

Table 5
Concurrent and Discriminant Validity with Total Score of Care Evaluation Scale and Satisfaction

	Total score of CES	Overall care satisfaction
Physical and psychological comfort		
6. Physical and psychological comfort	0.32 ^a	0.47 ^a
Place of care		
1. Environmental comfort	0.39 ^a	0.42 ^a
3. Dying in a favorite place	0.32 ^a	0.50 ^a
Decision-making and relation to medical staff		
7. Good relationship with medical staff	0.42 ^a	0.55 ^a
12. Receiving enough treatment	0.28 ^a	0.50 ^a
15. Unawareness of death	0.29 ^b	0.35 ^a
17. Natural death	0.34 ^a	0.45 ^a
Family relationship		
9. Good relationship with family	0.07	0.18 ^c
Psycho-existential issues		
2. Life completion	0.15 ^c	0.33 ^a
4. Maintaining hope and pleasure	0.27 ^a	0.33 ^a
5. Independence	0.08	0.11
8. Not being a burden to others	0.19 ^c	0.14
10. Being respected as an individual	0.27 ^a	0.28 ^a
11. Religious and spiritual comfort	0.05	0.12
13. Control over the future	0.14	0.25 ^a
14. Feeling that one's life is worth living	0.22 ^b	0.28 ^a
16. Pride and beauty	0.09	0.16 ^c
18. Preparation for death	0.16 ^c	0.27 ^a
All 18 domains	0.26 ^a	0.39 ^a
Core 10 domains	0.31 ^a	0.41 ^a
Optional eight domains	-0.02	0.10

Figures are Pearson's correlation coefficients.

^a $P < 0.001$.

^b $P < 0.01$.

^c $P < 0.05$.

except for "not being a burden for others" (ICC = 0.38). The ICC of all 18 domains was 0.52; of the total of the 10 core domains, it was 0.59; and of the total of the eight optional domains, it was 0.50.

Development of Short Version of the GDI

In accordance with the process described in the Analysis section, we selected 18 attributes for each domain to create the short version of the GDI (Table 7). Pearson's correlation coefficient between each attribute and the final domains ranged from 0.80 to 0.97. The Cronbach's alpha coefficient of all 18 attributes

Table 6
Internal Consistency and Reliability

Domains	Alpha	ICC
Core 10 domains		
1. Environmental comfort	0.92	0.57
2. Life completion	0.87	0.63
3. Dying in a favorite place	0.94	0.68
4. Maintaining hope and pleasure	0.91	0.67
5. Independence	0.82	0.52
6. Physical and psychological comfort	0.92	0.44
7. Good relationship with medical staff	0.83	0.87
8. Not being a burden to others	0.83	0.38
9. Good relationship with family	0.79	0.44
10. Being respected as an individual	0.74	0.58
Optional eight domains		
11. Religious and spiritual comfort	0.95	0.58
12. Receiving enough treatment	0.90	0.59
13. Control over the future	0.87	0.72
14. Feeling that one's life is worth living	0.86	0.60
15. Unawareness of death	0.81	0.53
16. Pride and beauty	0.84	0.51
17. Natural death	0.74	0.50
18. Preparation for death	0.78	0.61
All 18 domains	0.94	0.52
Core 10 domains	0.92	0.59
Optional eight domains	0.87	0.50

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.

was 0.85; of the 10 core attributes, it was 0.78; and of the eight optional attributes, it was 0.69. The ICC of all 18 attributes was 0.71; of the 10 core attributes, it was 0.64; and of the eight optional attributes, it was 0.59.

Discussion

We validated the GDI in Japanese bereaved family members. This assessment will allow us to evaluate end-of-life care from the bereaved family's perspective. The most useful finding is in regard to concurrent validity. Some GDI domains measuring end-of-life care that focus on structure and process of care correlated with the CES. However, other domains did not correlate with the CES or overall care satisfaction. This means that the GDI might measure different aspects of end-of-life care and that the results are consistent with the hypothesis that the GDI explains a significant portion of the bereaved family member's overall satisfaction.

As for the factor validity, we identified 18 possible domains. We conducted a nationwide opinion survey on this topic preceding the present study. The results of the present study

Table 7
Short Version of the Good Death Inventory

Attributes	Pearson's r^a
Core 10	
Living in calm circumstances	0.93
Feeling that one's life was completed	0.92
Having some pleasure in daily life	0.94
Being able to stay at one's favorite place	0.96
Being independent in daily activities	0.87
Being free from physical distress	0.96
Trusting physician	0.87
Not being a burden to others	0.89
Spending enough time with one's family	0.89
Being valued as a person	0.83
Optional eight	
Supported by religion	0.97
Receiving enough treatment	0.92
Knowing what to expect about one's condition in the future	0.95
Feeling that one's life is worth living	0.88
Dying without awareness that one is dying	0.87
Not exposing one's physical and mental weakness to family	0.87
Dying a natural death	0.80
Saying what one wants to dear people	0.87
Internal consistency	
All 18 attributes	Alpha 0.85
Core 10 attributes	0.78
Optional eight attributes	0.69
Test-retest reliability	
All 18 attributes	ICC 0.71
Core 10 attributes	0.64
Optional eight attributes	0.59

Alpha = Cronbach's alpha coefficient; ICC = Intraclass correlation coefficient.

^aPearson's correlation coefficient with each domain total score.

confirm the findings of the preceding study and confirm that a good death concept in the Japanese population is constituted by these 18 domains.²⁵

As for the concurrent and discriminant validity, physical and psychological comfort, environmental comfort, dying in a favorite place, good relationship with medical staff, receiving enough treatment, unawareness of death, and natural death were correlated with presumed items of the CES. However, good family relationship, life completion, maintaining hope and pleasure, independence, not being a burden to others, being respected as an individual, religious and spiritual comfort, control over the future, feeling that one's life is worth living, pride and beauty, and preparation for death either were not correlated or were weakly correlated with the items of the CES. These domains cover psycho-existential and

spiritual concerns in the Japanese population.^{26,27} As the CES measures the structure and process of care, these results are considered reasonable. The GDI might be able to measure outcomes of care based on individualized important issues in the dying process. In addition, as a whole, the domains of the GDI were more correlated with overall care satisfaction than with the CES. This means that the GDI might cover more comprehensive aspects of end-of-life care outcomes than the CES. The concept of satisfaction of bereaved family members is still unclear and using satisfaction as a measure of quality of care contains unresolved problems.²⁸ The results of our study would provide more information of the understanding of care satisfaction from bereaved family members' perspectives.

