Table 2. Evaluation of good death in PCU and general wards

	PCU		General wards		P-value
	Mean	SD	Mean	SD	
Ten core domains					
1. Environmental comfort	5.7	1.0	4.7	1.5	<0.001
2. Life completion	4.1	1.7	4.3	1.6	0.60
3. Dying in a favorite place	5.0	1.5	4.5	1.9	0.05
4. Maintaining hope and pleasure	4.1	1.5	3.8	1.7	0.31
5. Independence	3.6	1.8	4.0	1.8	0.10
6. Physical and psychological comfort	5.0	1.5	4.5	1.7	0.04
7. Good relationship with medical staff	5.6	1.0	5.3	1.3	0.07
8. Not being a burden to others	4.0	1.5	3.8	1.3	0.19
9. Good relationship with family	5.1	1.2	4.8	1.2	0.18
10. Being respected as an individual	5.9	0.9	5.4	1.3	0.01
Eight optional domains					
11. Religious and spiritual comfort	2.5	1.6	3.0	1.8	0.12
12. Receiving enough treatment	5.1	1.5	5.0	1.6	0.90
13. Control over the future	4.0	1.7	3.9	1.7	0.76
14. Feeling that one's life is worth living	5.2	1.3	5.2	1.3	0.89
15. Unawareness of death	3.6	1.4	4.0	1.5	0.10
16. Pride and beauty	3.4	1.3	3.5	1.6	0.83
17. Natural death	5.5	1.2	5.0	1.4	0.02
18. Preparation for death	4.8	1.4	4.8	1.3	0.92

Note: Statistical test comparing two places of care was by Welch's t test. PCU: Palliative Care Unit.

Table 3. Factors contributing to a good death (10 core domains)

	β	P-value
1. *Environmental comfort* ($R^2 = 0.219$)		
Place of care (PCU)	1.05	<0.001
Family member's age	0.03	<0.001
Family member's health	−0.31	0.02
2. *Life completion* ($R^2 = 0.257$)		
Place of care (PCU)	0.55	0.06
Patient's age	0.08	<0.001
Family relationship (spouse)	1.01	<0.001
3. *Dying in a favorite place* ($R^2 = 0.307$)		
Place of care (PCU)	0.10	0.76
Patient's age	0.03	0.003
Family relationship (spouse)	0.89	<0.001
Family member's education	−0.36	0.005
4. *Maintaining hope and pleasure* ($R^2 = 0.168$)		
Place of care (PCU)	0.34	0.32
Patient's age	0.02	0.04
Cancer staging	−0.72	0.01
Duration from diagnosis	0.01	0.04
Vasopressor	−2.21	<0.001
5. *Independence* ($R^2 = 0.018$)		
Place of care (PCU)	−0.54	0.11
6. *Physical and psychological comfort* ($R^2 = 0.312$)		
Place of care (PCU)	0.71	0.01
Patient's age	0.02	0.02
Family member's age	0.04	<0.001
Palliative sedation	−0.64	0.03
Antibiotic	−0.85	<0.001
7. *Good relationship with medical staff* ($R^2 = 0.196$)		
Place of care (PCU)	0.22	0.26
Patient's age	0.02	0.04
Family member's age	0.02	0.01
Cancer staging	−0.69	<0.001
Opioid medication	0.82	0.003
8. *Not being a burden to others* ($R^2 = 0.115$)		
Place of care (PCU)	0.52	0.06
Patient's age	0.03	0.005
Treatment experience (surgery)	−0.61	0.01
9. *Good relationship with family* ($R^2 = 0.115$)		
Place of care (PCU)	0.76	0.007
Household income	−0.18	0.02
Type of room (private)	0.87	0.03
Artificial hydration	−0.65	0.02
10. *Being respected as an individual* ($R^2 = 0.302$)		
Place of care (PCU)	0.48	0.04
Patient's age	0.02	0.003
Patient's marital status (married)	−0.46	0.04
Family relationship (spouse)	0.51	0.02
Cancer staging	−0.48	0.008
Treatment experience (chemotherapy)	0.52	0.004
Type of room (private)	0.73	0.03
Chemotherapy in the last 14 days	−1.31	0.002
Palliative sedation	0.46	0.03

Note: Multiple regression analyses with backward variable selection method ($P<0.05$). Place of death was included in the model absolutely. PCU: Palliative Care Unit.

surgery, $P = 0.01$). 'Good relationship with family' correlated with place of care (PCU, $P = 0.007$), low household income ($P = 0.02$), type of room (private, $P = 0.03$), and not receiving artificial hydration ($P = 0.02$). 'Being respected as an individual' correlated with place of care (PCU, $P = 0.04$), patient's older age ($P = 0.003$), patient's marital status (not married, $P = 0.04$), family member's relationship (spouse, $P = 0.02$), early cancer stage ($P = 0.008$), treatment experience (chemotherapy, $P = 0.004$), type of room (private, $P = 0.03$), not receiving chemotherapy in the last 14 days ($P = 0.002$), and palliative sedation ($P = 0.03$).

Factors contributing to evaluation of a good death (optional domains)

We show the results of multiple regression analyses regarding eight optional good death domains in Table 4. 'Religious and spiritual comfort' correlated with family member's younger age ($P = 0.01$) and family's religiousness ($P<0.001$). 'Receiving enough treatment' correlated with patient's older age ($P = 0.03$), family member's older age ($P = 0.01$), and opioid medication ($P = 0.009$). 'Feeling that one's life is worth living' correlated with the duration since diagnosis ($P = 0.04$). 'Unawareness of death' correlated with family member's older age ($P = 0.002$), patient's marital status (not married, $P = 0.006$), family member's sex (female, $P = 0.01$), and not receiving palliative sedation ($P = 0.001$). 'Pride and beauty' correlated with patient's older age ($P<0.001$), and opioid medication ($P = 0.003$). 'Natural death' was correlated with patient's marital status (not married,

Table 4. Factors contributing to a good death (8 optional domains)

