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## Evaluation of End-of-Life Cancer Care From the Perspective of Bereaved Family Members: The Japanese Experience

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Submitted December 14, 2007; accepted May 27, 2008.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/08/2623-3845/\$20.00

DOI: 10.1200/JCO.2007.15.8287

### ABSTRACT

Surveying bereaved family members could enhance the quality of end-of-life cancer care in inpatient palliative care units (PCUs). We systematically reviewed nationwide postbereavement studies of PCUs in Japan and attempts to develop measures for evaluating end-of-life care from the perspective of bereaved family members. The Care Evaluation Scale (CES) for evaluating the structures and processes of care, and the Good Death Inventory (GDI) for evaluating the outcomes of care were considered suitable methods. We applied a shortened version of the CES to three nationwide surveys from 2002 to 2007. We developed the CES as an instrument to measure the structures and processes of care and the GDI as an outcomes measure for end-of-life cancer care from the perspective of bereaved family members. We conducted three nationwide surveys in 1997, 2001, and 2007 (n = 850, 853, and 5,301, respectively). Although six of the 10 areas of the CES showed significant improvements between the two time points investigated, we identified considerable potential for further progress. Feedback from surveys of bereaved family members might help to improve the quality of end-of-life cancer care in inpatient PCUs. However, the effectiveness of feedback procedures remains to be confirmed. Furthermore, there is a need to extend the ongoing evaluation process to home care hospices and general hospitals, including cancer centers, identify the limitations of end-of-life care in all settings, and develop strategies to overcome them.

*J Clin Oncol* 26:3845-3852. © 2008 by American Society of Clinical Oncology

### INTRODUCTION

It is important to evaluate end-of-life cancer care to determine the quality of care provided by hospices and palliative care units (PCUs). The measurement and the evaluation of end-of-life care play important roles in clinical assessment, research, quality improvement, and public accountability.<sup>1</sup> However, asking the patients themselves for their views on the provision of end-of-life cancer care can be challenging. Many patients are too physically and/or mentally vulnerable to participate in such studies.<sup>2</sup> As a consequence, surveys of terminally ill patients are likely to be unrepresentative and/or biased.<sup>3</sup> As family members are potential proxies for terminally ill patients, it could be useful to conduct surveys of bereaved relatives. To this end, postbereavement evaluations of end-of-life care have been conducted worldwide.

Following pioneering work by Cartwright et al,<sup>4-6</sup> the Regional Study of Care for the Dying was conducted in the United Kingdom in 1990.<sup>7-9</sup> This study involved 3,696 patients, and many secondary findings were reported.<sup>10-13</sup> In the United

States, the large-scale Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments began in 1989.<sup>14</sup> Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments included a follow-up postbereavement study,<sup>15</sup> and the satisfaction of relatives was measured.<sup>16</sup> Several mortality follow-back surveys have also been conducted in the United States.<sup>17,18</sup> Teno et al<sup>19-22</sup> surveyed patient-centered and family-centered outcomes from a random sample of 1,578 representative individuals who died from chronic illnesses in the United States. Moreover, the National Hospice and Palliative Care Organization surveyed more than 29,292 family hospice users in 2004 and evaluated the care provided using a Web-based approach.<sup>23</sup> The Italian Survey of Dying of Cancer, which evaluated the experiences of Italian patients dying from cancer during 2002 and 2003, was based on a random sample of 2,000 individuals taken from death certificates.<sup>24-26</sup> In addition, numerous surveys have been performed with bereaved family members, including a large-scale survey in the United Kingdom,<sup>27</sup> surveys of intensive care units,<sup>28-31</sup> surveys focusing on the place of care,<sup>32</sup> home care,<sup>33</sup> community hospitals,<sup>34</sup> comparisons



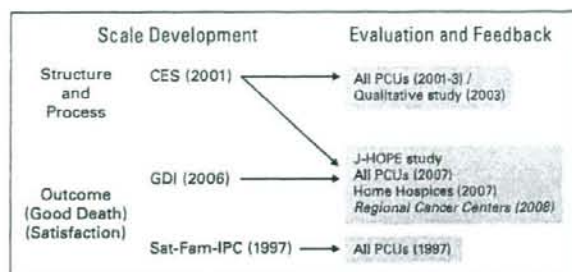


Fig 1. Overview of progress of quality evaluation projects for end-of-life care from the perspective of bereaved family members. CES, Care Evaluation Scale; GDI, Good Death Inventory; PCU, palliative care unit; J-HOPE, Japan Hospice and Palliative Care Evaluation study; Sat-Fam-IPC, Satisfaction Scale for Family Members Receiving Inpatient Palliative Care. Italic text indicates ongoing study.

between hospitals and hospices,<sup>35</sup> and access to hospices,<sup>36</sup> and surveys of end-of-life communication by health professionals,<sup>37</sup> advanced directives and quality of care,<sup>38</sup> and bereavement care.<sup>39</sup>

Obtaining valid measures of bereavement from family members is a crucial problem for many surveys. However, the progress made so far in postbereavement surveys has allowed some instruments to be developed. The Views of Informal Carers Evaluation of Services instrument was developed for the Regional Study of Care for the Dying<sup>40-42</sup> and was subsequently used in the Italian Survey of Dying of Cancer. The Toolkit Instruments to Measure End of life care instrument was developed by Teno et al<sup>43,44</sup> and was used in a subsequent mortality follow-back survey. Curtis et al<sup>45</sup> developed an instrument for assessing the bereaved family members of patients in intensive care units, which is known as the Quality of Dying and Death scale.

In Japan, we have developed measures to evaluate end-of-life cancer care from the perspective of bereaved family members. In addition, we have conducted three nationwide surveys of the quality of hospice and palliative care. An overview of the progress of the quality evaluation of end-of-life care by bereaved family members is shown in Figure 1. A summary of the evaluation studies is presented in Table 1.

The current review describes the progress made in Japanese surveys of bereaved family members and offers some future perspectives.

#### JAPANESE PALLIATIVE CARE SYSTEM FOR PATIENTS WITH CANCER

The Japanese Ministry of Health, Labor, and Welfare has strongly supported the provision of specialized palliative care services, and PCUs have been covered by National Medical Insurance since 1990. The number of PCUs has dramatically increased from just five in 1990 to 175 in 2007. PCUs for patients with cancer and HIV/AIDS are certified by the prefecture authorities based on several criteria. For example, they must have at least one full-time physician and a sufficient number of nurses, and they must meet structural requirements, such as providing sufficient floor space around beds, a visitor's room, a family room, and so on. Provided that the relevant PCU is certified, the hospital is reimbursed at the rate of 37,800 yen (US\$344) per patient per day by the health insurance system. The maximum amount of this fee that the patient pays is 30% or 11,340 yen (US\$103).<sup>46</sup> The most common type of specialized palliative care service in Japan is therefore the PCU. However, although the number of PCUs has been increasing, the proportion of deaths covered was only 6% in 2006 (Japanese Ministry of Health, Labor, and Welfare/Hospice Palliative Care Japan).

The growth of home care hospices has been slow in comparison, and the proportion of home deaths has gradually decreased. In 1960, 64% of deaths resulting from cancer occurred at home, compared with only 6% in 2006 (Japanese census data available online at <http://www.mhlw.go.jp>). Moreover, although there are several pioneering home care hospices, the numbers of these institutions and of specialized palliative home care practitioners are far lower than in the United States and United Kingdom.<sup>47</sup> Consequently, the Japanese Ministry of Health, Labor, and Welfare defined specialized home care support clinics in 2006. These are expected to provide home care for a wide range of patients in the community, with 24-hour care by physicians or nurses. In addition, these clinics are intended to support

Table 1. Summary of Evaluation Studies in Japan

Year	Instrument	Institutions	No. of Participants	Response Rate (%)	Major Findings
1997	Sat-Fam-IPC	50 PCUs	850	64	Development of Sat-Fam-IPC Identification of factors contributing to satisfaction
2001-2003	CES	70 PCUs	853	70	Development of CES National level of care evaluation for PCUs by families in 2001-2003 Triangulation with a qualitative study to explore dissatisfaction with PCUs Identification of necessity for improvement of PCUs
2006	GDI	1 regional cancer center	189	57	Development of GDI Exploring factors contributing to good death
2007-2008	CES	100 PCUs	5308	69	National level of care evaluation for PCUs, home care hospices, and regional cancer centers by families in 2007-2008
	GDI	14 home care hospices 60 regional cancer centers	294 3000-6000 (posting)	68 —	Comparison with 2001-2003 study Identification of factors contributing to satisfaction for all care settings Twelve additional questionnaires for PCUs

NOTE: Italics denote ongoing studies.