Some might consider it odd that domains XIV (control over the future) and XV (unawareness of death) would coexist in the Japanese concept of a good death. However, our previous study found that the Japanese population emphasized both concepts. Actually, these two domains are part of the eight optional domains. These optional domains are thought to be concepts with lesser importance to the individual. In contrast to Steinhauser et al.'s⁷ good death study, the Japanese population does not consider control over the future as important as the US population. The less autonomous attitude in the dying process might be unique to Japanese culture.^{7,25}

Although the domains of the GDI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value.²⁹ We think the reasons for moderate reliability would be as follows: (1) the period of test-retest was over one month; (2) we recruited participants until two years after death, so memory might be vague; (3) although we asked the primary caregiver to answer the questionnaire, we could not be sure that the identical person filled out the two questionnaires; and (4) the family member's assessment of the GDI might change over time. However, the moderate reliability of the study of bereaved family members is consistent with previous work.^{20,30} Therefore, these moderate ICCs would not be crucial drawbacks of the GDI. The relatively low ICC of "not being a burden to others" is reasonable because it is difficult for family members to infer the patient's viewpoint. Instead, we might appreciate

the sufficient internal consistency as a measure of reliability for a cross-sectional study.

In addition, we developed a short version of the GDI. Depending on the study objective, an investigator might be reluctant to use the full version. In that situation, the investigator would be able to use the short version. The psychometric properties of the short version of the GDI have been shown. This short version of the GDI could be used in any study setting.

Limitations and Future Perspectives

The limitations of this study are as follows: First, the response rate was 57%. We believe, however, this is not a fatal flaw because the objective of this study was to validate a scale, not to survey actual conditions. Second, this study was conducted at one regional cancer center. The results of this study might not be generalizable to other settings. Third, this study did not examine criterion validity. It is difficult to examine criterion validity, however, because the gold standard for measuring a good death has not yet been established.

In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should investigate the national level of a benchmark of the achievement of a good death and differences in the achievement of a good death among institutions or care settings. Furthermore, we should identify barriers to achieving a good death and develop methods for eliminating these barriers in all Japanese end-of-life care settings.

Conclusions

In conclusion, we validated the GDI as a measure for evaluating a good death from the bereaved family's perspective. The GDI has sufficient factor validity, concurrent validity, internal consistency, and acceptable test-retest reliability. The GDI is a valid scale for measuring comprehensive end-of-life care outcomes from the bereaved family members' perspective in Japan. In future studies, we would like to conduct a nationwide survey of the achievement of a good death using this scale. In addition, we should identify and eliminate barriers to achieving a good death in all Japanese end-of-life care settings.

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Appendix

Good Death Inventory (GDI)

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

- | | |
|---|--|
| <p>I. Physical and psychological comfort
Patient was free from pain.
Patient was free from physical distress.
Patient was free from emotional distress.</p> | <p>XI. Receiving enough treatment
Patient received enough treatment.
Patient believed that all available treatments were used.
Patient fought against disease until the last moment.</p> |
| <p>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.</p> | <p>XII. Natural death
Patient was not connected to medical instruments or tubes.
Patient did not receive excessive treatment.
Patient died a natural death.</p> |
| <p>III. Maintaining hope and pleasure
Patient lived positively.
Patient had some pleasure in daily life.
Patient lived in hope.</p> | <p>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.</p> |
| <p>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.</p> | <p>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.</p> |
| <p>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 (*).</p> | <p>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.</p> |
| <p>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.</p> | <p>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 (*).</p> |
| <p>VII. Independence
Patient was independent in moving or waking up.
Patient was independent in daily activities.
Patient was not troubled with excretion.</p> | <p>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.</p> |
| <p>VIII. Environmental comfort
Patient lived in quiet circumstances.
Patient lived in calm circumstances.
Patient was not troubled by other people.</p> | <p>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.</p> |
| <p>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.</p> | |
| <p>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.</p> | |

(* Inverse items.

Effect of a population-based educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care

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The effectiveness of population-based educational interventions in palliative care is unclear. We conducted an educational intervention study for the general public focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care and measured the change in perception about these issues. Participants were recruited from the 11 districts of Fukushima City, Japan. One-hour educational lectures were conducted in each district from April 2006 to March 2007. Meetings were held in a community centre or hall in each district. We asked participants to fill in a questionnaire before and after the educational lecture. Of 607 participants, 595 (98%) answered both pre- and post-intervention questionnaires. The feasibility of a home death changed from 9% before to 34% after the intervention ($P < 0.001$). In addition, preference for life-prolonging treatment and attitudes toward end-of-life care including symptom management at home, misconceptions about opioids, artificial hydration and communication issues between patient and medical practitioners were significantly improved after the intervention. Factors that were significantly associated with changing perceptions about the feasibility of a home death were male gender, change in beliefs regarding burden to family caregivers, anxiety regarding admission to the hospital with worsening physical condition and fear that pain would not be relieved at home. This population-based educational intervention was effective in changing beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward end-of-life care. *Palliative Medicine* (2008); 22: 376–382

Key words: barriers; education; home death; intervention studies; palliative care

Introduction

It is important for terminal cancer patients to be able to remain in their favourite place.¹ Over half of Japanese would like to be cared for at home.² However, in Japan, the growth of home-based palliative care programs has been slow.^{3,4} As a result, in 2004, only 6% of cancer deaths occurred in the home and over 90% occurred in hospitals.

There are many barriers to home care for end-of-life cancer patients.^{5–12} For example, previous studies have suggested that sex,¹² age,^{8,12} burden to the family^{6,7,12} and the ability of the family to care for the patient^{11,13} were factors associated with home care of terminal patients.

There are also many barriers to receiving appropriate palliative care for end-of-life cancer patients.^{14,15} For

instance, misconceptions about analgesics,^{16–19} misperceptions about life-prolonging treatment^{20–22} and lack of communication between patient and medical practitioner^{23,24} were reported to be potential barriers to palliative care.

In a large population-based survey of Japanese, we found many misconceptions about pain and opioids, communication with health care professionals, hydration and nutrition and legal issues about end-of-life options.²⁵ In addition, our previous study showed that misconceptions regarding opioid use and life-prolonging treatment prevented members of the general public from believing that they could live at home until death.²⁶

To overcome these barriers, it is important to provide appropriate education for the general public.¹⁵ Although education for cancer patients and their families has been conducted,^{27–33} educational interventions about palliative care for the general public have not been reported except for one regarding attitudes about cardiopulmonary resuscitation,³⁴ and a Canadian study using a trade show to educate the general public.³⁵ The effectiveness of population-based educational interventions is still

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unclear. Therefore, we conducted an educational intervention study for the general public focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care and measured the change in perception about these issues before and after the intervention.