	β	P-value
11. *Religious and spiritual comfort* ($R^2 = 0.369$)		
Place of care (PCU)	−0.25	0.35
Family member's age	−0.02	0.01
Family member's religiousness	0.99	<0.001
12. *Receiving enough treatment* ($R^2 = 0.137$)		
Place of care (PCU)	0.03	0.92
Patient's age	0.02	0.03
Family member's age	0.03	0.01
Opioid medication	1.10	0.009
13. *Control over the future*		
Place of care (PCU)	0.45	0.16
14. *Feeling that one's life is worth living* ($R^2 = 0.034$)		
Place of care (PCU)	0.06	0.83
Duration from diagnosis	0.01	0.04
15. *Unawareness of death* ($R^2 = 0.162$)		
Place of care (PCU)	0.31	0.23
Family member's age	0.03	0.002
Patient's marital status (married)	−0.70	0.006
Family member's sex (male)	−0.59	0.01
Palliative sedation	−0.72	0.001
16. *Pride and beauty* ($R^2 = 0.187$)		
Place of care (PCU)	−0.34	0.18
Patient's age	0.05	<0.001
Opioid medication	1.02	0.003
17. *Natural death* ($R^2 = 0.143$)		
Place of care (PCU)	0.26	0.27
Patient's marital status (married)	−0.72	0.002
Opioid medication	1.06	0.001
18. *Preparation for death* ($R^2 = 0.100$)		
Place of care (PCU)	−0.11	0.68
Patient's age	0.02	0.02
Frequency of family attending to patient	−0.32	0.02
Oxygen inhalation	−0.66	0.04
Opioid medication	0.72	0.05

Note: Multiple regression analyses with backward variable selection method ($P < 0.05$). Place of death was included in the model absolutely. PCU: Palliative Care Unit.

$P=0.002$) and opioid medication ($P = 0.001$). 'Preparation for death' correlated with patient's older age ($P = 0.02$), high frequency of family attending to patient ($P = 0.02$), oxygen use ($P = 0.04$), and opioid medication ($P = 0.05$).

Discussion

This is the first study to explore factors contributing to the evaluation of a good death from the bereaved family member's perspective using reliable measures. We found, first, that death in the PCU was described as a good death for some aspects including 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death.' These results suggest that Japanese inpatient PCUs provide the dying patient not only environmental comfort but also whole person care. On the other hand, there were no differences for the other good death domains. The preference for place of care was influenced by the patient's concept of a good death [25]. The referral to a PCU should be according to the patient's preferences and provision of information regarding the merits of the PCU. Second, we investigated many factors contributing to evaluation of a good death including not only patient and family demographics but also some medical variables. We found that patient's and family member's age and other demographic factors correlated with the evaluation of a good death. In addition, we found that life prolongation treatment and aggressive treatment such as chemotherapy in the last 2 weeks were barriers to attainment of a good death.

The patient's and family member's age was correlated with many aspects of a good death. Tsai *et al.* reported that patient age was not associated with a good death by proxy (medical practitioner) good death assessment [26]. This discrepancy may be due to the person doing the rating. Japanese bereaved family members evaluate a good death for older patient age. In other words, these results suggest that death at younger ages tended to be evaluated as a bad death. The older the family member, the more positively the family would look on the patient's death. The patient's marital status (not married) was associated with several good death domains. This might be because the mean age of unmarried patients was higher than married patients (76 vs 67). The reason for the mean age difference would be from including 'widow' in the unmarried population. In addition, several other demographic variables contributed to a good death. We should note that demographic variables influenced the evaluation of a good death from the bereaved family member's perspective, and for the proper evaluation of the intervention for a good death, we ought to adjust for these variables in the analysis.

Life-prolonging treatments such as vasopressors, antibiotics, and artificial hydration were barriers to achieving a good death. According to a nationwide opinion survey, most Japanese do not desire unnecessary life-prolonging treatment [27]. Withholding this type of treatment might contribute to a good death in Japan. Chemotherapy in the last 2 weeks was also a barrier to a good death. In Western countries, aggressive treatment for the dying cancer patient was identified as an indicator of poor quality [28–30]. Our results confirmed these previous studies. Withholding aggressive treatment for the dying patient contributes to a good death.

Opioid medication was positively associated with a good death. In Japan, opioid consumption per capita is significantly lower than in Western countries [31]. Appropriate opioid medication might contribute to a 'good relationship with medical staff' and 'receiving enough treatment' in the good death domains because bereaved family members valued appropriate medical treatment. In addition, opioid use contributed to a good death in the domains of 'pride and beauty,' 'natural death,' and 'preparation for death.' In Japan, although there are misconceptions regarding opioid medications, use of opioids might contribute to a good death from the bereaved family's perspective [32].

Palliative sedation was negatively associated with the evaluation of a good death. Many patients with palliative sedation probably suffered from physical and psychological symptoms. Therefore, the bereaved family members would evaluate this situation as a bad death for these patients. As a result, palliative sedation would be negatively associated with physical and psychological comfort. That is to say, physically and psychologically distressed patients would be more likely to receive palliative sedation. In addition, Morita reported that 25% of bereaved family members were distressed with palliative sedation therapy [33], expressing guilt, helplessness, and physical and emotional exhaustion [34]. The distress of family members might have influenced the rating of a good death. On the other hand, palliative sedation was positively associated with 'being respected as an individual.' This might indicate that the family felt that the palliative sedation was alleviating the patient's symptoms. In Japan, clinical guidelines for palliative sedation therapy have been established [35]. In accordance with these guidelines, it is important to provide sufficient information about palliative sedation to the patient and family and to allow for discussion.

Having a private room was positively correlated with a 'good relationship with family' and 'being respected as an individual.' Staying in a private room enhanced the family relationships and patient's dignity. Cancer staging was correlated with 'maintaining hope and pleasure,' 'good relationship with medical staff,' and 'being respected as an individual.' Communication with advanced-stage cancer patients and their families is a relevant issue in Japan [36].

The limitations of this study are as follows: First, the response rate was 48% of potential participants. We believe, however, this is not a fatal flaw because the objective of this study was to explore factors contributing to evaluation of a good death. Second, this study was conducted at one regional cancer center. Third, although over 80% of deaths occurred on general wards in Japan, only 26% of the deaths in this institution occurred on general wards. Therefore, the results of this study might not be generalizable to other settings. Lastly, R^2 values of multiple regression analyses are generally low. This implies that other potential variables associated with a good death exist. It is necessary to explore these factors in further research.