Abbreviations: Sat-Fam-IPC, Satisfaction Scale for Family Members Receiving Inpatient Palliative Care; PCU, palliative care unit; CES, Care Evaluation Scale; GDI, Good Death Inventory.



community-dwelling patients in cooperation with hospitals, other clinics, PCUs, and visiting nursing services. The clinics can obtain additional remuneration for their work with terminally ill patients at home and for deaths occurring at home. This new home care system is therefore expected to support patients with cancer at home and to increase the proportion of deaths occurring at home. Reports suggest that few of these clinics are involved in a significant number of deaths, suggesting that this system is still early in its development. This system is clearly still in the development phase in Japan.

According to the above-mentioned statistics, more than 80% of patients with cancer died in a general hospital ward. However, the opioid consumption in Japan is one sixth of that in the United States and one seventh of that in the United Kingdom.<sup>48</sup> Despite differences in the legal and medical regulations, as well as cultural differences, these data suggest that pain palliation is not being achieved for patients with cancer in general hospital wards in Japan. As a consequence, in 2002, the Japanese health insurance system established "palliative care additional fee" Palliative Care Team (PCT) services for patients with cancer and HIV/AIDS in general medical wards. This system provides financial support to certified PCTs based on several criteria. For example, the PCT must comprise at least three members of medical staff, including a palliative care physician, a psychiatrist, and a specialized palliative care nurse; at least one physician or nurse must be a full-time staff member who is dedicated to the PCT; and so on. Provided that the relevant PCT is certified, the hospital is reimbursed at a rate of 2,500 yen (US\$23) per patient per day by the health insurance system. The maximum proportion of this fee that the patient pays is 30% or 750 yen (US\$7).<sup>49</sup> This ground-breaking system is expected to improve the quality of hospital-based palliative care for patients with cancer and their families. However, the number of certified palliative care teams was only approximately 60 in 2007. By contrast, in 2007, there were approximately 8,000 hospitals, including 288 regional cancer centers and 1,113 teaching hospitals in Japan. This system is clearly also in the development stage in Japan.

#### PROGRESS IN EVALUATION OF END-OF-LIFE CANCER CARE FROM THE PERSPECTIVE OF BEREAVED FAMILY MEMBERS

### Step 1. Initial Nationwide Satisfaction Survey for Inpatient PCUs

The Japanese Association of Hospice and Palliative Care Units was established in 1991 to promote the quality of care provided by the certified PCUs belonging to the association. Along with an increase in the number of PCUs, the importance of monitoring the quality of their services has been acknowledged, and a Quality Audit Committee has been established. The committee initially established care standards through panel discussions in 1997. Its next task was to conduct a nationwide survey of bereaved family members to determine their levels of satisfaction with the PCU services.

Before conducting the survey, the Quality Audit Committee developed a postbereavement satisfaction scale instrument. The multidisciplinary committee, which comprised eight palliative care experts, developed the questionnaire through a consensus-building method. The answers to each question were represented on a six-point Likert scale ranging from "very dissatisfied" (0) to "very satisfied" (5). Through a pilot survey, the committee developed a final questionnaire that consisted of 50 questions.<sup>50</sup>

The survey was conducted by mail, and 50 PCUs participated. Of the 1,334 caregivers who were contacted, 850 completed the questionnaires (an effective response rate of 64%). In the development analysis phase, the 50 items were reduced to 34 by a ceiling-effect analysis, principal component analysis, and correlation analysis, which identified redundant items. After a final factor analysis, the resulting Satisfaction Scale for Family Members Receiving Inpatient Palliative Care (Sat-Fam-IPC) was composed of seven subscales: symptom palliation, nursing care, information, facilities, access to an inpatient PCU, family care, and cost. The internal consistency of the Sat-Fam-IPC domains was shown to be satisfactory.<sup>50</sup>

In addition, an explanatory analysis was conducted to clarify the factors contributing to caregiver satisfaction using the Sat-Fam-IPC. This analysis was intended to identify not only the sociodemographic variables but also the organization-related variables that contributed to the Sat-Fam-IPC ratings. The satisfaction score for family care was significantly lower in bereaved individuals who were male, younger, and employed. The satisfaction scores for symptom palliation, facilities, family care, and cost were significantly higher in bereaved relatives of older patients. The satisfaction score for access to an inpatient PCU was significantly lower in cases with shorter admission periods.<sup>50</sup>

Among the organization-related variables, the caregiver satisfaction with nursing care was significantly related to the nursing system, the number of nurses working the night shift, and the presence of attending medical social workers. The satisfaction with symptom palliation was significantly related to the total number of attending physicians and the number of physicians per bed. The satisfaction score for the facilities was significantly higher in the responses from institutions with a larger average floor space per bed. The satisfaction with availability demonstrated a significant positive association with the presence of attending medical social workers. The satisfaction with cost was significantly correlated with the average extra charge for a private room. However, the organization-related variables investigated were not significantly related to the family members' satisfaction with information and family care.<sup>50</sup>

### Step 2. Development of the Care Evaluation Scale and Necessity for Improvement of PCUs

Unfortunately, the Sat-Fam-IPC was not well validated and measured the satisfaction only of bereaved family members. In addition, as a general satisfaction scale, the Sat-Fam-IPC showed a skewed distribution in the "satisfied" direction, and a ceiling effect made it difficult to identify the factors that needed to be improved. This type of satisfaction scale also tended to be influenced by the psychological state of the respondent (for example, by depression or grief).<sup>3</sup> Therefore, from 2001 to 2003, we developed the Care Evaluation Scale (CES) as a new instrument to measure the structures and processes of care from the perspective of bereaved family members. The design of the CES was based on pooled data from the following sources: the items used to describe the structures and processes required to assess the quality end-of-life care from the Sat-Fam-IPC, multidisciplinary expert opinion discussions of the Quality Audit Committee, and an extensive systematic literature review. The questions were designed so that the respondents evaluated the necessity to improve each item on a six-point Likert scale ranging from "improvement is not necessary" (1) to "improvement is highly necessary" (6).<sup>51</sup>



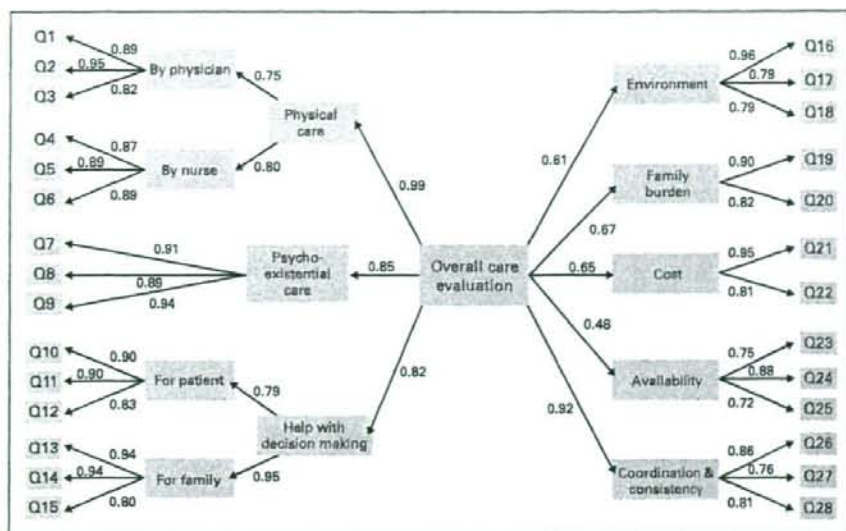


Fig 2. Confirmatory factor analysis of the Care Evaluation Scale.