Methods

Subjects

Potential participants were recruited from the 11 districts of Fukushima City, Fukushima Prefecture, Japan. Fukushima City has a population of 288,000 and is the most urban city in Fukushima Prefecture. However, Fukushima Prefecture is a relatively rural region. The lectures were held during a periodic regional community meeting. Before the meeting a simple pamphlet about the lecture was distributed. No special invitation was conducted. A total of 607 community-dwelling residents attended the lecture.

Intervention

One-hour educational lectures were held in each district from April 2006 to March 2007. Meetings were held in a community centre or hall in each district. The themes of the educational lectures were as follows: limitations of cancer treatment, life-prolonging treatment for end-of-life cancer patients, correct information about opioids, artificial hydration, communication between patient and physicians, feasibility of home care for end-of-life cancer patients and district health resources for terminally-ill cancer patients. The lecturer for all the sessions was one physician (M.S.).

Procedure

We asked participants to fill out the questionnaire before and after the lecture. We described the aim of the study, protection of privacy and voluntary nature of participation by written document and oral explanation.

Questionnaire

Feasibility of home death

We asked participants to consider the feasibility of home death by answering 'possible', 'impossible' or 'unsure' to the questions.

Barriers to home care at the end-of-life setting

We explored barriers to home care in the end-of-life setting by asking whether participants agreed that the following were attributes of home care: absence of visiting physician, absence of visiting nurse system, absence of 24-h consultation system, absence of family caring for me, burden of care on family, anxiety about worsening

physical condition, anxiety about admission to the hospital when physical condition worsens, concern that one's residence would be too small, economic burden and pain would not be relieved at home.

Preference for life-prolonging treatment

We asked about the preference for life-prolonging treatment using a 4-point Likert scale with the possible responses: 'want to receive', 'probably want to receive', 'probably do not want to receive' and 'do not want to receive'. Questions asked were regarding artificial hydration, artificial nutrition, vasopressors, mechanical ventilation and cardiopulmonary resuscitation.

Attitudes toward end-of-life care

We asked about the attitudes toward end-of-life care using a 5-point Likert scale: 'strongly agree', 'agree', 'unsure', 'disagree' and 'strongly disagree'. Questions were identical to our previous study, as follows:²⁵ 'absence of sufficient medical system for treatment or care at home', 'in my circumstance, it is difficult to be cared for at home', 'cancer pain is sufficiently relieved if treatment is adequate', 'opioids shorten life', 'opioids cause addiction', 'consciousness is clear if pain medication is not used', 'artificial hydration and nutrition should be continued as the minimum standard until death', 'artificial hydration and nutrition relieve symptoms', 'physicians are generally poor at communicating bad news', 'physicians are uncomfortable discussing death', 'it would be intolerable if I was told I had incurable cancer', 'cancer treatment has only limited effectiveness', 'I want to receive cancer treatment as long as possible', 'death at home indicates to relatives that the family cannot provide sufficient medical care for the patient', 'death at home indicates to neighbors that the family cannot provide sufficient medical care for the patient' and 'large hospitals provide better quality medical treatment than clinics'.

Satisfaction with lecture

We asked about satisfaction with the lecture using the following responses: 'lecture was interesting', 'lecture was easy to understand', 'lecture would be of help in the future' and 'lecture gave me the chance to consider end-of-life medical treatment'.

Participant characteristics

We asked participant's age, gender, education, health status, experience of hospital admission, number of family members living together, ability to talk about end-of-life concerns with family and experience of bereavement over the past 10 years.

Analyses

Regarding feasibility of home death, we compared the proportion of 'possible' responses between the pre- and

post-intervention questionnaires with the Wilcoxon's signed rank test. We used the same test for comparing pre- and post-intervention barriers to home care at the end-of-life setting, preference for life-prolonging treatment and attitudes toward end-of-life care. In addition, we explored factors associated with changing perceptions regarding the feasibility of home death by logistic regression analysis among participants answering 'impossible' or 'unsure' in the pre-intervention questionnaire. The dependent variable was the answer to the feasibility of home death in the post-intervention questionnaire. The explanatory variables were: participant characteristics and changing perceptions regarding barriers to home care in the end-of-life setting, reference to life-prolonging treatment and attitudes toward end-of-life care from pre-intervention to post-intervention. The backward variable selection method with $P > 0.05$ criterion was used. In all analyses, the significance level was set at $P < 0.05$, and a 2-sided test was used. All analyses were conducted using statistical package SAS (SAS Institute, Cary, North Carolina, USA).

Ethical consideration

This study was approved by the institutional review board of the Fukushima Medical University and was conducted in accordance with the Helsinki Declaration.

Results

Of 607 participants, 595 (98%) answered both the pre- and post-intervention questionnaires. Participant characteristics are shown in Table 1. Mean age \pm SD was 66 ± 11 years; 67% were female; 24% had a college or university education; 84% reported *excellent or good* health status; 58% had a hospital admission; 87% were living with someone; 81% talked about end-of-life concerns with family members and 66% experienced bereavement during the previous 10 years.

Table 2 shows responses regarding the feasibility of home death. In the pre-intervention questionnaire, only 9% of respondents answered 'possible' to this question, whereas in the post-intervention survey 34% answered 'possible' ($P < 0.001$). Barriers to home care at the end of life are shown in Table 3. The following responses showed significant improvement as a result of the intervention: 'absence of visiting physician', 'absence of visiting nurse system', 'burden of care on family', 'anxiety about worsening physical condition', 'anxiety about admission to the hospital when physical condition worsens', 'economic burden' and 'pain would not be relieved at home'.

Table 4 shows preferences for life-prolonging treatment. The proportion that preferred artificial hydration, artificial nutrition and vasopressors was significantly

Table 1 Participant characteristics ($n = 595$)

	<i>n</i>	%
Age, years (mean \pm SD)	66 \pm 11	
Gender		
Male	191	32
Female	396	67
Education		
Junior high school	141	24
High school	304	51
College	77	13
University	63	11
Health status		
Excellent	249	42
Good	253	43
Fair	78	13
Poor	4	1
Experience of hospital admission		
Yes	343	58
No	240	40
Number of family members living together		
None	74	12
1	179	30
2 or 3	176	30
4 or more	158	27
Discuss end-of-life concerns with family		
Frequently	81	14
Sometimes	400	67
Rarely	92	15
Never	7	1
Experience of bereavement over 10 years		
Yes	395	66
No	187	31

Percentages do not add up to 100% because of missing values.