Conclusions

In conclusion, we found that death in the PCU achieved a good death for some domains including 'environmental comfort,' 'physical and psychological comfort,' 'being respected as an individual,' and 'natural death'. We found that the patient's and family member's age and other demographic factors, life-prolonging treatment, and aggressive treatment were barriers to attainment of a good death. Moreover, opioid medication might have contributed to a good death. Withholding life-prolonging treatment and aggressive treatment from the dying patient and appropriate use of opioids may be associated with the achievement of a good death in Japan.

Appendix

Good Death Inventory (GDI)

How do you think the patient felt during the end-of-life period? Please check the appropriate number. 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.

I. Physical and psychological comfort
    Patient was free from pain.
    Patient was free from physical distress.
    Patient was free from emotional distress.
II. Dying in a favorite place
    Patient was able to stay at his or her favorite place.
    Patient was able to die at his or her favorite place.
    The place of death met the preference of the patient.
III. Maintaining hope and pleasure
    Patient lived positively.
    Patient had some pleasure in daily life.
    Patient lived in hope.
IV. Good relationship with medical staff
    Patient trusted the physician.
    Patient had a professional nurse with whom he or she felt comfortable.
    Patient had people who listened.
V. Not being a burden to others
    Patient was not being a burden to others. (*)
    Patient was not being a burden to family members. (*)
    Patient had no financial worries. (*)
VI. Good relationship with family
    Patient had family support.
    Patient spent enough time with his or her family.
    Patient had family to whom he or she could express feelings.
VII. Independence
    Patient was independent in moving or waking up.
    Patient was independent in daily activities.
    Patient was not troubled with excretion.

VIII. Environmental comfort
    Patient lived in quiet circumstances.
    Patient lived in calm circumstances.
    Patient was not troubled by other people.
IX. Being respected as an individual
    Patient was not treated as an object or a child.
    Patient was respected for his or her values.
    Patient was valued as a person.
X. Life completion
    Patient had no regrets.
    Patient felt that his or her life was completed.
    Patient felt that his or her life was fulfilling.
XI. Receiving enough treatment
    Patient received enough treatment.
    Patient believed that all available treatments were used.
    Patient fought against disease until the last moment.
XII. Natural death
    Patient was not connected to medical instruments or tubes.
    Patient did not receive excessive treatment.
    Patient died a natural death.
XIII. Preparation for death
    Patient met people whom he or she wanted to see.
    Patient felt thankful to people.
    Patient was able to say what he or she wanted to dear people.
XIV. Control over the future
    Patient knew how long he or she was expected to live.
    Patient knew what to expect about his or her condition in the future.
    Patient participated in decisions about treatment strategy.
XV. Unawareness of death
    Patient died without awareness that he or she was dying.
    Patient lived as usual without thinking about death.
    Patient was not informed of bad news.
XVI. Pride and beauty
    Patient felt burden of a change in his or her appearance. (*)
    Patient felt burden of receiving pity from others. (*)
    Patient felt burden of exposing his or her physical and mental weakness to family. (*)
XVII. Feeling that one's life is worth living
    Patient felt that he or she could contribute to others.
    Patient felt that his or her life is worth living.
    Patient maintained his or her role in family or occupation.
XVIII. Religious and spiritual comfort
    Patient was supported by religion.
    Patient had faith.
    Patient felt that he or she was protected by a higher power.
    (*) Inverse items

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The relationship between health-related quality of life and social networks among Japanese family caregivers for people with disabilities

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Abstract

Aims: The purpose of this study was to examine HRQOL depending on whether the participants have family members with disabilities or not. In addition, we examined the relationship between HRQOL and social networks among family caregivers in Japan.

Methods: The study has a cross-sectional design. Survey forms were distributed to 9205 people aged 30 and older who visited a dispensing pharmacy within fifteen areas of Japan. We collected data on gender, age, job status, and care giving status for persons with disabilities. Moreover, we assessed support size, social support, and HRQOL. Out of the 2029 questionnaires returned, 1763 (male: 663, female: 1100, mean age = 63.06 ± 13.34) were valid for statistical analyses (the available response rate was 19.15%).

Results: A significant difference in HRQOL was identified between family caregivers and non-family caregivers. Further, in males (N = 101), the results confirmed that only social support predicted the PCS and MCS scores, while other variables did not predict either score. On the other hand, in females (N = 144), it was found from the second step of hierarchical multiple regression analysis that only age explained the PCS score, while job status and support size explained the MCS score.

Conclusion: It is reasonable to conclude that the HRQOL of family caregivers was lower than that of non-family caregivers, and that the HRQOL of family caregivers was estimated by their social networks.

Findings

It is important to assist family members in caring for persons with disabilities. The important role of family caregivers in maintaining their disabled members in the community is becoming increasingly recognized [1]. In addition, Japan has various care requirements for persons with disabilities. It often becomes very important that support is available from family caregivers. Transitional community-based care has increased awareness of the extent of the importance of family caregivers [2].

Caring for persons with disabilities places a chronic physical and mental burden on family caregivers. Thus, it is important that physical, mental and social aspects, in other words, QOL of a family caregiver, are discussed. Canam and Acorn [2] suggest that QOL has emerged as an important concept for determining the impact of community-based care on family caregivers. However, few studies have attempted to explore how the QOL of family caregivers for persons with disabilities is different from the QOL of non-family caregivers. Any potential study should also identify whether there are gender differences in a caregiver's QOL because a caregiver's QOL can be influenced by gender [3].

Some studies have related HRQOL to social networks. Hellström et al. [4] described that the social network determined a high QOL among people aged 75 years and over. Another study has suggested that higher levels of social support increases the self-reported QOL of male workers [5]. Here we show that, as has previously been reported, the QOL of family caregivers might be explained by social network variables.

The purpose of this study was to examine differences in HRQOL depending on whether the participants have family members with disabilities or not. Moreover, we also examined the relationship of HRQOL and social networks among family caregivers.

