

previous work, whereas those of *action-diagnosis* and *action-prognosis* are told less. This difference may be because the contents explained by patients in lower stages are harder to avoid disclosure. Patients in these stages, especially in *action-hospitalization and surgery*, can be expected to tell their children about their illness although they find more negative aspects than positive aspects for telling. Therefore, it is possible that they have great distress and special needs for support from others. A significant finding of this research is how to identify the group of patients who have special needs for support by dividing patient's actions that tell about illness to children into detailed aspects. A quantitative study using the categories found in this study will empirically prove the detailed mechanism of the patients' decision-making process. And based on the results of a future quantitative study, guidelines for supporting patients in telling their children are expected to be developed.

In addition, this study found that the categories that have high frequency differ between stages. Especially the categories of factors that promote explanation that were indicated varied most by preparatory stage. This means that the positive aspects of telling about illness significantly recognized by patients depend on which stage they are in. In our research, the categories that seem to be in common with previous research [1], such as *fostering comprehension of the situation*, occur more in lower stages but not so much in higher stages. On the other hand, the categories of factors that prevent explanation that show high frequency were common to *action-hospitalization and surgery*, *action-diagnosis*, and *action-prognosis*. In the four action stages, there were many references to *increasing concerns* and *increasing emotional burden*. Other than this, there were many remarks about negative aspects for their children. This result contradicts the fact that many children benefit from being told about their parent's illness [1, 13]. Considering these results, it may be most effective to emphasize the merit of telling about illness according to the patient's stage, thereby reducing patient concerns about negative effects to their children regardless of stage and supporting the patient. For example, it will be helpful to hand out leaflets about the benefit of disclosing about illness. This study has several limitations. First, the number of participants is small. However, compared with previous qualitative studies of this kind [1, 18], the number in this study can be said to be relatively sufficient. Second, the patient remarks about lower stages did not occur so often. Participants were encouraged to talk freely about their experience from the point when they were told about their diagnosis till the present retrospectively, but there were few participants who told about their experiences when they have told their children nothing about their illness. Further research about the relevant factors for

patients who have not disclosed their illness to children is needed for practical support. Third, all participants were recruited from a cancer institution. In previous studies, it was reported that the percentage of patients who reveal a diagnosis to their children is about 50% [2]. However, in our study, over 70% of participants told their children that they were diagnosed with cancer. This may be because all of the participants were patients in a cancer institution and it is difficult not to reveal the diagnosis when their children visit them in hospital. Fourth, we did not consider the influence of stage of cancer, developmental stage of children, and the time point of data collection in relation to diagnosis. Especially it is hard to consider the influence of developmental stage of children. This is because, in this study, many of participants had two or more children and, thus, it is difficult to identify which child the patients regarded each positive or negative aspects of disclosure. These factors can be thought to relate with patients' communication style and positive or negative aspects of disclosure which patients consider. It is expected to explore these relations in a further study with bigger sample size.

## Conclusion

This study identified the six stages of decision-making by Japanese breast cancer patients about telling their children regarding their illness and named these stages as follows: *contemplation*, *preparation*, *action-hospitalization and surgery*, *action-adjuvant therapy*, *action-diagnosis*, and *action-prognosis*. Patients in lower stages, especially in *action-hospitalization and surgery*, can be expected to tell their children about their illness although they consider more negative aspects than positive aspects and have great distress and special needs for support from others. The result of this study provided us with some useful information on establishing support guideline for breast cancer patients telling their children about their illness.

**Acknowledgements** This study was supported by a Grant-in-aid for Hospice and Palliative Care from Sasakawa Health Science Foundation and partly by a Grant-in-aid for Scientific Research (no. 19730430). We would like to thank Shinji Ohno, Yoshiaaki Nakamura, Hiroshi Yamaguchi, Yoko Uchida, Mayumi Ishida, Yoko Hata, and Akemi Kataoka for assistance.