We then conducted a second nationwide survey of 70 PCUs. The survey was sent in the mail to 1,225 potential participants, 853 of whom responded (an effective response rate of 70%). During the development phase, the respondents were asked to report their perceptions of the necessity for improvement for 67 items. We then reduced the number of items by removing those that had large amounts of missing data, a weak correlation with the overall satisfaction scores, or a skewed distribution. During the validation phase, we conducted two surveys to determine the test-retest reliability. We used a confirmatory factor analysis to examine the construct validity. The final version of the CES comprised 28 items in 10 domains. These domains and examples of the items are shown in Appendix Table A1 (online only). The results of the confirmatory factor analysis are shown in Figure 2. The CES had good psychometric properties (Table 2). In addition, it was not correlated with the depression scale. The CES could thus measure a participant's evaluation of the structures and processes of end-of-life cancer care independent of their psychological condition.<sup>51</sup>

This survey not only evaluated the level of end-of-life care but also identified several areas that needed improvement via a subsequent qualitative interview study. The following areas were highlighted: lack of perceived support for maintaining hope, lack of perceived respect of individuality, perceived poor quality of care, inadequate staffing and equipment, poor availability of timely admission into the PCU, lack of accurate information about PCUs, and economic burden.<sup>52</sup> The results of the survey were fed back to the participating institutions. This feedback process identified the specific weaknesses of each participating PCU, and the institutions were expected to improve these areas in accordance with the findings. This project is thus expected to contribute to the quality control in Japanese PCUs.

### Step 3. Development of the Good Death Inventory

Before our third nationwide survey, we developed an outcomes measure for end-of-life cancer care. The CES mainly focused on the structures and processes of end-of-life care. A major goal of palliative

Table 2. Psychometric Properties of CES and GDI

Property	CES	GDI
Reliability		
Alpha	0.87-0.95 (good)	0.74-0.95 (good)
ICC	0.56-0.71 (acceptable)	0.38-0.72 (acceptable)
Validity		
Factor	Sufficient	Sufficient
Construct	Correlated with satisfaction and perceived experience ( $r = 0.36-0.52$ and $0.39-0.60$ , respectively)	More correlated with overall care satisfaction than CES (total score $r = 0.39$ and $0.26$ )
Discriminant	Domains were not correlated with depression, expectation of care, and social desirability	Domains were not correlated with CES items
Sensitivity	Significant differences among clinical settings, such as PCUs, general wards, and hematology wards	Significant differences for some domains between general wards and PCUs

Abbreviations: CES, Care Evaluation Scale; GDI, Good Death Inventory; Alpha, Cronbach's  $\alpha$  coefficient; ICC, intra-class correlation coefficient; PCUs, palliative care units.



care is achieving a good dying process.<sup>53-55</sup> However, only a few studies have investigated the concept of a good death as an appropriate outcome of end-of-life cancer care in Japan. We therefore developed a measure for evaluating good death from the perspective of bereaved family members. Initially, we conducted a nationwide qualitative study in Japan to explore the attributes of a good death for 63 participants, including patients with advanced cancer and their families, physicians, and nurses.<sup>56</sup> We then conducted a quantitative study to rate the necessity of a good death among a large sample of the general Japanese population, including bereaved family members.<sup>57</sup>

On the basis of the results of these studies, we developed the Good Death Inventory (GDI) to evaluate whether the patients had a good death from the perspective of bereaved family members. To test this instrument, we surveyed 333 bereaved family members at a regional cancer center in 2006. In total, 189 responses were analyzed (an effective response rate of 57%). The GDI consisted of 30 attributes for core domains and 24 items for optional domains. These domains and examples of the items are shown in Appendix Table A2 (online only). The GDI measured the comprehensive end-of-life care outcomes not only for the structures and processes of care, but also for the physical comfort, relationship, dignity, and psycho-existential domains. The psychometric properties of the GDI were found to be satisfactory (Table 2).<sup>57,58</sup> We therefore confirmed the suitability of these instruments to measure the structures and processes (the CES) and the outcomes (the GDI) of end-of-life cancer care in a postbereavement survey in Japan.

#### Step 4. Large-Scale Nationwide Evaluation Survey of Inpatient PCUs

In 2007, we began a third large-scale nationwide evaluation survey, known as the Japan Hospice and Palliative Care Evaluation (J-HOPE) study. In total, 100 PCUs participated in the J-HOPE study. We mailed questionnaires to 7,659 participants, and 5,308 responses were analyzed. The questionnaire consisted of a shortened version of the CES (10 items), a shortened version of the GDI (18 items), and some additional questions. Details of the study design and participating institutions are available elsewhere.<sup>59</sup> The results of a comparison of the shortened version of the CES and the 2002 study are provided in Table 3. Among the 10 questions, the following six items showed a statistically significant improvement between 2002 and 2007: the doctors dealt promptly with the discomforting symptoms of the patient (item 1;  $P = .0001$ ); the nurses had adequate knowledge and skills (item 2;  $P = .0001$ ); the staff tried to maintain the patient's hopes (item 5;  $P = .0001$ ); the patient's room was convenient and comfortable (item 6;  $P = .0001$ ); there was good cooperation among staff members, such as doctors and nurses (item 9;  $P = .0001$ ); and consideration was given to the health of the patient's family (item 10;  $P = .0001$ ). However, the following four items did not improve between 2002 and 2007: the doctors sufficiently explained the expected outcome to the patient (item 3;  $P = .68$ ); the doctors sufficiently explained the expected outcome to the family (item 4;  $P = .42$ ); the total cost was reasonable (item 7;  $P = .13$ ); and admission (use) was possible when necessary without waiting (item 8;  $P = .98$ ).

#### Step 5. Expanding Research to Broader Treatment Settings and Future Perspectives

While implementing the J-HOPE study, we also surveyed Japanese home care hospices using the same questionnaire. In

total, 14 home care hospices participated in the study. From the 435 questionnaires that were mailed, 294 responses were received (an effective response rate of 68%). The information obtained from this study was preliminary and only related to home care hospices. We plan to extend the survey to the general wards of regional cancer centers in 2008 and have invited all 288 such institutions in Japan to participate in the study. By March 2008, 70 hospitals had indicated their willingness to participate. Once this survey is completed, we plan to evaluate the end-of-life care provided by the general wards of regional cancer centers and home care hospices and to compare them with the results for the PCUs. Mortality follow-back surveys are difficult to conduct in Japan because of the law for the protection of personal information. It is therefore necessary to approach bereaved relatives in clinical settings. Until now, the main focus of end-of-life care evaluation has been PCUs. However, this research should be expanded to broader treatment settings. It will be important to evaluate not only PCU systems but also specialized home care support clinics, PCTs, the general wards of regional cancer centers, and nursing homes. In addition, the data should be fed back to the institutions as a quality assurance measure. In PCU settings, this data feedback might help to improve the quality of end-of-life cancer care. Such quality control systems should be extended to all hospital or clinical settings for end-of-life cancer care.