This study was approved by the institutional review board of the Department of Psychology and Behavioral Sciences, Graduate School of Human Science, Osaka University. The study was a cross-sectional, anonymous mail survey. In this study, we used a convenient sampling technique (e.g. Syad et al., 2008 [6]). The survey forms, "the questionnaire about medicine and lifestyle", were distributed to 9205 people aged 30 and older who visited a dispensing pharmacy within fifteen areas of Japan. These areas included the twelve prefectures in the Kanto, Chubu, Kinki, Chugoku, Shikoku, and Kyushu regions. Staff members in the dispensing pharmacies handed out the questionnaires. If a person who came to a dispensing pharmacy looked like they were over 30 years old, the staff handed the questionnaire to that person. The staff explained the study to the person as follows: 1. Participation in this research is on a voluntary basis. 2. This survey is being conducted on medical care and lifestyle. 3. If you participate in this study by completing a questionnaire, you will receive incentives which include some flower seeds. Moreover, we explained the purpose of the study on the questionnaire and the fact that returning the questionnaire would be regarded as consent for participation, though we asked the participants to return the questionnaires anonymously. The study was carried out from November 2006 to January 2007.

We collected data on the gender, age, and job status of participants. In order to identify family caregivers, we also collected data about whether the participants had family members with disabilities or not. The relevant question was "Are you living with a family member who has a disability?" In this study, we defined somebody as a family caregiver if the response to the question was "Yes".

We used two scales to assess social support that was recognized by participants. One scale was the tangible social support scale [7] to rate support size, i.e. the quantitative amount of social support. The scale was "If you have problems, how many people around you do you have to help you?" The other scale was a social support scale [8], which was altered to suit people of all ages in order to assess the qualitative amount of social support. The scale was "If you have worries or problems how many of your family and friends will listen to you?", and was a 5-point Likert scale. Although these scales have not been validated in a Japanese population, some Japanese studies have used these scales (e.g. Shiozaki et al. [9] and Okabayashi et al. [8])

For this study, we used the Japanese version of the MOS SF-8 which was administered to assess HRQOL. The SF-8 is divided into an 8 dimension health profile (PF, RP, BP, GH, VT, SF, RE, and MH) and 2 summary scores (PCS and MCS). The SF-8 is comprised of 8 items that are assessed by a 5 or 6-point Likert scale. The 8 domain scaled scores range from 0 to 100, with 100 representing optimal health and functioning. The Japanese version of the SF-8 has good reliability and validity among the Japanese population [10].

All data were analyzed using SPSS 15.0J. If missing data were found in the scale, the scores of the corresponding factors were excluded from the analysis. Out of the 2029 questionnaires returned, 1763 were valid for statistical analyses. The available response rate was 19.15% (male: 663, female: 1100, mean age = 63.06 ± 13.34). The rest (n = 266) were invalid due to a lack of major information (gender, age, or care giving status), or because the respondent was below thirty years old.

The results of the chi-squared tests for demographic data showed that more family caregivers were not holding a job than non-family caregivers (care giving status × gender: $\chi^2(1) = 1.47$, n.s./care giving status × job status: $\chi^2(1) = 8.00$, $p < .01$). The result of a *t*-test identified that the family caregivers' mean age (66.54 ± 12.11) was significantly higher than that of non-family caregivers (62.28 ± 13.48) ($t(1761) = 5.23$, $p < .001$).

With respect to whether the participants were family caregivers or not, the analyses indicated significant differences in all HRQOL scores (Table 1). However, support size and social support were not different in either group.

To examine potential factors that explain PCS and MCS scores in men (N = 101) and women (N = 144), two-step hierarchical regression analyses were performed by entering age and job status as a set in the first step, and support size and social support as a set in the second step for males and females (Table 2). In males, the results confirmed that only social support predicted the PCS and MCS scores, while other variables did not predict either score. As for the coefficient of multiple determinations, a significant value was gained with MCS only in the second step. Further, the R^2 changes identified by the hierarchical regression analysis in the second step were significant in the PCS and MCS scores. On the other hand, in females, it was found from the second step of hierarchical multiple regression analysis that only age explained the PCS score and job status, and support size explained the MCS score. For the coefficient of multiple determinations, a significant value was achieved for PCS and MCS in the first and second steps. The R^2 change was not significant for either analysis of the female data.

One of the important findings that this study identified was a significant difference in HRQOL depending on whether the participants were family caregivers or not. This finding suggests that health care providers should encourage family caregivers to improve their HRQOL more than non-family care givers. Furthermore, there was not a significant difference between family caregivers and non-family caregivers in social network variables.

The second important finding of this study was that the relationship between social networks and HRQOL differed by gender. Specifically, social support explained the PCS and MCS in males, while support size explained the MCS in females. Likewise, according to the present study, R^2 changes were significant for the MCS in males. From the results of this study, male family caregivers did not necessarily require many supporters to maintain their HRQOL, but rather an attentive listener to their worries or problems. By contrast, the better physical component of female family caregivers was only explained by lower age. Female family caregivers had a preferred mental component if they had a job and many people who support them.

This survey has several limitations. First, because this study was a cross-sectional design, we cannot refer to inferring causal paths. Second, there was a significant difference in HRQOL depending on whether the participants were family caregivers or not, but there were also significant differences in mean age between family caregivers and non-family caregivers. Third, we did not collect data about the degree of care giving for persons with disabilities. Because little research has been directed at evaluating strategies for preserving caregivers physical functioning in addition to their psychological well-being [11], it is very worthwhile to identify social networks as important for the HRQOL of family caregivers. Fourth, in this study, the response rate and R^2 values that were significant were relatively low. It should be noted in the interpretation of the results.

In the future, further studies of family caregivers for persons with disabilities should be conducted in detail. For example, research about the specific disability of the family member (e.g. physical disability, mental disabilities, or intellectual disability) should be done. Additionally, we recommend that future research include an investigation of interventions for family caregivers for persons with disabilities to increase support size and social support.

