating palliative care was identified as one of the most important areas to be improved. To disseminate quality palliative care, The Ministry of Health, Welfare, and Labor obliged more than 200 regional cancer centers to establish a palliative care team, and approved palliative care team activity was targeted for national insurance coverage. In 2008, there were 351 cancer centers with palliative care teams in Japan, and 48 of them had palliative care units. In addition, 135 palliative care units are certified. Although the change that followed the Cancer Control Act could diminish late referral to palliative care units—the most common specialized palliative care service in Japan—no nationwide follow-up survey has been performed since 2003, and palliative care team activity has not been evaluated, except for a single institution study.<sup>10</sup>

The primary aims of this study were, thus, to 1) clarify the family-perceived appropriateness of the timing of referral to palliative care units after the encouragement of palliative care team activity by the Cancer Control Act, and 2) to determine the effects of the involvement of the palliative care team on the family-perceived referral timing. An additional aim of this study was to clarify the family-perceived usefulness of the palliative care team for symptom control, emotional support, support for the family, and care coordination.

### **Methods**

This study was part of a large cross-sectional anonymous nationwide survey of the bereaved