#### ADDITIONAL POSTBEREAVEMENT RESEARCH IN JAPAN

Many surveys of bereaved family members have been conducted in Japan, and their findings have contributed to the development of end-of-life cancer care from both clinical and research viewpoints. The topics of previous research have included the following: the control and treatment of symptoms, such as delirium,<sup>60</sup> appetite loss and bronchial secretion,<sup>61</sup> and sedation;<sup>62,63</sup> psychiatric symptoms, such as a desire for death;<sup>64</sup> decision making, such as late referral to the PCU,<sup>65</sup> and communication about the end point of anticancer treatment;<sup>66</sup> attitudes toward palliative care, such as the notion of a good death and preferences for end-of-life care,<sup>67,68</sup> knowledge about palliative care,<sup>69</sup> and impressions of PCUs;<sup>70</sup> and the experience of home death.<sup>71</sup> As mentioned above, studies of bereaved family members have had an important impact on Japanese end-of-life care settings, not only for the evaluation of end-of-life care but also in solving related problems.

#### COMMENTS

We conducted systematic nationwide postbereavement studies of PCUs, in the course of which we developed measures of the structures, processes, and outcomes of care. The next task is to expand the evaluation to home care settings, general hospitals, and other clinical settings. A comparison of the CES results between 2002 and 2007 revealed improvements in six of the 10 items tested. This might have been the result of the feedback of data from 2002 to the participating institutions. The satisfaction with the explanations given to patients and family members had not changed because of a ceiling effect: as these items were rated as satisfactory in 2002, no subsequent improvement was perceived. The cost was influenced by the medical and



Table 3. Evaluation of Structures and Processes of Care From 2002 to 2007

Item and Year	Improvement of Structures and Processes of Care												P
	Highly Necessary		Considerably Necessary		Necessary		Slightly Necessary		Rarely Necessary		Not Necessary		
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
(1) The doctors dealt promptly with discomforting symptoms of the patient													.0001
2002	35	4.1	31	3.6	52	6.1	109	12.8	356	41.7	233	27.3	
2007	63	1.2	127	2.4	325	6.1	606	11.4	2,151	40.5	1,821	34.3	
(2) The nurses had adequate knowledge and skills													.0001
2002	33	3.9	35	4.1	62	7.3	116	13.6	361	42.3	214	25.1	
2007	49	0.9	135	2.5	378	7.1	664	12.5	2,163	40.7	1,703	32.1	
(3) The doctors sufficiently explained the expected outcome to the patient													.6823
2002	15	1.8	33	3.9	56	6.6	128	15.0	263	30.8	194	22.7	
2007	88	1.7	173	3.3	447	8.4	936	17.6	2,271	42.8	1,111	20.9	
(4) The doctors sufficiently explained the expected outcome to the family													.4204
2002	33	3.9	30	3.5	38	4.5	94	11.0	293	34.3	322	37.7	
2007	69	1.3	159	3.0	377	7.1	729	13.7	2,149	40.5	1,618	30.5	
(5) The staff tried to maintain the patient's hopes													.0001
2002	29	3.4	27	3.2	41	4.8	86	10.1	329	38.5	271	31.8	
2007	45	0.8	105	2.0	300	5.7	472	8.9	2,086	39.5	2,075	38.1	
(6) The patient's room was convenient and comfortable													.0001
2002	34	4.0	28	3.3	60	7.0	127	14.9	307	36.0	267	31.3	
2007	75	1.4	122	2.3	317	6.0	616	11.6	1,786	33.6	2,192	41.3	
(7) The total cost was reasonable													.1270
2002	27	3.2	21	2.5	76	8.9	96	11.3	346	40.6	236	27.7	
2007	88	1.7	160	3.0	459	8.8	748	14.1	1,871	35.2	1,688	32.0	
(8) Admission (use) was possible when necessary without waiting													.9796
2002	51	6.0	54	6.3	71	8.3	138	16.2	251	29.4	249	29.2	
2007	328	6.2	283	5.3	611	11.5	814	15.3	1,341	25.3	1,719	32.4	
(9) There was good cooperation among staff members, such as doctors and nurses													.0001
2002	27	3.2	32	3.8	50	5.9	96	11.3	343	40.2	266	31.2	
2007	63	1.2	132	2.5	275	5.2	569	10.7	2,208	41.6	1,845	34.8	
(10) Consideration was given to the health of the family													.0001
2002	28	3.3	24	2.8	63	7.4	134	15.7	312	36.6	191	22.4	
2007	61	1.1	143	2.7	378	7.1	756	14.2	2,274	42.8	1,461	27.5	

NOTE. The total numbers of participants were 853 in 2002 and 5,308 in 2007. The sum of the proportions was not 100% due to missing values.

hospital systems and by factors such as the additional fees charged for private rooms. However, the time taken for admission remained a problem.

Another task for future studies is the evaluation of end-of-life care based on patient surveys. To avoid biases in the responses, short and easily administrated measures are needed. The development of quality indicators from reviews of administrative data and/or medical charts could also be helpful to evaluate end-of-life care.<sup>72,73</sup> Such quality indicators will be valuable because their measurement does not burden patients or their families. An important challenge is thus to develop a quality indicator that can easily and accurately be used for the quality control of end-of-life care in Japan.

The evaluation of end-of-life care from the perspective of bereaved family members remains a challenge.<sup>1,2</sup> Many problems persist concerning whether it is appropriate to use proxy raters,<sup>74-77</sup> tele-

phone interviews, or postal questionnaires,<sup>40,78</sup> the timing of the survey,<sup>3,4,42</sup> the sequence of the questions,<sup>79</sup> and the properties of the questionnaire from a cognitive psychology perspective.<sup>80</sup> These issues have not yet been examined in Japan. These methodologic problems must be solved before a comprehensive postbereavement study can be realized.

In summary, we conducted systematic nationwide postbereavement surveys of PCUs in Japan and developed measures to evaluate end-of-life care from the perspective of bereaved family members. The care evaluation by family members improved between 2002 and 2007. Feedback from such surveys could help to improve the quality of end-of-life cancer care in PCUs; however, the effectiveness of feedback procedures remains to be confirmed. Future studies should expand the ongoing evaluations to home care settings, general hospitals, and other clinical settings to identify and overcome current limitations. There is also a need to develop measures for patients with advanced



cancer and to identify quality indicators from reviews of administrative data and/or medical charts.

#### AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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### Acknowledgment

We thank T. Kashiwagi, Y. Shima, S. Tsuneto, and Y. Uchitomi for conducting the studies of Japanese bereaved family members.

### Appendix

The Appendix is included in the full-text version of this article, available online at [www.jco.org](http://www.jco.org). It is not included in the PDF version (via Adobe® Reader®).



## Measuring the regret of bereaved family members regarding the decision to admit cancer patients to palliative care units

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### Abstract

**Objective:** The purposes of this study were to develop a bereaved family regret scale measuring decision-related regret of family members about the admission of cancer patients to palliative care units (PCUs) and to examine the validity and reliability of this scale.

**Method:** Bereaved families of cancer patients who had died in one regional cancer center from September 2004 to February 2006 received a cross-sectional questionnaire by mail. The questionnaire contained seven items pertaining to decision-related regret about the patient's admission to the PCU, the Care Evaluation Scale (CES), an overall care satisfaction scale, and a health-related quality-of-life (QOL) scale (SF-8). One month after receiving a completed questionnaire, we conducted a retest with the respondent.

**Results:** Of the 216 questionnaires successfully mailed to the bereaved families, we received 137 questionnaires and were able to analyze the responses for 127 of them, as the other 10 had missing data. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This scale had sufficient convergent validity with CES, overall care satisfaction, SF-8, sufficient internal consistency, and acceptable test-retest reliability.

**Conclusion:** We have developed and validated a new regret scale for bereaved family members, which can measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs.