decreased after the intervention. Attitudes toward end-of-life care are presented in Table 5. There was a significant change in agreement with the following items: 'absence of sufficient medical system for treatment or care at home', 'in my circumstance, it is difficult to be cared for at home', 'opioids shorten life', 'opioids cause addiction', 'consciousness is clear if pain medication is not used', 'artificial hydration and nutrition should be continued as the minimum standard until death', 'artificial hydration and nutrition relieve symptoms', 'physicians are generally poor at communicating bad news', 'physicians are uncomfortable discussing death', 'it would be intolerable if I was told I had incurable cancer', 'death at home indicates to relatives that the family cannot provide sufficient medical care for the patient', 'death at home indicates to neighbors that the family cannot pro-

Table 2 Feasibility of home death pre- and post-intervention

	Pre		Post		<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	
Possible	54	9	203	34	0.001
Impossible	314	53	163	27	
Unsure	199	33	191	32	

Table 3 Barriers to home care in the end-of-life setting pre- and post-intervention

	Pre (%)	Post (%)	P value
Absence of visiting physician	34	28	0.001
Absence of visiting nurse system	24	19	0.004
Absence of 24-h consultation system	21	23	0.484
Absence of family caring for me	19	21	0.402
Burden on family of care	78	66	0.001
Anxiety about worsening physical condition	62	52	0.001
Anxiety about admission to hospital if worsening physical condition	43	34	0.001
Insufficient resources at home	18	17	0.320
Economic burden	43	24	0.001
Pain would not be relieved at home	42	20	0.001

vide sufficient medical care for the patient' and 'large hospitals provide better quality medical treatment than clinics before death'. However, there was no significant change in agreement with 'cancer pain is sufficiently relieved if treatment is adequate'.

We show factors associated with the change of feasibility of home death by logistic regression in Table 6. The significant independently-associated factors with change in the feasibility of home death were: male gender, burden of care on family (changed from yes to no), anxiety about admission to the hospital with worsening physical condition (changed from yes to no) and concern that pain would not be relieved at home (changed from yes to no).

As for satisfaction with the lecture, participants answered that the lecture was interesting (95%), easy to understand (96%), would be of help for the future (95%) and provided the opportunity to consider end-of-life medical treatment (94%).

Discussion

We showed that a 1-h educational intervention regarding palliative care could change beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward end-of-life care, including symptom management at home, misconceptions about opioids and

Table 4 Preference for life-prolonging treatment pre- and post-intervention

	Pre (%)	Post (%)	P value
Artificial hydration	62	52	0.001
Artificial nutrition	49	38	0.001
Vasopressor	38	32	0.004
Mechanical ventilation	23	21	0.428
Cardiopulmonary resuscitation	25	22	0.098

Figures are total percentage of 'desired' and 'probably desired'.

artificial hydration and communication between patients and medical practitioners. Regarding the feasibility of home care, the percentage answering 'possible' was increased nearly 4 times compared with pre-intervention. Most Japanese believe that it is difficult to be cared for at home at the end of life. However, the provision of appropriate information would make it more likely that people will choose this option.

This intervention study was conducted during regular regional community meetings. Participants did not have a special interest in this topic. However, the educational intervention had a significant effect on the participants. The results of this study might be applied to the other regions in Japan.

In the multivariate analysis exploring factors associated with the change of feasibility of home death, we found that four independent factors contributed to a change in such beliefs. In the bivariate analyses, many factors including preference for life-prolonging treatment and attitudes toward end-of-life care were associated with change regarding the feasibility of home death. However, multivariate analysis showed four determinant factors. Men generally less concern about home care. Therefore, they might view the lecture more positively. However, we might consider a different strategy for addressing concerns of women. The change of opinion regarding the burden to the family was significantly associated with the change in feasibility of home care. The burden of caregiving on the family is the most relevant barrier in the pre-intervention survey, as seen in Table 3. The alleviation of the burden on the family and the ability of family members to provide care are important issues concerning home death.^{6,7,11-13} Change in degree of anxiety about admission to the hospital for worsening physical condition is another independent factor. We believe that this has two important implications. One is that it is important for hospitals to hold beds open for these patients. Patients and families would feel easier about staying at home knowing that hospital beds would be available when needed. Another implication is that Japanese home hospice services would develop. Sufficient home hospice care and information provision would relieve the patient's and family's anxiety about home care. This should be confirmed because the change in attitude about inadequate pain relief at home was the most influential factor associated with the feasibility of home care.

As for life-prolonging treatment, although the desire for artificial hydration and artificial nutrition decreased after the intervention, 38-52% of participants still expressed a preference for receiving such treatment. Because many Japanese patients and families hope to receive artificial hydration,³ it is important to discuss this in the clinical setting. However, the preference for mechanical ventilation and cardiopulmonary

Table 5 Attitudes toward end-of-life care pre- and post-intervention

	Pre (%)	Post (%)	P value
Home care system			
Absence of sufficient medical system for treatment or care at home	61	32	0.001
In my circumstance, it is difficult to be cared for at home	61	32	0.001
Pain and opioid use			
Cancer pain is sufficiently relieved, if treatment adequate	68	81	0.001
Opioids shorten life	31	7	0.001
Opioids cause addiction	23	5	0.001
Consciousness is clear if pain medication is not used	31	29	0.004
Artificial hydration			
Artificial hydration and nutrition should be continued as the minimum standard until death	50	31	0.001
Artificial hydration and nutrition relieve symptoms	35	24	0.001
Communication			
Physicians are generally poor at communicating bad news	31	23	0.001
Physicians are uncomfortable discussing death	18	12	0.001
It would be intolerable if told I had incurable cancer	42	27	0.001
Cancer treatment			
At present, there are limits to cancer treatment	65	63	0.062
I want to receive cancer treatment as long as possible	47	48	0.241
Attitude toward home care			
Death at home indicates to relatives that family cannot provide sufficient medical care for patient	16	10	0.001
Death at home indicates to neighbours that family cannot provide sufficient medical care for patient	17	13	0.001
Large hospital provides better quality medical treatment than clinic before death	51	15	0.001

Figures are total percentage of 'strongly agree' and 'agree'.

resuscitation did not change. If the effectiveness of mechanical ventilation and cardiopulmonary resuscitation were more widely known; however, the answer would probably be different.³⁴

The beliefs that opioids shorten life and cause addiction were significantly decreased from 31% to 7% and 23% to 5%, respectively. Although misconceptions about analgesics are a great barrier to palliative care,¹⁶⁻¹⁹ educational interventions could overcome these barriers. In addition, the beliefs that the absence of an adequate medical system for treatment or care at home and 'in my circumstance, it is difficult to be cared for at home' were both significantly decreased from 61% to 32%. Interventions such as this help educate the general public that pain can be relieved at home. The belief that 'large hospitals provide better quality medical treatment than clinics before death' decreased significantly from 51% to 15%. In Japan, the general public tends to think that large hospitals are necessary to adequately care for patients, espe-

cially at the end of life. Two reasons for this are that home hospice care has not been developed and the general public is not informed. Moreover, the educational intervention changed the belief that 'it would be intolerable if I was told I had incurable cancer'. This intervention could not only correct this misconception and increase the feasibility of home care but also bolster the sense of security for people who get incurable cancer.