## References

1. Barnes J, Kroll L, Burke O, Lee J, Jones A, Stein A (2000) Qualitative interview study of communication between parents and children about maternal breast cancer. *BMJ* 321(7259):479–482

2. Barnes J, Kroll L, Lee J, Burke O, Jones A, Stein A (2002) Factors predicting communication about the diagnosis of maternal breast cancer to children. *J Psychosom Res* 52(4):209–214
3. Bloom JR, Kessler L (1994) Emotional support following cancer: a test of the stigma and social activity hypotheses. *J Health Soc Behav* 35(2):118–133
4. Fallowfield LJ, Hall A, Maguire P, Baum M, A'Hern RP (1994) Psychological effects of being offered choice of surgery for breast cancer. *BMJ* 309:448
5. Forrest G, Plumb C, Ziebland S, Stein A (2006) Breast cancer in the family—children's perceptions of their mother's cancer and its initial treatment: qualitative study. *BMJ* 332(7548):998–1003
6. Hirai K, Komura K, Tokoro A, Kuromaru T, Ohshima A, Ito T, Sumiyoshi Y, Hyodo I (2008) Psychological and behavioral mechanisms influencing the use of complementary and alternative medicine (CAM) in cancer patients. *Ann Oncol* 19(1):49–55
7. Kroll L, Barnes J, Jones A, Stein A (1998) Cancer in parents: telling children. *BMJ* 316(7135):880
8. Lauver DR, Henriques JB, Settersten L, Bunann MC (2003) Psychosocial variables, external barriers, and stage of mammography adoption. *Health Psychol* 22:649–653
9. Light RJ (1971) Measures of response agreement for qualitative data: some generalizations and alternatives. *Psychol Bull* 76:365–377
10. Maguire P (1994) ABC of breast diseases—psychological aspects. *BMJ* 309:1649–1652
11. Manne S, Markowitz A, Winawer S, Meropol NJ, Haller D, Rakowski W, Babb J, Jandorf L (2002) Correlates of colorectal cancer screening compliance and stage of adoption among siblings of individuals with early onset colorectal cancer. *Health Psychol* 21:3–15
12. Marugame T, Kamo K, Katanoda K, Ajiki W, Sobue T (2006) Cancer incidence and incidence rates in Japan in 2000: estimates based on data from 11 population-based cancer registries. *Jpn J Clin Oncol* 36(10):668–675
13. Nelson E, Sloper P, Charlton A, While D (1994) Children who have a parent with cancer: a pilot study. *J Cancer Educ* 9:30–36
14. Prochaska JO, DiClemente CC (1983) Stages and processes of self-change of smoking: toward an integrative model of change. *J Consult Clin Psychol* 51:390–395
15. Prochaska JO, DiClemente CC (1984) Self change processes, self efficacy and decisional balance across five stages of smoking cessation. *Prog Clin Biol Res* 156:131–140
16. Rait D, Lederberg M (1990) The family of the cancer patient. In: Holland JC, Rowland JH (eds) *Handbook of psychooncology*. Oxford University Press, New York, p 589
17. Rosenheim E, Reicher R (1985) Informing children about a parent's terminal illness. *J Child Psychol Psychiatry* 26:995–998
18. Shands ME, Lewis FM, Zahlis EH (2000) Mother and child interactions about the mother's breast cancer: an interview study. *Oncol Nurs Forum* 27(1):77–85
19. Statistics and Information Dept., Minister's Secretariat, Ministry of Health, Labor and Welfare: *Vital Statistics of Japan* (2000) Health and Welfare Statistics Association Press, Tokyo
20. Stinson CH, Milbranch C, Reidbord SP (1994) Thematic segmentation of psychotherapy transcripts for convergent analyses. *Psychotherapy* 31:36–48
21. Wolf AW, Lozoff B (1989) Object attachment, thumbsucking, and the passage to sleep. *J Am Acad Child Adolesc Psych* 28:287–292

# Preference of place for end-of-life cancer care and death among bereaved Japanese families who experienced home hospice care and death of a loved one

JiEun Choi · Mitsunori Miyashita · Kei Hirai · Kazuki Sato · Tatsuya Morita · Satoru Tsuneto · Yasuo Shima

Received: 11 May 2009 / Accepted: 12 October 2009  
© Springer-Verlag 2009

## Abstract

**Purpose** The aim of this study was to clarify factors related to the preference of place for end-of-life cancer care and death, from the perspective of the bereaved family.