Table 1: Mean (SD) and results of t-tests for HRQOL and social network by caregiver status

	family caregivers			non-family caregivers			t value	
	mean	SD	N	mean	SD	N		
PF	45.31	8.74	291	47.10	7.17	1328	3.70	***
RP	45.95	7.90	295	47.35	7.74	1340	2.80	**
BP	47.14	8.27	308	48.85	8.09	1369	3.33	***
GH	46.96	7.28	302	48.33	6.87	1290	3.07	**
VT	49.09	7.24	306	50.24	6.55	1373	2.71	**
SF	45.09	9.04	302	46.75	8.92	1353	2.92	**
RE	47.33	7.91	300	48.85	6.93	1328	3.34	***
MH	48.49	7.50	307	49.86	6.84	1363	3.11	**
PCS	44.94	7.52	261	46.11	7.20	1172	2.36	*
MCS	48.11	7.59	261	49.29	6.99	1172	2.42	*
support size	3.91	2.75	296	3.96	2.66	1353	0.31	n.s.
social support	3.79	0.74	311	3.80	0.81	1387	0.11	n.s.

*$p < .05$, **$p < .01$, ***$p < .001$

Table 2: Result of hierarchical multiple regression to explain PCS and MCS by sex of the family caregiver

PCS: male	β		PCS: female	β	
	step 1	step 2		step 1	step 2
age	-.13	-.13	age	-.33***	-.33***
job status	.02	.02	job status	-.03	-.03
support size		.09	support size		-.02
social support		.22*	social support		-.03
R^2	.02	.09	R^2	.09***	.08**
R^2 change		.07*	R^2 change		.00
MCS: male	β		MCS: female	β	
	step 1	step 2		step 1	step 2
age	-.07	-.06	age	.18*	.16
job status	-.02	-.02	job status	.20*	.19*
support size		.14	support size		.19*
social support		.25*	social support		.02
R^2	-.02	.07*	R^2	.04*	.06*
R^2 change		.11**	R^2 change		.04

*$p < .05$, **$p < .01$, ***$p < .001$

List of Abbreviations

HRQOL: health-related quality of life; QOL: quality of life; MOS: Medical Outcomes Study; SF-8: Short Form 8-Item Health Survey; PF: physical functioning; RP: role functioning- physical; BP: bodily pain; GH: general health perception; VT: vitality; SF: social functioning; RE: role functioning-emotional; MH: mental health; PCS: summary scores for the physical components of health; MCS: summary scores for the mental components of health.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

HA performed the statistical analysis. All authors contributed to the study design, carried out this study, and approved the final version of this paper.

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Barriers to referral to inpatient palliative care units in Japan: a qualitative survey with content analysis

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Abstract

Objectives We investigated the barriers to referral to inpatient palliative care units (PCUs) through a qualitative study across various sources of information, including terminal cancer patients, their families, physicians, and nurses.

Materials and methods There were 63 participants, including 13 advanced cancer patients, 10 family members, 20 physicians, and 20 nurses in palliative care and acute care cancer settings from five regional cancer institutes in Japan. Semi-structured interviews were conducted regarding barriers to referral to PCU, and data were analyzed by content analysis method.

Results A total of 21 barriers were identified by content analysis. The leading barriers were (1) a negative image of PCUs by patients and families (n=39), (2) delay of termination of anti-cancer treatment by physicians in the general wards (n=24), (3) unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families (n=22), (4) patient's wish to receive care from familiar physicians and nurses (n=20), and (5) insufficient knowledge of PCUs by medical staff in general wards (n=17).

Conclusions To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image of PCUs from the general population, patients, families, and medical staffs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

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Introduction

Palliative care specialists are faced with extensive barriers to providing effective end-of-life care [1, 14, 15, 30]. It is important to explore barriers to referral to hospice because late referral results in low family satisfaction with care [25]. Many studies have been done regarding obstacles to hospice referral [3–6, 10, 13, 19, 21, 23, 29], and various barriers have been identified. They include the difficulty of predicting prognosis [3, 29], lack of physician acceptance of terminal diagnosis and death [1, 6, 14], physician's unwillingness to refer to hospice service [1, 5], physician's unfamiliarity with hospice [5], physician's negative opinion of hospice service [5], insufficient knowledge of physician about hospice service [1], insufficient education for physicians about palliative care [1, 6, 14], a medical system that does not include hospice as standard care [14, 30], patient's and family's unwillingness to use hospice [1, 19, 23], patient's and family's desire for life-prolonging treatment [29], lack of acceptance of a terminal diagnosis by the patient and family [23, 29, 30], insufficient knowledge by the general population and patients and families about hospice service [10, 13], and social attitudes toward death [30].

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services. National Medical Insurance has covered inpatient palliative care units (PCUs) for terminal cancer patients since 1991, and the number of PCUs has dramatically increased from 5 in 1991 to 162 in 2006. On the other hand, the growth of home-based palliative care programs has been slow, and palliative care teams were not covered by National Medical Insurance until 2002. Therefore, the most common type of specialized palliative care service in Japan is the PCU [7, 9, 17]. Although western studies are focused on referral to home hospice, in Japan, referral is usually to the PCU. As there is a difference in medical systems and cultural background, Japanese barriers to referral to the PCU should be examined [27].

Morita explored reasons for late referral to the PCU in Japan and found misconceptions about palliative care among families, inadequate communication with physicians, and insufficient preparation of the family for the deterioration of the patient's condition [17]. However, Morita's study sample included only bereaved family members of PCU patients. He did not include the families of patients who were not referred or were denied admittance to the PCU. About 5% of cancer deaths occur in PCUs in Japan. Many patients who should have been referred to the PCU are assumed to have died in general wards. Nonetheless, in Japan, there has been no research exploring barriers to referral to the PCU. Therefore, we investigated the barriers to referral to inpatient PCUs using a qualitative study across various sources of information, including terminal cancer patients and their families, physicians, and nurses.

Materials and methods

Participants

Participants were advanced cancer patients, their family members, physicians, and nurses in palliative care and acute care cancer settings of five regional cancer institutes in Japan (Ibaraki, Gunma, Shizuoka, Hiroshima, and Yamaguchi prefectures). We predetermined that we needed to recruit 20 participants in each group as the sufficient number required for a qualitative study. Then 16 participants (four for each group) were allocated for each institution, and the patients who met the following conditions were recruited: having incurable advanced cancer, knowing their diagnosis, having no cognitive impairment, and being aged 20 to 80 years. The physicians and the nurses in acute care settings were required to have had more than 2 years of clinical experience in cancer treatment. The physicians and nurses in palliative care settings were also required to have had more than 2 years of clinical experience in specialized palliative care service. We obtained written informed consent from all the participants.