Although many attitudes toward end-of-life care did change as a result of this intervention, two beliefs, 'at present, cancer treatment has limited effectiveness' and 'I want to receive cancer treatment until death' did not change. Although the limitations of cancer treatment were covered in the lecture, the general public still desires such treatment to prolong life. Fighting against cancer and receiving sufficient treatment are important issues in the Japanese concept of a good death.¹

This intervention survey has some limitations. First, the intervention was shown to have only a short-term

Table 6 Factors associated with the change in feasibility of home death

	Odds ratio	95% CI ^a	P value
Gender (male)	1.82	1.08-3.09	0.026
Burden on family to care (changed from yes to no)	1.72	1.03-2.87	0.039
Anxiety about admission to hospital when physical condition worsens (changed from yes to no)	2.03	1.25-3.30	0.004
Pain would not be relieved at home (changed from yes to no)	2.28	1.42-3.66	0.001

Logistic regression analysis with backward variable selection method ($P < 0.05$).

Among the participants who answered 'impossible' or 'unsure' before lecture, we explored the associated factors with the change of answer to 'possible'.

^a95% confidence interval.

effect. Therefore, the sustainability of change of beliefs is unknown. We plan to study the long-term effects of this intervention. The planned follow-up study will occur at least 6 months after the educational intervention. If possible, we want to follow-up over several years. Second, this study was conducted in Fukushima City, Fukushima Prefecture, in a rural area in Japan. It might be difficult to extrapolate to urban areas in Japan.

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Revisiting depression in palliative care settings: the need to focus on clinical utility over validity

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Objective: To review the literature on depression in palliative care patients to identify implications for development of clinical practice and individual patient care. **Method:** A qualitative review of depression prevalence studies in palliative care settings. We explore the utility of existing prevalence studies for clinical practice through testing two hypotheses: that high prevalence rates are associated with increased risk factors in study samples, and that poor methodological quality of the studies artefactually inflate prevalence estimates. Eighteen studies were identified in the search and included in this review. **Results:** Risk factors may contribute to depression prevalence but through a complex interaction of factors making individual risk levels hard to determine. Measurement artefact cannot, alone, account for elevated levels of depression in this population but may contribute to imprecision. The importance of organic decline as a potential confounding variable is highlighted. **Conclusion:** Future research into the causes and prevalence of depression should adopt longitudinal approaches using large samples, and consider the impact of organic disorder as an important confounding factor. Clinical practice and care of individual patients may be better supported by development of a prognostic index considering the predictive power of depressive symptoms and risk factors on well-being. *Palliative Medicine* (2008); 22: 383–391

Key words: depression; palliative care; prevalence; utility

Introduction

The palliative care literature highlights depression as an important condition, which affects the well-being and quality of life of many terminally ill patients.^{1–6} Depression, although a common problem, is not an inevitable part of dying,^{2,7,8} but a treatable condition, which may respond to pharmacological intervention.^{5,9–12} Current guidance, therefore, recommends proactive screening for, and treatment of, depression in this population group.⁵

A number of reviews, including that of Hotopf, *et al.*² writing in this journal, highlight the prevalence of this condition^{1–6} and its association with a range of risk factors including age, gender, tumour type, poorly controlled physical symptoms, reduced functional status, previous history of depression and inadequate social support.^{4,6} However, the reviews report substantial variability in depression estimates across different studies; between 1% and 69%.^{1–6,13} Heterogeneity of populations sampled and risk-factor prevalence are presumed to account for some of the variability (*ibid*), although the relative impact of each has not been quantified. Variability may also result from imprecision related to methodological concerns.

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None of the published reviews include an assessment of individual study quality, although do comment on issues such as small sample sizes or the use of non-validated measurement tools.^{2,13} Meta-analysis of existing study data could offer further insights, but is contraindicated, given the heterogeneity of study designs and quality.

Quality concerns are compounded by uncertainty with regard to the nature and identification of a pathological state of depression. The validity, or legitimacy of a pathological state, that is, depression is contested.^{14–19} There are currently two diagnostic definitions of depression described within ICD-10²⁰ and DSM-IV²¹ but with only 83% concordance between the two.²² Problems of definition and diagnosis are compounded in palliative care settings, because many of the physical symptoms used within the diagnostic framework for depression are also symptoms of the underlying physical disease such as cancer (e.g., tiredness, weight loss, appetite change).^{2,4,6} Modified diagnostic criteria have been identified for use in terminally ill populations.^{23,24} The use of stricter criteria for defining depression is associated with lower prevalence estimates,^{2,4–6} but as yet, there is no consensus with regards to the optimal diagnostic approach.⁵ Despite acknowledged concerns with a pathological account of depression, its utility in predicting clinical course and outcomes supports its continued use.¹⁹

The absolute contribution of each element – risk factor distribution, diagnostic definition and study quality – to variability in estimates is uncertain. Previous authors have

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The Japan HOspice and Palliative Care Evaluation Study (J-HOPE Study): Study Design and Characteristics of Participating Institutions

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This article describes the study design and background data of participating institutions in the Japan HOspice and Palliative care Evaluation (J-HOPE) study. The J-HOPE study is a large nationwide survey about the dying experience of cancer patients. The primary aim of this article is to describe the design of the J-HOPE study for the bereaved family members of Japanese inpatient palliative care units and home hospices. Secondly, the aim was to describe characteristics of participating institutions. The authors conducted a cross-sectional questionnaire survey in 2007. One hundred Japanese inpatient palliative care units and 14 home hospices

participated. The questionnaires were sent to 7955 bereaved family members of the Japanese inpatient palliative care units and 447 of the home hospices. The authors describe the structure of the Japanese inpatient palliative care units and home hospices, including type of staff, architectural structure, number of patients, and death. In addition, the authors describe available treatments at the Japanese inpatient palliative care units and home hospices.