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**Keywords:** regret; the bereaved family; decision-making; cancer; oncology

Received: 10 May 2007  
Revised: 24 October 2007  
Accepted: 31 October 2007

### Introduction

Researchers into end-of-life issues have recognized the value of what they have called a 'good death'. Critical to achieving a 'good death' is the 'completion of life,' which entails one's being prepared for dying, a feeling that one's life has been completed, no regrets about one's death, and family members who also have no regrets about one's death. Thus, minimizing the regret of cancer patients and their families is an important issue for achieving a 'good death' [1, 2]. However, bereaved

family members who have lost a loved one may find themselves experiencing self-blame feelings of regret along the lines of, 'I may have had to do it for my loved one' or 'I may not have had to do it for my loved one' [3].

Such feelings are a component of regret, the painful sensation that can result from recognizing that 'what is' compares unfavorably with 'what might have been' [4]. Early regret studies have found that a bad outcome resulting from action seemed more regrettable than the same bad outcome resulting from inaction [5] and that regretta-



ble feelings may exhibit a temporal reversal, with action evoking more regret in the short term and inaction evoking more regret in the longer term [6]. Subsequent research has categorized regrets in the daily decision context into three types according to their target: outcome regret, option regret, and process regret [7]. For each of these regret types, researchers have examined the effects of anticipated regret on decision-making as well as the effect of decision-making on experienced regret. Investigators have explored various theories and models to try to explain decision-related regret. Connolly and Zeelenberg, for instance, have recently proposed a new model called decision justification theory (DJT) [8]. DJT postulates two core components of decision-related regret: evaluation of the outcome and the feeling of self-blame for having made a poor choice. The overall feeling of regret at the decision is the combination of these two components. Thus DJT might offer a new explanation as to how people still feel regret even when they experience a situation in which the actual outcome is good. In contrast, most regret studies to date have evaluated regret by examining either the past decision or the self-blame feeling.

With respect to cancer patients, regret studies have typically focused on fatal decisions regarding what course of treatment to follow, e.g. [9] or whether to undergo a screening test [10]. Several studies of prostate cancer patients have established that patients can feel substantial regret following their cancer-related fatal decisions [11–13] and that such treatment-related regret is associated with worse current health-related quality of life (QOL) [11] and with worse quality of life and emotional well-being [12]. Future research should further explore how aspects of the fatal decision process affect later regret in cancer patients and their families.

Family members will face various decisions as well as the cancer patients themselves during the course of illness. However, no reports are available regarding decision-related irretrievable regret among family members within bereaved families. Cohesiveness and control are much greater within Japanese than within western families [14]. Also, the opinions of family members tend to exert greater influence on clinical decision-making in Japan than in the United States [15, 16]. The assessment of current irretrievable regret can retrospectively color past decision-making processes. Current irretrievable regret also can strongly affect future psychological status. Developing a vigilant decision-making model focused on the regret of bereaved family could help provide useful information for improving decision-making by cancer patients and their families. One important area of decision-making for cancer patients and their families involves the decision process by which physicians

initially refer patients to palliative care units (PCUs) [17]. This study thus endeavored to develop a bereaved family regret scale measuring irretrievable regret regarding the decision to admit cancer patients into PCUs and to examine the validity and reliability of this scale.

## Methods

### Participants and procedure

Our initial set of potential study participants comprised family members of patients who had died from September 2004 to February 2006 in Ibaraki prefecture, Japan. Inclusion criteria were as follows: the patient had died in a PCU; the patient was 20 years of age or older; and the patient had been admitted to the PCU at least three days prior to death. Exclusion criteria were as follows: the family member participant had already been recruited for another questionnaire survey for bereaved family members; the family member's primary physician determined that the participant would suffer serious psychological distress from participation in the study; the patient's cause of death was either directly treatment related or secondary to a treatment-related injury; or no member of the bereaved family was 20 years of age or older, capable of replying to a self-reported questionnaire, or aware of the patient's diagnosis of malignancy.

We mailed questionnaires to potential respondents in October 2006 and mailed reminders in November 2006 to those who had not responded. We asked respondents who did not wish to participate in the survey to indicate that they did not wish to participate and to return the questionnaire. To examine test-retest reliability, we sent a follow-up questionnaire one month after we received a completed questionnaire. The institutional review boards of Tsukuba Medical Center Hospital approved the ethical and scientific validity of this study.

Of the 224 questionnaires sent to eligible bereaved families, eight were undeliverable. We received 137 of the remaining 216 questionnaires, among which we had to exclude 10 due to missing data. Thus, we analyzed 127 responses (effective response rate, 59%). Among these 127 respondents who submitted analyzable test questionnaires, we sent retest questionnaires to the 121 bereaved families who responded during the study period; the other six families submitted their test responses too late to be included in the retest program. We received 82 retest questionnaires, among which we excluded 11 due to missing data. In total, we analyzed 71 retest questionnaires (effective response rate, 59%).



## Measures

### Decision-related regret about admission to PCUs

The questionnaires asked participants to rate on a 5-point self-reported Likert scale (strongly disagree–strongly agree) their level of agreement with each of seven possible regrets that they may have experienced regarding their decision-making in the past about admitting their loved ones to a PCU. Most previous studies have evaluated regret only for single statements, such as 'how do you feel regret concerning XX'. In addition, we collected from prior studies three statements measuring the evaluation of decisions in the past [11, 18] and three other statements measuring severity and intensity of regret [19]. The evaluation-of-decision statements included, 'I made the right decision' and 'I would make the same decision if I had to do it again'. The severity and intensity of regret statements included, 'Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters' and 'I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind'. We constructed the wording of these statements based upon the palliative physicians' and psychologists' comments regarding understandability and wording.

### Care evaluation scale, short version

We used the Care Evaluation Scale (CES), short version, to examine concurrent validity [20]. The questionnaire design has the respondent evaluating the necessity of improvement for each item on a 6-point Likert scale (improvement is not necessary–highly necessary). The short version of CES used in this study comprises 10 items covering the following 10 domains: help with decision-making for patient, help with decision-making for family, physical care by physician, physical care by nurse, psycho-existential care, environment, cost, availability, coordination of care, and family burden.

### Overall care satisfaction

We assessed overall care satisfaction as part of our examination of concurrent validity by asking the following question, developed in a previous study [21]: 'Overall, were you satisfied with the care provided in the hospital?' The participant again responded on a 6-point Likert scale.

### Health-related QOL

We used the SF-8 Japanese version [22], the short form, which is derived from the health-related QOL scale called the MOS 36-Item Short Form Health survey (SF-36). The eight items cover the eight concepts measured by the SF-36 (one item per concept), using a 5- or 6-point Likert scale. The

SF-8 provides two summary scores for physical and mental health: a Physical Component Scale and a Mental Component Scale. Scores for each item and summary measurements range from 0 to 100, with higher scores indicating better health. This scale includes questions such as the following: 'Overall, how would you rate your health during the past 4 weeks'; 'During the past 4 weeks, how much did physical health problems limit your usual physical activities (such as walking or climbing stairs)'; and 'During the past 4 weeks, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health?'

### Participant characteristics

We extracted information concerning the patient's age, sex, and hospital days from a medical database. We asked the respondent bereaved family members to provide the following personal information about themselves: age, sex, health status during caregiving period, relationship with patient, frequency of attending the patient, presence of other caregivers, living status with patient, faith, education, and household income during the caregiving period.

### Analysis

We utilized the Statistical Package for SPSS for Windows (Version 14.0) for all data analyses. To examine validity of our regret scale, we conducted an exploratory and a confirmatory factor analysis along with correlation analyses of our regret scale vs CES, overall satisfaction, and QOL. To examine the reliability of the regret scale, we assessed the internal reliability of its two subscales with Cronbach's  $\alpha$  coefficients. We used correlation coefficients to assess test-retest reliability.

## Results

### Characteristics of participants

Table 1 shows the demographic characteristics of the 127 participants included in the development analysis. We compared the demographic characteristics of these 127 participants with those of the 71 participants included in the validation analysis. We identified no significant differences between the two groups with respect to all demographic characteristics. Table 1 also shows descriptive statistics of decision-related regret, CES, overall satisfaction, and health-related QOL.