Interview procedure

Semi-structured interviews were conducted by five interviewers, including the authors of this article (M. M. and K. H.), two graduate school students of psychology, and one research nurse. The interview followed guidelines developed by the authors through careful consideration of the purpose of this study. There were two sets of questions. One set contained predetermined, open-ended questions for patients and family members, such as the following: "If you were offered referral to the PCU, what would be the barriers to admittance to the PCU?" The other set included predetermined, open-ended questions for physicians and nurses, as follows: "What do you think are barriers to referral of patients to the PCU?" For both procedures, the participants were asked to respond freely to the questions.

Analysis

All the interviews were audiotaped and transcribed. Content analysis was performed on the transcribed data [11]. First, a research nurse (M. M.) and a psychologist (K. H.) extracted all statements from the transcripts related to the study topics, such as barriers to referral to inpatient palliative care units. Then, under the supervision of an experienced palliative care physician (T. M.), they carefully conceptualized and categorized the attributes from the transcripts based on similarities and differences in the content and created definitions for all the attributes. Finally, two coders among the research nurses independently determined whether each participant had made remarks that belonged to any of the attributes according to the definitions. When their coding was inconsistent, a third coder was the final judge. The concordance rate and Kappa coefficient by the two independent coders were 89% and 0.55, respectively.

In addition, we conducted descriptive analyses on the frequencies of the attributes. We summarized four groups into non-medical populations (patient and family) and medical staff (physician and nurse), and Fisher's exact test was used to test group differences in the responses for each attribute. Significance level was set 0.05, and a two-tailed test was conducted. All statistical analyses were performed using statistical package SAS for Windows version 9.1 (SAS Institute, Cary, NC).

Results

Respondent characteristics

There were a total of 63 participants, including 13 patients, 10 family members, 20 physicians (10 PCU, 10 general ward), and 20 nurses (10 PCU, 10 general ward; Table 1). In several institutions, the enrollment of non-medical populations was insufficient because of the absence of suitable participants. Although several institutions did not recruit the required number due to the absence of suitable participants during the study periods, we did not recruit additional participants because the number of extracted attributes was satisfactorily saturated by the end of the planned study period. Fifty-seven percent of the participants were female, and the mean age was 45 years. The patients' primary sites of cancer were the lungs (n=5), pancreas (n=5), liver (n=2), and others (n=2). Patient expected survival time from interviews was 1–3 months (n=6), 3–6 months (n=2), 6 months–1 year (n=3), and unknown (n=2). Patient performance status (ECOG PS) was 0 (n=2), 1 (n=3), 2 (n=4), 3 (n=3), and 4 (n=2).

Barriers to referral to PCU in Japan

A total of 21 barriers were identified by content analysis. We classified these barriers into three categories: (1) patient- and family-related barriers, (2) medical staff-related barriers, and (3) PCU system-related barriers. Their frequency is shown in Table 2. The leading attribute was a negative image of the PCU by patients and families (n=39). Second was delaying the termination of anti-cancer treatment by general ward physicians (n=24). The third barrier was unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families (n=22). Fourth was the patient's wish to receive care by the accustomed physician and nurse (n=20). And the fifth barrier was insufficient knowledge of PCUs by medical staff in the general ward (n=17).

Table 1 Participants' demographics

	Patient (n=13)	Family (n=10)	Physician (n=20)	Nurse (n=20)
Age, mean (SD), year	62.2 (11.7)	54.4 (11.5)	38.6 (6.5)	34.9 (7.6)
Male, n (%)	7 (53)	1 (10)	19 (95)	0 (0)
Professional career, mean (SD), year	NA	NA	13.3 (6.1)	12.8 (6.6)

Table 2 Barriers to referral to PCU in Japan (n=63)

	Number	Percent
Patient- and family-related barriers		
(1) Negative image of PCU among patients and family members	39	62
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	22	35
(3) Patient's wish to receive care by accustomed physician and nurse	20	32
(4) Family's request for patient not to be admitted to PCU	10	16
(5) Insufficient knowledge of the PCU among patients and family members	8	13
General ward medical staff-related barriers		
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	24	38
(7) Insufficient knowledge of PCU among medical staff in general ward	17	27
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	15	24
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	13	21
(10) Not proposing PCU as an alternative by medical staff in the general ward	11	17
(11) Negative image of PCU by medical staff in general ward	10	16
(12) Desire of medical staff in general ward to care for patient until death	10	16
(13) Insufficient communication skills of medical staff in general ward	6	10
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	5	8
PCU-related barriers		
(15) Poor access to PCUs (shortage of PCUs, inconvenient locations)	12	19
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	10	16
(17) Poor communication between PCU staff and medical staff in general ward	9	14
(18) Discontinuation of anti-cancer treatment in PCU	7	11
(19) Economic problems (expensive private room fee, expensive hospital bill)	6	10
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules for admission)	5	8
(21) Prospective payment system of PCU	3	5

PCU Palliative care unit

Table 3 shows the differences in responses among groups. For patients, families, and nurses, a negative image of the PCU by patients and families was the leading barrier. For physicians, however, it was delaying the termination of anti-cancer treatment. The following barriers were significantly different among the studied groups: (1) negative image of PCU among patients and family members, (2) insufficient knowledge of the PCU among patients and