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

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from 5 in 1990 to 175 in 2007. In contrast, the growth of home hospice has been slow; inpatient 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.¹⁻³

It is important to ensure and improve the quality of palliative care in the specialized palliative care service.⁴⁻⁶ With this aim, we conducted 2 nationwide surveys on PCUs in collaboration with Hospice Palliative Care Japan as a part of a national quality-control project. First, in 1999, we developed the questionnaire "satisfaction scale for family members receiving inpatient palliative care" (Sat-Fam-IPC) and surveyed 37 PCUs in Japan.^{7,8} However, Sat-Fam-IPC was not a well-validated instrument and measured only satisfaction of bereaved family members. In addition, as a general satisfaction scale, Sat-Fam-IPC had a skewed distribution toward the satisfied direction, and the ceiling effect made it difficult to identify what factors should be improved. Therefore, from 2001 to 2003, we developed a new instrument to measure the structure and process of care from the viewpoint of bereaved family members, the Care Evaluation Scale (CES). At the same time, we conducted the second

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nationwide survey of 70 PCUs.⁹ This survey, with 1225 subjects, not only evaluated the level of palliative care at that time but also revealed several areas that needed improvement, such as lack of perceived support for maintaining hope, lack of perceived respect of individuality, perceived poor quality of care, inadequate staffing and equipment, unavailability of timely administration of the PCU, lack of accurate information about PCUs, and economic burden.¹⁰ The results of the 2 surveys were reported to the participant institutions, and these projects contributed to maintaining the quality of care in the PCUs in Japan.

In addition, one of the most important goals of palliative care is achieving a good death or a good dying process. In Western countries, elaborate efforts have been devoted to conceptualizing a good death¹¹⁻¹⁴ and quantitative research has been conducted by Steinhauser et al.¹⁵ Teno et al conducted a nationwide mortality follow-up study to evaluate end-of-life care from the bereaved family member's view.¹⁶ In Japan, it is also important to conceptualize what constitutes a good death. Therefore, both qualitative and quantitative research have been done, and 18 important concepts of a good death were identified.^{17,18} For the next step, we developed a measure for evaluating a good death from the bereaved family member's perspective: the Good Death Inventory (GDI).¹⁹ We then completed the preparation for the evaluation of palliative care by the structure and process of care (CES) and outcome (GDI).

In October 2006, there were 162 institutions with PCUs. Quality assurance, evaluation, and improvement are important issues in Japan. Therefore, we planned a third nationwide project to evaluate hospice and palliative care, the J-HOPE study. For the J-HOPE study, we recruited home hospices. This multicenter survey of home hospice is the first of its kind in Japan. We used the same methodology and questionnaire for both PCUs and home hospices. In this article, we first describe the design of the J-HOPE study. Secondly, we depict participating institutions' characteristics, including structure of care, available treatment in these care settings, and bereavement care for family members.

Methods

Participating Institutions

All PCUs (n = 153) of Hospice Palliative Care, Japan, approved before September 2005 were recruited for

this study. Of these, 103 responded. Three institutions did not participate because of rejection by the institutional review board. Finally, 100 PCUs (65%) participated in the study. We asked 17 institutions to participate, and 14 institutions responded for home hospice. Finally, 14 home hospices (82%) participated in this study. We asked the institutions to describe their structure of care, available treatment, and bereavement care for family members.

Study Design

We conducted a cross-sectional questionnaire survey in June 2007. To find potential subjects, we asked each institution to identify bereaved family members of patients who died from November 2004 to October 2006, up to 80 subjects in each institution. The inclusion criteria were as follows: (a) patient died at PCU or home, (b) patient was aged 20 years or more, and (c) bereaved family member was aged 20 years or more. The exclusion criteria were as follows: (a) could not identify the bereaved family member's address, (b) participant would have suffered serious psychological distress as determined by the primary physician, and (c) participant was incapable of replying to a self-reported questionnaire. For the PCUs, 8508 potential study subjects were listed and 553 were excluded in accordance with the above criteria. Finally, we mailed questionnaires to 7955 subjects. For the home hospices, 467 potential study subjects were listed and 20 were similarly excluded. Finally, we mailed questionnaires to 447 subjects. The study's secretariat office prepared the complete set of questionnaires and sent them to the institutions. Each institution's collaborator then sent questionnaires to the individual subjects.

Questionnaires

Questionnaires were composed of 2 sections: the common questionnaires and additional questionnaires. The outline of the questionnaires is displayed in Figure 1.

Common Questionnaires

Care Evaluation Scale. The CES evaluates the structure and process of end-of-life care from the bereaved family's perspective by rating the need for improvement for each item on a 6-point Likert scale from 1: improvement is not necessary to 6: improvement is

Place of death

Questionnaires

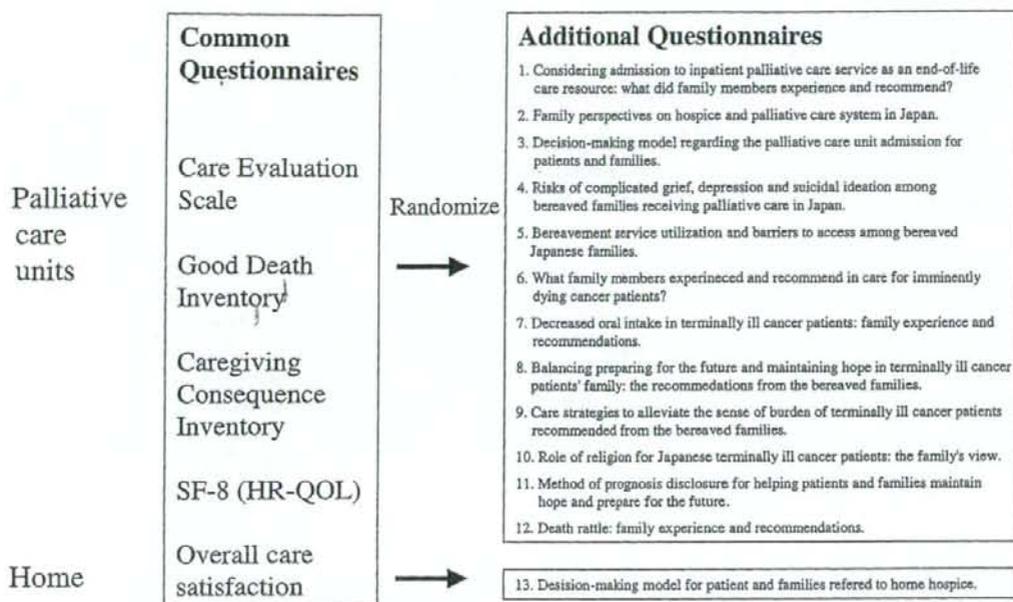


Figure 1. Contents of questionnaire of J-HOPE study.

highly necessary.⁹ The score was transformed to a 0 to 100 point scale, with a high score indicating excellent care. We used a short version of the CES in this study. The short version consisted of 10 items from each domain of the original CES, and validity and reliability were confirmed. The items are described in Appendix A.