### Validity

All of the seven items had a moderate degree of variance, and no item evidenced bias. Using these



**Table 1.** Characteristics of the bereaved family and patient

	N = 127 Patient numbers or mean $\pm$ SD	%
<i>Bereaved family</i>		
Age	55.85 $\pm$ 12.11	
Sex, male	44	34.6
<i>Health status during caregiving period</i>		
Good	33	26
Somewhat good	71	55.9
Bad	20	15.7
Strongly bad	2	1.6
<i>Relationship to patient</i>		
Spouse	61	48
Parent	42	33.1
Parent-in-law	13	10.2
Others	10	7.9
<i>Frequency of attending patient</i>		
Everyday	96	75.6
4-6 days/week	11	8.7
1-3 days/week	15	11.8
None	3	2.4
Presence of other caregivers	89	70.1
Living with patient	106	83.5
<i>Education</i>		
Less than high school	17	13.4
High school	56	44.1
Some college	28	22
Postgraduate	25	19.7
<i>Household income during caregiving period</i>		
Less than 250	13	10.2
250-500	58	45.7
500-750	25	19.7
750-1000	14	11
More than 1000	14	11
Care Evaluation Scale	75.49 $\pm$ 17.63	
Overall satisfaction	4.76 $\pm$ 0.96	
SF8; Physical Component Scale	48.78 $\pm$ 7.81	
SF8; Mental Component Scale	48.52 $\pm$ 6.37	
<i>Patient</i>		
Age	68.12 $\pm$ 12.28	
Sex, male	68	53.5
Hospital days	41.63 $\pm$ 33.90	

seven items, we conducted an exploratory factor analysis with promax rotation and the maximum-likelihood method. A minimal eigenvalue  $> 1$  yielded a 2-factor solution (Table 2), in which these two factors explained 74% of the variance. The correlation coefficient between the two factors was 0.32 ( $p < 0.01$ ). Factor 1, which measured the degree of focus on regret, we named 'intrusive thoughts of regret'; factor 2, which measured evaluation of decision-making in the past, we named 'decisional regret.'

Then, to confirm the adequacy of the scale structures, we conducted a confirmatory factor analysis with these seven items. The results

indicated that item 3 was the item with highest factor loadings for both factors 1 and 2. We then constructed two models, shown in Figure 1, and compared the fit indexes of the two models. We adopted model 2 because its fit index was higher than that of model 1.

Table 3 contains the Pearson correlation coefficients showing the correlation between the scores of regret subscales and scores for CES, overall care satisfaction, and health-related QOL. As expected, the scores for CES and overall care satisfaction negatively correlated with each regret subscale. Physical QOL and mental QOL correlated with only the intrusive thoughts subscale.

### Reliability

We assessed the internal reliability of the two subscales with Cronbach's  $\alpha$  coefficients. Internal consistency was high for both 'intrusive thoughts of regret' ( $\alpha = 0.85$ ) and 'decisional regret' ( $\alpha = 0.79$ ) subscales. We then defined the sums for each sub-factor as the intrusive thoughts of regret score and the decisional regret feeling score, respectively. Using these scores, we assessed test-retest reliability using correlation coefficients. Among the 71 participants who responded in both surveys, correlation coefficients among subscales were moderately high for factor 1 ( $r = 0.69$ ,  $p < 0.01$ ) and factor 2 ( $r = 0.70$ ,  $p < 0.01$ ).

### Discussion

The purpose of this study was to develop a PCU's admission-related regret scale for the bereaved family and to identify its validity and reliability. Among the bereaved families, decisional-related regret was irretrievable. Furthermore, most families had thought that their past decision was fatal for the patients. By exploratory factor analysis and confirmatory factor analysis, we identified two key factors: intrusive thoughts of regret and decisional regret. This study provided good evidence of the reliability and validity of these two factors within this Japanese population. Using these two factors, we developed a new regret scale for bereaved family members, which was able to measure their intensity of regret and their self-evaluation about their decision to admit their loved ones to PCUs. Since this regret scale contains a small number of items and a simple structure, the scale is open to broad use.

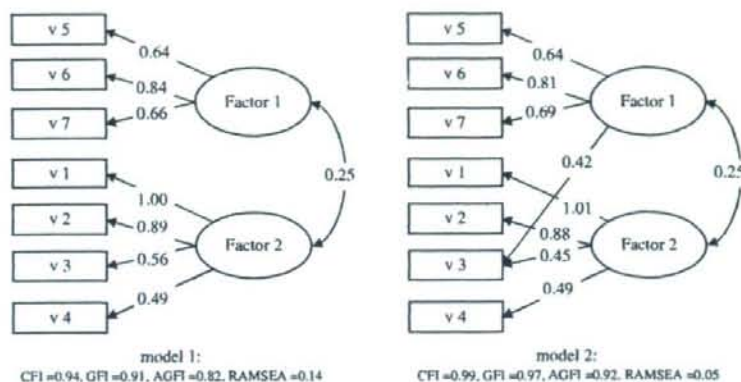
We were able to delineate the structure of our two factors, intrusive thoughts of regret and decisional regret. These two factors appear to correspond to the two core components of DJT (intensity of regret and their self-evaluation) [8]: Intrusive thoughts of regret correspond to intensity of self-blame feelings, and decisional regret corre-



**Table 2.** Results of exploratory factor analysis

Items	Mean $\pm$ SD	Factor loadings		Communality
		F1	F2	
Once I start thinking about possible outcomes had I made a different decision, I find it difficult to think about other matters (v6)	1.88 $\pm$ 1.15	<b>0.90</b>	0.22	0.67
I had difficulty concentrating on daily activities because thoughts about regret kept entering my mind (v7)	1.72 $\pm$ 1.10	<b>0.83</b>	0.18	0.62
I could not stop thinking that the situation might have changed if I had made a different decision (v5)	2.03 $\pm$ 1.16	<b>0.81</b>	0.33	0.59
It was the right decision (v1*)	1.63 $\pm$ 0.75	0.30	<b>0.99</b>	0.82
I would make the same decision if I had to do it again (v2*)	1.73 $\pm$ 0.90	0.25	<b>0.89</b>	0.79
I regret the decision that was made (v3)	1.69 $\pm$ 0.08	0.56	<b>0.57</b>	0.48
I am satisfied with the decision (v4*)	2.06 $\pm$ 1.04	0.12	<b>0.49</b>	0.26

\*Reversed item.

**Figure 1.** The results of confirmatory factor analysis and fit indices**Table 3.** Criterion validity as measured by Pearson correlations

Scales	CES	Overall care satisfaction	Physical QOL	Mental QOL
F1: intrusive thoughts about regret	-0.33**	-0.33**	-0.22*	-0.37**
F2: decisional regret	-0.27**	-0.46**	-0.08	-0.09

\* $p < 0.05$ , \*\* $p < 0.01$ .

sponds to evaluation of decision-making and subsequent outcome. Each of the two factors contained four of the seven statements; one statement overlapped both factors. The overlapping statement, 'I regret the decision that was made', directly represented the overall regret of bereaved family members about their decision-making. Our regret scale could thereby measure three aspects of the bereaved families' regret: overall degree of regret, evaluation of decisional regret, and severity of intrusive thoughts about regret. Evaluation of the details of regret assists greatly in formulating an appropriate plan of regret management and therapy. Several recent studies have examined regret management and therapy for cancer patients [23,24]. However, to develop better evidence-based regret management or regret therapy, future research should explore the effects of

the decision-making process or options on subsequent irremediable regrets. We believe that psychosocial theories such as reference comparisons theory or justifications theory can provide a basis for utilizing our new scale to establish effective regret management and therapy.