---

J. Choi · K. Sato  
Department of Adult Nursing/Palliative Care Nursing,  
School of Health Sciences and Nursing,  
Graduate School of Medicine, The University of Tokyo,  
7-3-1 Hongo, Bunkyo-ku,  
Tokyo 113-0033, Japan

K. Hirai  
Center of the Study for Communication Design,  
Psychology and Behavioral Sciences, Graduate School of Human  
Sciences, & Department of Complementary and Alternative  
Medicine, Graduate School of Medicine, Osaka University,  
Osaka, Japan

T. Morita  
Department of Palliative and Supportive Care, Palliative Care  
Team and Seirei Hospice, Seirei Mikatahara Hospital,  
Shizuoka, Japan

S. Tsuneto  
Department of Palliative Medicine, Graduate School of Medicine,  
Osaka University,  
Osaka, Japan

Y. Shima  
Department of Palliative Medicine,  
Tsukuba Medical Center Hospital,  
Ibaraki, Japan

M. Miyashita (✉)  
Department of Palliative Nursing, Health Sciences,  
Graduate School of Medicine, Tohoku University,  
2-1 Seiryō-machi, Aoba-ku,  
Sendai 980-8575, Japan  
e-mail: miyasita-ky@umin.net

**Methods** In June 2007, in Japan, a cross-sectional anonymous questionnaire, which included a well-validated scale of component factors of hospice outcome, was administered to the bereaved family members ( $N=294$ ) of cancer patients who had died at home at least 6 months ago. Participants were recruited from 14 home hospices across the nation. We asked the preference of place for end-of-life care and death. **Results** Fifty-eight percent of participants preferred home settings for end-of-life care and 68% preferred to die at home. Multivariate logistic regression identified: (1) males, participant who had other caregivers, a higher-good death concept, and those who experienced mastery as a consequence of caregiving were more likely to prefer home for end-of-life cancer care and (2) males, participant who had other caregivers, and experienced reprioritization as a consequence of caregiving and those who were enrolled in home hospice services for more than 60 days were more likely to prefer to die at home.

**Conclusions** Home hospice services need to be developed in Japan so that family support programs can be initiated early enough to support the family burden of household maintenance and caring for the patient. Quality improvement of home hospice services will support patients and families through end-of-life care and facilitate a good death at home.

**Keywords** Preference · Hospice care · Home care service · Place for end-of-life care · Place of death

## Introduction

Although approximately half of Japanese people express a preference for home care after being diagnosed with a

terminal illness [1], 94% of patients with cancer died in hospital wards, and only 6% of patients died in their own homes (Japanese census data available online at <http://www.mhlw.go.jp>). Compared with other countries, the proportion of home deaths in Japan is very small [2–6]. Dying and death at a preferred place is an important consideration for a good death [7], but there is discordance between preference and actual location and place of death because decision-making about cancer care and death are related to hope and complicated by matters such as quality of care, human resources, emotional and physical burdens, and the experience and attitude of patients and their families.

The Japanese Ministry of Health, Labor, and Welfare has supported the provision of palliative care services with National Medical Insurance since 1990. Specialized home care support clinics were defined in 2006 and are expected to provide home care for patients in the community, with 24-h care provided by physicians or nurses. In addition, these clinics are intended to support community-dwelling patients in cooperating with hospitals, other clinics, palliative care units (PCUs), and visiting service by doctor, nurse, helper, pharmacist, volunteer, clergy complying with patient and family's request. The clinics can obtain additional remuneration for their work with terminally ill patients at home and for deaths occurring at home. This new homecare system is expected to support patients with cancer at home and to increase the proportion of deaths occurring at home [8]. But, there are few specialized home care support clinics and few palliative care teams or home hospices in Japan.

While there is general agreement that the majority of cancer patients prefer home death, there is continuing discussion over the effects of home death on caregivers. The caregiver role has a negative impact on such areas as caregiver health, personal schedule, anxiety, energy, social life, finances, and family relationships [5, 9–11]; however, there are also positive influences such area as patient's quality of life, death in the location the patient desired, emotional support, overall assessment about quality of care [12–15]. If political and economical forces compel a shift from hospital care to community care, in order to reduce social medical expenses, there could be a failure to meet the end-of-life needs of cancer patients and their families [16].

Informal care resources, management of the physical symptoms, experience of service, and existential perspectives are influential in preference of place of death [17]. For the most part, recent critical debate about the place for end-of-life care and place of death have tended to center around the detection of participant's demographic and clinical characteristics and structural and institutional aspects. There is a lack of research about the experience of service and the existential perspectives and relation to preference. To

improve quality of home hospice services, we need to consider the essential elements that promote positive outcomes of service rather than trying to control difficult factors. We selected Good Death Inventory (GDI), Care Evaluation Scale (CES), and Caregiving Consequences Inventory (CCI) to measure outcomes for hospice care because these instruments were developed to evaluate good death, structure and process of care, and caregiving consequences, respectively. This article focuses on preference of cancer care location and place of death and the relationship of the actual experiences of the bereaved family in caring, dying, death, and evaluation of services.