Table 3 Differences in responses among groups

Barriers	Patient (n=13)		Family (n=10)		Physician (n=20)		Nurse (n=20)		P value
	N	%	n	%	n	%	n	%	
Patient- and family-related barriers									
(1) Negative image of PCU among patients and family members	7	54	3	30	11	55	18	90	0.006
(2) Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patient and family	3	23	2	20	10	50	7	35	0.33
(3) Patient's wish to receive care by accustomed physician and nurse	2	15	1	10	9	45	8	40	0.12
(4) Family's request for patient not to be admitted to PCU	0	0	1	10	4	20	5	25	0.24
(5) Insufficient knowledge of the PCU among patients and family members	0	0	0	0	8	40	0	0	0.001
General ward medical staff-related barriers									
(6) Delaying the termination of anti-cancer treatment by the physician in the general ward	0	0	0	0	13	65	11	55	0.001
(7) Insufficient knowledge of PCU among medical staff in the general ward	0	0	1	10	8	40	8	40	0.013
(8) Failing to communicate a bad prognosis by the medical staff in the general ward	0	0	0	0	8	40	7	35	0.006
(9) Insufficient explanation of PCU by medical staff to the patients and families in general ward	0	0	0	0	4	20	9	45	0.003
(10) Not proposing PCU as an alternative by medical staff in the general ward	0	0	0	0	6	30	5	25	0.047
(11) Negative image of PCU by medical staff in general ward	0	0	0	0	4	20	6	30	0.051
(12) Desire of medical staff in general ward to care for patient until death	0	0	0	0	4	20	6	30	0.051
(13) Insufficient communication skills of medical staff in general ward	0	0	0	0	4	20	2	10	0.24
(14) Uncertainty of limits of anti-cancer treatment by medical staff in general ward	0	0	0	0	4	20	1	5	0.19
PCU-related barriers									
(15) Poor access to PCU (shortage of PCUs, inconvenient location)	2	15	1	10	6	30	3	15	0.59
(16) Environment of PCU (private room, loneliness, and isolation from general ward)	2	15	1	10	4	20	3	15	0.96
(17) Poor communication between PCU staff and medical staff in general ward	0	0	0	0	4	20	5	25	0.12
(18) Discontinuation of anti-cancer treatment in PCU	2	15	0	0	3	15	2	10	0.77
(19) Economic problems (expensive private room fee, expensive hospital bill)	0	0	1	10	1	5	4	20	0.27
(20) Doctrinaire beliefs of PCU (emphasis on philosophy, stringent rules of admission)	0	0	0	0	2	10	3	15	0.43
(21) Prospective payment system of PCU	0	0	0	0	2	10	1	5	0.77

PCU Palliative care unit

family members, (3) delaying the termination of anti-cancer treatment by the physician in the general ward, (4) insufficient knowledge of the PCU among medical staff in the general ward, (5) failing to communicate a bad prognosis by the medical staff in the general ward, (6) insufficient explanation of the PCU by medical staff to the patients and families in the general ward, and (7) not proposing PCU as an alternative by medical staff in the general ward. The comparison between PCU staff (PCU physicians and nurses) and general ward staff (general ward physicians and nurses) was not significantly different for any attributes (data not shown).

Discussion

This is the first study to investigate the barriers to referral to the inpatient PCU in Japan. A negative image of the PCU is recognized as the most important barrier by patients, families, and medical staffs. They described the PCU as a place of death in that once a patient was admitted to the PCU, he or she could not be discharged alive. They also believed that the PCU shortens the patient's life, isolates patients from the community, and does not offer medical treatment. The opinion that the PCU shortens the patient's life coincides with the findings of Morita's study of late referral [17]. Sanjo reported that the belief that the PCU isolates patients from the community contributes to avoidance of the PCU [24].

Although PCUs are recognized by the general Japanese population and bereaved family members as services that provide compassionate care, helping patients die peacefully and with dignity, providing care for families, and falleviating pain, they still view the PCU as a place that shortens patients' lives and isolates dying patients from the community and as an expensive place where people are only waiting to die (Sanjo et al., submitted for publication). In addition, Shiozaki investigated dissatisfaction of bereaved family members in the PCU and reported a negative image of the PCU as one of the major reasons for dissatisfaction [26]. Of note, many medical staff reported that the dissemination of these unfavorable images was by patients to patients and families to families. Patients admitted to the general wards and their families were told that the PCU was a place of death by other patients and families. Although some of these images were true [26], Morita showed that the unfavorable opinions could be changed through the experience of being cared for in the PCU [17]. Therefore, of these negative images, several are misconceptions or misunderstandings. To correct these misconceptions, it is important to disseminate accurate information about PCUs to the general population, patients, and families [18].

Delay in ending anti-cancer treatment by physicians in the general ward could be due to the difficulty of predicting prognosis [3, 29]. In addition, it may be associated with the physician's lack of acceptance of the patient's terminal diagnosis and death [1, 6, 14]. Several study participants in the general wards said that even if a physician recognized that a patient might be in a terminal phase, the introduction of palliative care is postponed by the patient's desire for anti-cancer treatment and the uncertainty of the prognosis made the physician. In Japan, the palliative care option is seldom introduced to patients who are receiving anti-cancer treatment. Therefore, it is difficult for the physician to have the opportunity to communicate bad news, especially because physician education in this area is so poor. In addition, determining the time to stop anti-cancer treatment is difficult for the oncologist. Therefore, early introduction of the palliative care option to the patient [8] and communication skills training regarding breaking bad news are relevant issues [2, 20].

Unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by the patient and family are major problems. Some patients with terminal cancer seek out anti-cancer treatment even if the possibility of cure is low [12, 28]. In addition, a Japanese study revealed that a number of bereaved families experienced serious emotional burden with the ending of anti-cancer treatment and transition to palliative care [16]. Early introduction of the palliative care option and careful and sophisticated communication with the patient and family are important [16]. To that end, it is necessary for the medical staff in the general ward to have accurate information about the PCU and palliative care.

In our study, although most of the barriers to inpatient PCU care are similar to those reported by western countries, several issues unique to Japan were found. Ten participants told of the family's request for the patient not to be admitted to the PCU. In Japan, it is traditional for the family to intervene in decision-making [22]. Twelve participants told of poor access to a PCU. Only 5% of cancer deaths occur in the PCU. Therefore, the number of PCUs is insufficient and many patients die in the general ward while awaiting admission to the PCU. In addition, some PCUs have stringent admission rules, such as compelling the patient to recognize the diagnosis or prognosis, restrictions on the patient's physical and cognitive condition, and a correct understanding of the purpose of the PCU by patients. The shortage of PCUs is an important barrier to providing specialized palliative care in Japan. An increase in the number of PCU beds and the development of home hospices are needed to deliver palliative care to all dying patients.

The barriers to PCU admission significantly differed according to the group. Patients and families were not aware of physicians' attitudes and were not familiar with their barriers. This indicates an asymmetry of information regarding medical systems among patients, families, and medical staffs.