We found good evidence for the reliability and validity of our regret scale. Examination of the convergent validity of this scale determined that the score of CES and overall satisfaction negatively correlated with each regret subscale, indicating that this regret scale could adequately measure regrets regarding decision-making about admission to PCUs. On the other hand, both physical and mental QOL scores did not correlate with decisional regret but correlated only with intrusive thoughts of regret. This pair of findings indicates that the bereaved family's QOL is not influenced by



how much they regret their decision but rather by how often their regretful thoughts come to mind. The finding that intrusive thoughts of regret were associated with health-related QOL is in accord with the results of previous studies among adults [25]. We believe that decisional regret and intrusive thoughts of regret comprise different concepts and thus should be measured separately. Our findings suggest that intrusive thoughts of regret have the potential to affect the health-related QOL of bereaved family members.

One limitation of our study is the somewhat small sample size of our study, especially for the retest survey. We sent out retest questionnaires one month after we received a completed questionnaire. Although our study design assumed that the regret of the bereaved family did not change during this one-month period, empirical confirmation of this assumption is lacking. Our analysis of test-retest reliability yielded correlation coefficients among subscales that were moderately high.

Utilizing this new scale to assess the regret of the bereaved family should help clinicians evaluate decision-making about the admission of cancer patients into PCUs retrospectively. Use of this scale in multi-institutional outcome surveys should assist evaluation of quality differences between institutions in the decision-making process. Developing a vigilant decision-making model of cancer patients and their families and examining the association of this model with irretrievable regret will require future studies in order to provide useful information about decision-making aids. Our new scale thus represents the first step for these future studies.

#### Acknowledgements

This research was supported by a Health and Labor Sciences Research Grant for a third term comprehensive control research for cancer.

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## Original Article

## Perceptions of Specialized Inpatient Palliative Care: A Population-Based Survey in Japan

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**Abstract**

This study aimed to clarify and compare the awareness and perceptions of the specialized inpatient palliative care service. A cross-sectional questionnaire survey was performed on the general population selected by stratified two-stage random sampling ( $n = 2,548$ ) and bereaved families who actually received specialized inpatient palliative care at 12 palliative care units (PCUs) in Japan ( $n = 513$ ). The respondents reported their awareness and perceptions of PCUs. Thirty-eight percent of the general population answered that they had "considerable" or "moderate" knowledge of PCUs, but 24% answered that they had "no" knowledge. Bereaved families who received PCU care (PCU-bereaved families) were likely to have better perceptions of PCUs than the general population: "alleviates pain" (68% of the general population and 87% of PCU-bereaved families agreed), "provides care for families" (67% and 86%, respectively), and "provides compassionate care" (67% and 87%, respectively). Both groups, however, expressed concerns about PCUs: "a place where people only wait to die" (30% and 40%, respectively) and "shortens the patient's life" (8% and

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This study was supported by a Health and Labor Sciences Research Grant entitled the Third Term Comprehensive Control Research for Cancer Grant.

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Accepted for publication: April 30, 2007.



17%, respectively). These perceptions were associated with overall satisfaction with received care, and differed among the 12 PCUs. In conclusion, public awareness of PCUs was insufficient in Japan. Although PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, both groups shared concerns that a PCU was a place where people only wait to die. To facilitate appropriate use of specialized palliative care services, more efforts to inform the general population about the actual palliative care system are needed. In addition, the role of PCUs might be reconsidered in terms of the continuum of cancer care. *J Pain Symptom Manage* 2008;35:275-282. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

#### **Key Words**

*Palliative care, end-of-life care, neoplasm, health knowledge*

## **Introduction**

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself.<sup>1-3</sup> One recognized impediment to palliative care is that the general population has insufficient knowledge about palliative care and hospices.<sup>3-8</sup> Population-based surveys have revealed that although the majority of the general population had heard of specialized palliative care, many are relatively ill-informed about what it comprises.<sup>8,9</sup> In Japan, the most common type of specialized palliative care service is inpatient care, that is, care provided in palliative care units (PCUs), because home-based specialized palliative care programs and palliative care teams are still being developed.<sup>10-12</sup> Although the number of PCUs has increased dramatically from only five in 1991 to 135 in 2004, no population surveys have been conducted to clarify the public awareness and perceptions of PCUs in Japan.

Moreover, patients are concerned about transition to palliative care services based on the perception that palliative care equates to imminent death,<sup>13</sup> and families fear that palliative care shortens the patient's life before determining the use of PCUs.<sup>10</sup> These concerns may impede appropriate referrals. Nonetheless, retrospective surveys of bereaved families who had actually chosen PCUs as a place of end-of-life care and received specialized inpatient palliative care showed that these negative perceptions of PCUs improved markedly after using the service.<sup>10</sup> Given the necessity of providing sufficient and correct information about PCUs, it is important to understand

the differences in perceptions of PCUs between the general population and bereaved families who have actually received specialized palliative care (PCU-bereaved families). Although a recent qualitative study suggested that negative perceptions of PCUs, for example, "a place where one dies" and "somewhere from which you can never return," were associated with dissatisfaction with received care among PCU-bereaved families,<sup>14</sup> this association has not yet been quantitatively investigated. Clarifying the association between the perception of PCUs and overall satisfaction with received care can provide valuable clues as to how health care providers should offer information about PCUs and issues that should be addressed when providing end-of-life care.

This survey, therefore, had the following aims: 1) to clarify the awareness and perceptions of PCUs among a representative sample of the Japanese general population and PCU-bereaved families, 2) to clarify the differences in perceptions of PCUs between these two groups, and 3) to explore the association between perceptions of PCUs and overall satisfaction with received care among PCU-bereaved families.

## **Methods**

### *Subjects*

This study was part of a nationwide survey, and the protocol has been described in detail previously.<sup>15</sup> We initially identified four target areas to obtain a wide geographic distribution for the nationwide sample; these comprised an urban prefecture (Tokyo) and three mixed



urban-rural areas (Miyagi, Shizuoka, and Hiroshima). A cross-sectional questionnaire survey was performed in a sample of the general population selected by stratified two-stage random sampling and a sample of bereaved families who actually received specialized inpatient palliative care at one of 12 PCUs (PCU-bereaved families). We initially identified 5,000 subjects within the general population (that is, the nonbereaved general population and the bereaved general population) using stratified two-stage random sampling of residents in the four areas. We mailed questionnaires to potential participants in March 2004 and sent a reminder postcard two weeks later.

To identify bereaved family members, we initially identified all 37 PCUs in the four areas as potential participating institutions. We then approached the 18 PCUs with available collaborative researchers. Ultimately, 12 of the PCUs (two in Miyagi, five in Tokyo, two in Shizuoka, and three in Hiroshima) agreed to participate in the survey. Primary care physicians identified bereaved families in which the caregiver fulfilled the following inclusion criteria: 1) primary caregiver of an adult patient with cancer, 2) older than 20 years, 3) capable of replying to a self-reported questionnaire, 4) aware of the diagnosis of malignancy, and 5) without serious psychological distress as determined by the physician. We mailed self-report questionnaires to potential participants in August 2004, and resent them in October 2004 to those who did not respond; we requested that the primary caregiver filled in the questionnaire.

The protocol was approved by the institutional review board of each participating PCU, and met the requirements of the Helsinki Declaration.

#### *Questionnaire (Available from the Authors)*

The questionnaire was constructed through an extensive literature review,<sup>4-9,13</sup> expert consensus among the authors, and on the basis of a previous study.<sup>10</sup> We investigated three topics in this survey: 1) public awareness of PCUs, 2) perceptions of PCUs, and 3) overall satisfaction with received specialized inpatient palliative care. In addition, we investigated respondents' age and gender. The general population was asked whether they had been bereaved through cancer within the previous 10 years. PCU-bereaved families were asked about length of

hospital stay, time since the patient's death, and the level of the patient's physical distress on a five-point Likert-type scale (1: not distressed at all, 2: not too distressed, 3: unsure, 4: distressed, 5: very distressed). Despite the possibility of a recall bias, we selected 10 years as the limit of experience of bereavement through cancer in the general population, because a limit of five years yielded essentially the same conclusion in this survey.