Good Death Inventory. The GDI measures the outcome as evaluation of a good death from the bereaved family's perspective by rating the agreement for each item on a 7-point Likert scale from 1: strongly agree to 7: strongly disagree. A high score indicates achievement of a good death. We used the short version of the GDI in this study. The short version consisted of 18 items from each domain of the original GDI, and validity and reliability were confirmed.¹⁹ The items are described in Appendix B.

Caregiving Consequence Inventory. The CCI measures the caregiver's experience from both positive and negative aspects by rating the agreement for each item on a 7-point Likert scale from 1: strongly

agree to 7: strongly disagree. The CCI has 16 items in 5 domains: mastery, appreciation for others, meaning in life, reprioritization, and 1 perceived burden domain (Sanjo M, RN, MHLth Sci, et al, unpublished data, 2008). The validity and reliability of CCI were confirmed.

MOS Short Form 8 (SF-8). The SF-8 measures general quality of life of bereaved family members.²⁰ The SF-8 consists of the following items: physical functioning, role physical, bodily pain, general health perception, vitality, social functioning, role emotional, and mental health. We used the Japanese standardized version of the SF-8. We were able to calculate 2 summary scores: physical component summary and mental component summary in accordance with scoring rules.

Overall Care Satisfaction. We asked the participants about their overall care satisfaction to examine concurrent validity. The question was, "Overall, were you satisfied with the care in the PCU (home)?" The participant answered using a 6-point Likert scale from 1: absolutely dissatisfied to 6: absolutely satisfied.

Subject Characteristics

The age, sex, number of hospital days, and type of cancer of the patient were extracted from medical databases. We asked the bereaved family member's age, sex, health status during the caregiving period, relationship with the patient, frequency of attending the patient, presence of other caregivers, and financial expenditure during the last month.

Additional Questionnaires

As for the bereaved family members of the PCU patients, 12 additional questionnaires were randomly assigned. In particular, we sent No.10 additional questionnaires (role of religion) to all bereaved families of 4 selected PCUs with a full-time priest, and we sent 2 No.10 questionnaires to other PCUs. We considered these additional questions to be independent studies from the J-HOPE study. Twelve additional questionnaires were as follows:

1. Considering admission to inpatient palliative care service as an end-of-life care resource: what did family members experience and recommend?
2. Family perspectives on hospice and palliative care system in Japan.
3. Decision-making model regarding the PCU admission for patients and families.
4. Risks of complicated grief, depression, and suicidal ideation among bereaved families receiving palliative care in Japan.
5. Use of bereavement service and barriers to access among bereaved Japanese families.
6. What did family members experience and recommend for care of imminently dying cancer patients?
7. Decreased oral intake in terminally ill cancer patients: family experience and recommendations.
8. Balancing preparing for the future and maintaining hope in terminally ill cancer patient's family: the recommendations from the bereaved families.
9. Care strategies to alleviate the sense of burden of terminally ill cancer patients recommended from the bereaved families.
10. Role of religion for Japanese terminally ill cancer patients: the family's view.
11. Method of prognosis disclosure for helping patients and families maintain hope and prepare for the future.
12. Death rattle: family experience and recommendations.

As for the bereaved family members of the home hospice, the following additional questionnaires were assigned for all subjects.

13. Decision-making model for patient and families referred to home hospice.

Ethical Consideration

The ethical and scientific validity of this study was approved by the institutional ethical review of each participant institution and the University of Tokyo (Secretariat Office). We explained the aim of the study, sampling method, and anonymity to the subjects. In addition, we prepared 1 question regarding participation of this study on the cover of the questionnaire in consideration of the emotional burden of mourning.

Results

The structure of the PCUs, including type of staff, availability of staff, number of patients, number of deaths, and associated services are shown in Table 1. Similar items are displayed in Table 2 for home hospices. Available treatments, such as surgery, oral chemotherapy, intravenous chemotherapy, radiation therapy, intravenous hydration, intravenous hyperalimentation, pleurocentesis and paracentesis, nerve block, physiotherapy, and complementary and alternative medicine at the PCU or home hospices, are shown in Table 3. Intravenous hydration, intravenous hyperalimentation pleurocentesis and paracentesis physiotherapy, and complementary and alternative medicine were available at almost all PCUs. However, surgery and intravenous chemotherapy were available at only a few PCUs. As for home hospice, intravenous hydration, physiotherapy, and complementary and alternative medicine were available at almost all locations. Moreover, surgery, intravenous chemotherapy, and radiation therapy were not available at all home hospices. The availability of other treatments varied among PCUs and home hospices.

Most PCUs offered regular meetings for the bereaved, communicated with them after discharge by mail, and provided other bereavement services (Table 4). However, medical practitioners from home hospice were more likely to participate in funerals than those from PCUs.

Table 1. Structure of the PCUs (N = 100)

	Mean	Median	SD	Range
No. of physicians (full-time)	2.0	2.0	1.1	1-7
No. of physicians (part-time)	0.6	0.0	0.9	0-4
No. of patients per physician	9.5	9.0	3.7	2.5-25
No. of physicians per bed	0.1	0.1	0.1	0.04-0.4
Physician's system at night				
General doctor on duty in the hospital (n, %)	41	41		
Palliative care physician is doctor on duty every day (n, %)	3	3		
Palliative care physician is called by phone (n, %)	70	70		
No. of nurses (full-time)	16.0	16.0	4.3	9-41
No. of nurses (part-time)	0.3	0.0	0.7	0-4
No. of nurses per bed	0.9	0.2	0.9	0.4-1.8
No. of specialized trained nurses	0.8	1.0	0.8	0-4
No. of patients per nurse (weekday)	3.8	4.0	1.0	1.8-9
No. of patients per nurse (holiday)	4.6	4.5	1.2	1.8-10
No. of nurses in the midnight shift	2.2	2.0	0.4	2-3
No. of nurses in the twilight shift	2.2	2.0	0.4	2-3
No. of patients per nurse in the midnight shift	7.8	8.0	1.9	2-14
No. of patients per nurse in the twilight shift	7.6	7.8	1.9	2-12
Nursing shift				
2 shifts (n, %)	62	62		
3 shifts (n, %)	36	36		
Other (n, %)	2	2		
Psychiatrist				
Full-time for the PCU (n, %)	4	4		
Part-time for the PCU (n, %)	63	63		
None (n, %)	33	33		
Psychotherapist				
Full-time for the PCU (n, %)	5	5		
Part-time for the PCU (n, %)	32	32		
None (n, %)	63	63		
Medical social worker				
Full-time for the PCU (n, %)	16	16		
Part-time for the PCU (n, %)	76	76		
None (n, %)	6	6		
Religious staff				
Full-time for the PCU (n, %)	6	6		
Part-time for the PCU (n, %)	48	48		
None (n, %)	46	46		
No. of volunteers	2.6	2.0	3.5	0-29
No. of beds	18.9	20.0	5.5	6-50
No. of private rooms	16.0	16.0	5.5	6-38
Percentage of private rooms	86	100	21	45-100
No. of charge-free private rooms	8.6	10.0	5.6	0-27
Percentage of charge-free private rooms	47	50	30	0-100
Average extra charge of private room (\$: 1\$ = 120Yen)	74	60	69	0-475
No. of family rooms	1.8	2.0	0.9	1-8
Percentage of presence of family bath	86	86		
No. of admitted patients/year	142	133	56	27-392
No. of discharged patients/year	137	132	54	34-389
No. of deaths/year	117	114	41	28-277
Percentage of deaths discharge	87	89	9	44-100
Average number of patients/day	15.1	15.0	4.5	5.1-37.3
Bed availability rate (%)	80	82	11	44-100
Average hospitalized days	41.6	40.2	11.6	18.6-94.1
Years from initiation of hospice	8.3	7.3	5.3	1.2-25.6
Years from initiation of official PCU fee	7.0	6.5	3.8	1.2-16.5