Our study has several limitations. First, we surveyed a limited number of institutions, and all participating institutions were hospitals with PCUs. If patients, families, and medical staff in general wards with non-PCU hospitals had participated, there may have been more emphasis on access to PCUs. Therefore, generalizing the present results is difficult. Second, barriers identified by patients and families were of low frequency. It was difficult to elicit barriers from patients in terminal stages of cancer and their families. Therefore, a study targeting an earlier phase might be required. Third, although we predetermined that we needed to recruit 20 participants for each group, we could not achieve such number among patient and family member groups. However, we believe that the variety of participants would assure the content validity of this study. Finally, because the number of participants in the four groups were different, determining the importance of each barrier by summing up the answers of the four groups might be not conclusive.

Conclusions

In conclusion, we identified 21 barriers to referral to the PCU and determined the frequency of these barriers. The leading barriers were a negative image of the PCU by patients and families, delaying the termination of anti-cancer treatment by general ward physicians, unwillingness to end anti-cancer treatment and denial of the fatal nature of the disease by patients and families, the patient's wish to receive care by the accustomed physician and nurse, and insufficient knowledge of PCUs by medical staff in the general ward.

To correct these unfavorable images and misconceptions of PCUs, it is important to eliminate the negative image that the general population, patients, families, and medical staff have of PCUs. In addition, early introduction of palliative care options to patients and communication skills training regarding breaking bad news are relevant issues for a smooth transition from anti-cancer treatment to palliative care.

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REVIEW ARTICLE

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

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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.

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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.[1] 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.[2] As a consequence, surveys of terminally ill patients are likely to be unrepresentative and/or biased.[3] 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,[4-6] the Regional Study of Care for the Dying was conducted in the United Kingdom in 1990.[7-9] This study involved 3,696 patients, and many secondary findings were reported.[10-13] In the United States, the large-scale Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments began in 1989.[14] Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments included a follow-up postbereavement study,[15] and the satisfaction of relatives was measured.[16] Several mortality follow-back surveys have also been conducted in the United States.[17,18] Teno et al[19-22] 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.[23] 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.[24-26] In addition, numerous surveys have been performed with bereaved family members, including a large-scale survey in the United Kingdom,[27] surveys of intensive care units,[28-31] surveys focusing on the place of care,[32] home care,[33] community hospitals,[34] comparisons

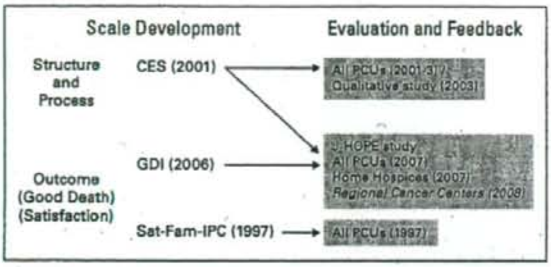

Fig 1. Overview of progress of quality evaluation projects for end-of-life care from the perspective of bereaved family members. CES, Care Evaluation Scale; GDI, Good Death Inventory; PCU, palliative care unit; J-HOPE, Japan Hospice and Palliative Care Evaluation study; Sat-Fam-IPC, Satisfaction Scale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

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

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[40-42] 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[43,44] and was used in a subsequent mortality follow-back survey. Curtis et al[45] 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).[46] 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.[47] 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	294	68	*Comparison with 2001-2003 study*
		60 regional cancer centers	*3000-6000 (posting)*	—	*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.[48] 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).[49] 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.[50]

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.[50]

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.[50]

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.[50]

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).[3] 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).[51]

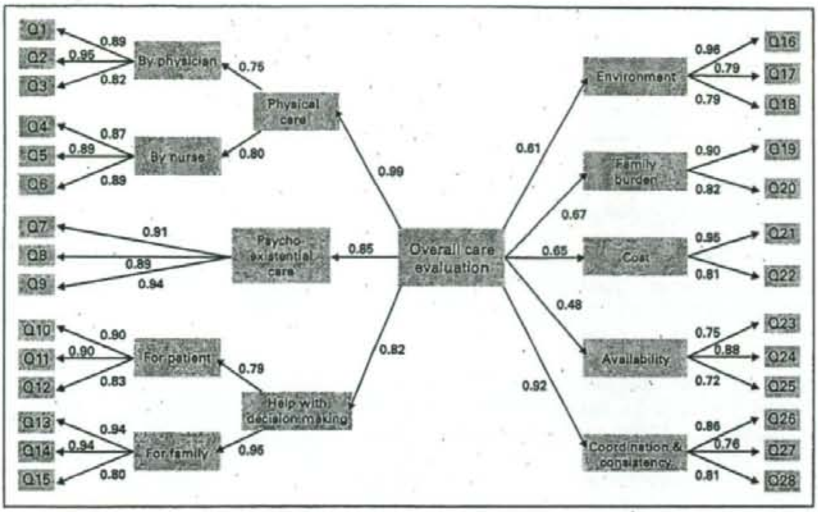

Fig 2. Confirmatory factor analysis of the Care Evaluation Scale.

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.[51]

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.[52] 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 α coefficient; ICC, intra-class correlation coefficient; PCUs, palliative care units.

care is achieving a good dying process.[53-55] 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.[56] 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.[57]

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).[57,58] 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.[59] 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,[60] appetite loss and bronchial secretion,[61] and sedation;[62,63] psychiatric symptoms, such as a desire for death;[64] decision making, such as late referral to the PCU,[65] and communication about the end point of anticancer treatment;[66] attitudes toward palliative care, such as the notion of a good death and preferences for end-of-life care,[67,68] knowledge about palliative care,[69] and impressions of PCUs;[70] and the experience of home death.[71] 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

	Improvement of Structures and Processes of Care												
	Highly Necessary		Considerably Necessary		Necessary		Slightly Necessary		Rarely Necessary		Not Necessary		
Item and Year	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	*P*
(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	2271	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	38.6	271	31.8	
2007	45	0.8	105	2.0	300	5.7	472	8.9	2,096	39.5	2,075	39.1	
(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	8.6	748	14.1	1,871	35.2	1,698	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	2,209	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.[72,73] 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.[1,2] Many problems persist concerning whether it is appropriate to use proxy raters,[74-77] telephone interviews, or postal questionnaires;[40,78] the timing of the survey;[3,4,42] the sequence of the questions;[79] and the properties of the questionnaire from a cognitive psychology perspective.[80] 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