We asked the general population to rate their level of awareness of PCUs on a four-point Likert-type scale (1: no knowledge, 2: some knowledge, 3: moderate knowledge, 4: considerable knowledge).

We asked participants who identified themselves as having at least some knowledge of PCUs to rate their levels of agreement with 10 statements regarding a PCU on a five-point Likert-type scale (1: strongly disagree, 2: disagree, 3: unsure, 4: agree, 5: strongly agree). The statements were "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," "alleviates pain," "expensive," "provides no medical treatments," "a place where patients are isolated from the community," "a place where people only wait to die," and "shortens the patient's life."

PCU-bereaved families were asked to rate the levels of overall satisfaction with received specialized palliative care on a seven-point Likert-type scale (1: very dissatisfied, 2: dissatisfied, 3: somewhat dissatisfied, 4: unsure, 5: somewhat satisfied, 6: satisfied, 7: completely satisfied).

#### *Analyses*

Initially, we clarified public awareness of PCUs using descriptive statistics. Then, we confirmed similar distributions of variables between the four areas sampled, and explored factors associated with public awareness of PCUs using univariate and multivariate regression analyses. The independent variables were age, gender, and experience of bereavement through cancer. Next, perceptions were analyzed using descriptive statistics for the two study groups (the general population and PCU-bereaved families) and compared the mean between two groups using a *t*-test. We explored the factors that affect perceptions of PCUs using *t*-tests, linear regression, and



analysis of variance, as appropriate. The independent variables were age and gender (for both groups), levels of awareness of PCUs and experience of bereavement due to cancer (only for the general population), and length of PCU stay, time since the patient's death, institution (as data were collected regarding 12 PCUs), and level of patient's physical distress (only for PCU-bereaved families). These analyses were conducted separately for the general population and PCU-bereaved families. Finally, we explored the correlation between perceptions of PCUs and overall satisfaction with received care using Spearman's rank correlation. As a large sample size may result in an excess of statistically significant results ( $P < 0.05$ ), we have mainly described "clinically significant" results for which the effect size (ES) was over 0.5.<sup>16</sup> This criterion indicates that the mean value difference as an absolute figure between two extreme categories was over half of the pooled standard deviation.

All analyses were performed using the SAS Statistical Package (version 9.1). Significance level was set at  $P < 0.05$  (two-tailed).

## Results

Of the 5,000 questionnaires sent to the general population, 26 were undeliverable and 2,670 were returned to the authors. Among these respondents, eight refused to participate, 14 were excluded due to missing data, and 2,548 responses were analyzed (effective response rate, 51%). Among the respondents from the general population, 25% ( $n = 649$ ) had lost family members from cancer during the previous 10 years. There were no differences in gender and age between these respondents and the general population according to the vital statistics data for 2003.<sup>17</sup>

Among the 866 respondents from PCU-bereaved families considered as potential participants, 72 were excluded due to serious psychological distress ( $n = 30$ ), lack of competent adult family members ( $n = 17$ ), and other reasons. Of 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned to the authors. Within this group, 27 individuals refused to participate, 12 were excluded due to missing

data, and 513 responses were analyzed (effective response rate, 70%). Comparing the backgrounds of respondents and nonrespondents revealed no differences in gender, age, or time since patient's death, but a significant difference in the length of patient's hospital stay (mean = 44 vs. 36 days). Table 1 summarizes the backgrounds of the respondents.

### Public Awareness of PCUs (Table 2)

Although 4.3% of respondents answered "very knowledgeable," 34% answered "moderate knowledge," 38% reported having "some knowledge," and 24% had "no knowledge" of PCUs. Female respondents were more likely to be knowledgeable about PCUs (standardized partial regression coefficient;  $\beta = 0.18$ ,  $P < 0.001$ ), while experience of bereavement due to cancer was not significantly associated with knowledge of PCUs ( $\beta = 0.02$ ,  $P = 0.15$ ).

### Perceptions of PCUs (Table 3)

Overall, 67%–72% of the general population and 75%–87% of PCU-bereaved families agreed that a PCU "supports patients in living peacefully," "supports patients in living with dignity," "provides care for families," "provides compassionate care," and "alleviates pain." On the other hand, approximately 30% of the general population and 30%–45% of PCU-bereaved families agreed that a PCU "provides no medical treatments," "isolates patients from the community," and "is a place where people only wait to die." In addition, 61% of the general population and 41% of PCU-bereaved families agreed that PCUs were "expensive" and 8% of the general population and 17% of PCU-bereaved family thought that they "shorten the patient's life." PCU-bereaved families were clinically significantly more likely than the general population to agree that a PCU "provides care for families," "provides compassionate care," "alleviates pain," and "provides no medical treatments." However, they were less likely to agree that PCUs are "expensive."

### Factors Associated with Perceptions of PCUs

Among the general population, better awareness of PCUs was clinically significantly associated with agreement that PCUs "provide care for families" (ES = 0.53,  $P < 0.001$ ), while other factors (i.e., age, gender, and



Table 1  
Demographic Backgrounds of the Respondents

	General Population (n = 2,548)		Bereaved Families from PCUs (n = 513)	
	%	n	%	n
Age (years)				
<49	25	613	21	104
50-59	30	758	29	144
60-69	28	710	29	146
>70	17	420	22	110
Gender				
Male	47	1,186	32	158
Female	53	1,326	68	343
Bereavement experience*	25	649	100	513
Length of hospital stay: days (mean ± SD/median)			44 ± 49/29	
Time since patient's death: months (mean ± SD/median)			28 ± 7/28	
Satisfaction with received care				
Very dissatisfied			1.4	7
Dissatisfied			1.6	8
Somewhat dissatisfied			2.8	14
Unsure			7.5	37
Somewhat satisfied			15	76
Satisfied			32	160
Very satisfied			27	134
Completely satisfied			12	60

SD = standard deviation; PCUs = palliative care units.

\*Experience of losing a family member from cancer during the previous 10 years.

bereavement experience) were not significantly associated with perceptions (data not shown).

Among the PCU-bereaved families, the respondents who thought their patient had experienced less pain were clinically significantly likely to agree that a PCU "alleviates pain" (ES = 0.56,  $P < 0.001$ ). There were also significant differences among institutions with regard to perceptions that a PCU was "a place where people only wait to die" (ES = 1.02,  $P < 0.001$ ), was "expensive" (ES = 1.01,  $P < 0.001$ ), "provides no medical treatments" (ES = 0.94,  $P < 0.001$ ), "isolates patients from the community" (ES = 0.82,  $P = 0.02$ ), "supports patients in living with dignity" (ES = 0.73,  $P = 0.005$ ), "supports patients in living peacefully" (ES = 0.72,  $P = 0.03$ ), and "shortens the patient's life" (ES = 0.70,  $P = 0.01$ ). Other variables, such as age and gender, were not significantly associated with agreement with any statement (data not shown).

#### Association Between Perceptions of PCUs and Overall Satisfaction with Received Care (Table 4)

Four statements of perception of PCUs had moderate correlations with overall satisfaction:

"provides compassionate care," "provides care for families," "supports patients in living peacefully," and "supports patients in living with dignity." Another four statements had weak correlations with overall satisfaction: "alleviates pain," "a place where patients are isolated from the community," "shortens the patient's life," and "a place where people only wait to die." Neither agreement with "expensive" nor with "provides no medical treatments" was significantly correlated with overall satisfaction.

#### Discussion

This study is, to our knowledge, the first large population-based survey to clarify the

Table 2  
General Population Awareness  
of PCUs (n = 2,548)

Awareness of PCUs	%	n
No knowledge	24	591
Some knowledge	38	936
Moderate knowledge	34	855
Considerable knowledge	4.3	106

PCUs = palliative care units.