(continued)

Table 1. (continued)

	Mean	Median	SD	Range
Type of the PCU				
Part of a ward in the hospital (n, %)	72	72		
Independent ward in the hospital (n, %)	25	25		
Fully independent hospital (n, %)	3	3		
Presence of palliative care clinic (n, %)	99	99		
Treatment at home (n, %)	45	45		
Home nursing care (n, %)	45	45		

Note: PCU; palliative care unit.

Table 2. Structure of the Home Hospices (N = 14)

	Mean	Median	SD	Range
No. of physicians (full-time)	1.9	2	1.1	0-4
No. of physicians (part-time)	0.9	0	1.4	0-5
No. of nurses (full-time)	5.7	4	4.8	2-17
No. of nurses (part-time)	1.9	1	2.1	0-7
No. of caregivers (full-time)	1.9	0	4.0	0-14
No. of caregivers (part-time)	0.8	0	1.4	0-5
No. of home care patients	118.2	72	141.0	12-507
No. of home care cancer patients	69.0	29.5	83.8	9-281
No. of deaths at home	28.3	13	48.8	4-193
No. of cancer deaths at home	23.1	10.1	40.0	2-157
Presence of beds in the clinic (n, %)	6	43		
No. of beds in the clinic (N = 6)	19.7	19.0	4.1	16-27
Registered home care assist clinic (n, %)	11	79		
Allied facility with the clinic				
Visiting nursing station (n, %)	4	29		
Home care support station (n, %)	5	36		
Helper station (n, %)	3	21		
Others	2	14		
Around-the-clock care				
Physician and/or nurse (n, %)	13	93		
Nurse only (n, %)	1	7		
Cooperation with inpatient unit (general wards)				
Possible and easy (n, %)	10	71		
Possible and not easy (n, %)	4	29		
None (n, %)	0	0		
Cooperation with inpatient palliative care unit				
Possible and easy (n, %)	10	71		
Possible and not easy (n, %)	3	21		
None (n, %)	1	7		
Cooperation with visiting nursing station				
Possible and easy (n, %)	12	86		
Possible and not easy (n, %)	1	7		
None (n, %)	1	7		

Discussion

In this article, we describe the design of the J-HOPE study. We obtained valuable information on the characteristics of the participant institutions regarding

structure of care, available treatment for patients, and bereavement care for family members. For the PCUs, the participation rate in this study was 65%, and the data are probably representative for the Japanese specialized inpatient PCUs. However, in

Table 3. Available Medical Treatment at the PCU or Home Hospice

	PCU			Home Hospice	
	n	%		n	%
Surgery					
Available at the PCU	8	8	Available at the home	2	14
Available on another ward	67	67	Refer to the hospital	9	64
Not available at the hospital	25	25	Not available	3	21
Chemotherapy by mouth					
Available at the PCU	44	44	Available at the home	10	71
Available on another ward	44	44	Refer to the hospital	2	14
Not available at the hospital	12	12	Not available	2	14
Chemotherapy by transvenous					
Available at the PCU	9	9	Available at the home	2	14
Available on another ward	68	68	Refer to the hospital	9	64
Not available at the hospital	23	23	Not available	3	21
Radiation therapy					
Available at the PCU	31	31	Available at the home	0	0
Available on another ward	8	8	Refer to the hospital	11	79
Not available at the hospital	61	61	Not available	3	21
Intravenous hydration					
Available at the PCU	100	100	Available at the home	13	93
Available on another ward	0	0	Refer to the hospital	1	7
Not available at the hospital	0	0	Not available	0	0
Intravenous hyperalimentation					
Available at the PCU	97	97	Available at the home	11	79
Available on another ward	2	2	Refer to the hospital	3	21
Not available at the hospital	1	1	Not available	0	0
Pleurocentesis/abdominocentesis					
Available at the PCU	99	99	Available at the home	9	64
Available on another ward	1	1	Refer to the hospital	5	36
Not available at the hospital	0	0	Not available	0	0
Nerve block					
Available at the PCU	68	68	Available at the home	4	29
Available on another ward	10	10	Refer to the hospital	10	71
Not available at the hospital	22	22	Not available	0	0
Physiotherapy					
Available at the PCU	91	91	Available at the home	10	71
Available on another ward	3	3	Refer to the hospital	2	14
Not available at the hospital	6	6	Not available	2	14
Complementary and alternative medicine					
Available at the PCU	93	93	Available at the home	12	86
Available on another ward	1	1	Refer to the hospital	1	7
Not available at the hospital	6	6	Not available	1	7

Note: PCU; palliative care unit.

Japan, progress of home hospice is very slow. The information obtained from this study is only preliminary for home hospices in Japan.

Regarding the structure of the PCUs, nursing care-related variables were similar to those obtained in a previous study in 1999.⁸ The information regarding physicians and allied medical workers was new. The percentage of private rooms increased from 72% in 1999 to 86% in 2005. Moreover, the mean number

of patients per year increased from 112 in 1999 to 142 in 2005, and the average number of hospital days decreased from 51 in 1999 to 42 in 2005. We believe that end-of-life care shifted from acute care facilities to some PCUs, and more individualized care was provided in the PCU during these 6 years. However, the percentage of deaths discharge varied from 44% to 100%. The institutional characteristics differed among Japanese PCUs. As for other structure