## Methods

### Participants and procedures

This study was part of a nationwide survey in Japan, and the protocol has been described previously [18]. We asked 17 home hospice agencies to participate, and 14 home hospice agencies (82%) agreed. The geographical distribution of facilities was nationwide. We asked each home hospice agency to identify eligible bereaved family members for this study who had experienced the death of a loved one from November 2004 to October 2006. The inclusion criteria were as follows: (1) patient died at home before at least 8 months ago, (2) patient was aged 20 years or more, and (3) bereaved family member was aged 20 years or more. Finally, 467 potential study subjects were listed, and 20 were excluded by exclusion criteria: (1) could not identify the bereaved family member's address, (2) participant would have suffered serious psychological distress as determined by the primary physician, and (3) participant was incapable of replying to a self-reported questionnaire [18]. Finally, we mailed 447 questionnaires for cross-sectional survey in June 2007, and a reminder was sent after 1 month to those who did not respond. We asked the primary caregiver to complete the questionnaire. Thirteen questionnaires were undeliverable, and 311 were returned. Among the respondents, 17 refused to participate, and finally, 294 responses were analyzed (effective response rate=68%). The ethical and scientific validity of this study was approved by the institutional review boards of each participating institution and the University of Tokyo (Secretariat Office).

### Measurements

#### *Preference of place for end-of-life cancer care and place of death*

Participants were asked to choose a preferred place for end-of-life care and death from three options: a home setting, an

acute hospital unit, or a PCU. They were instructed to make the choice under the assumptions that life expectancy was 1–2 months due to incurable cancer; physical symptoms would be controlled, and assistance would be required to accomplish daily activities.

#### *Good death inventory, short version*

The GDI was developed for evaluating good death from the bereaved family member's perspective by rating the agreement for each item on a seven-point Likert scale [7]. A high score indicated achievement of good death. The validity and reliability of GDI short version were confirmed (Chronbach's alpha=0.84 in this study) [19].

#### *Care evaluation scale, short version*

We used the CES short version to evaluate the structure and process for end-of-life care from the bereaved family's perspective by rating each item on a six-point Likert scale. The score transformed to a 0-to-100-point scale, and a high score indicated excellent care. The validity and reliability were confirmed (Chronbach's alpha=0.92 in this study) [20].

#### *Caregiving consequence inventory*

We used the CCI to measure the caregiver's experience by rating each item on a seven-point Likert scale. The CCI has four perceived reward domains (mastery, appreciation for others, meaning in life, and reprioritization) and one perceived burden domain with 16 attributes. The validity and reliability of this scale were tested [21], and Chronbach's alpha of each domain in this study ranged from 0.86 to 0.92.

#### *Overall care satisfaction*

We asked the question: "Overall, were you satisfied with the home hospice service?" The participants were asked to respond using a six-point Likert scale from 1: absolutely dissatisfied to 6: absolutely satisfied.

#### *Participant characteristics*

Information was collected about the bereaved family member's age, sex, and health status during the caregiving period; relationship with the patient; frequency of attending to the patient; presence of other caregivers; and financial expenditures during the last month of the patient's life. Information about the patient's age, sex, site of cancer, hospital days, and length of time since death was also collected.

## **Analysis**

The characteristics of participants were analyzed using descriptive statistics. To define the potential determinants of place for end-of-life cancer care and death, the dependent variables were split into two categories: home and facilities (hospital and palliative care unit), and preliminary univariate analyses were conducted using Chi square test, Fisher exact test, linear-by-linear association, and univariate linear logistic regression as appropriate. The univariate analyses and multiple logistic regression via backward elimination analysis ( $p < 0.2$ ) were performed. Then, the final determinants of preference of place for end-of-life cancer care and death using independent variables were identified by univariate analyses ( $p < 0.2$ ). The significance level was set at  $p < 0.05$  (two-tailed), and all data analyses were conducted using SPSS 14.0 Japanese version for Windows.

## **Results**

### Characteristics of participants

Characteristics of participants are shown in Table 1. Sixty-two percent of the respondents were male. The mean length of home hospice days was  $68 \pm 95$ . For the bereaved family members, 20% were males; 93% attended to the patient every day, and 32% had no other caregiver.

### Preference of place for end-of-life cancer care and death

Preferences of place for end-of-life cancer care and death are shown in Fig. 1. Of 294 participants, 170 (58%) and 200 (68%) preferred the home as the place for end-of-life cancer care and the place of death, respectively; 109 (37%) and 82 (28%) preferred the palliative unit for care and death, respectively; and 15 (5%) and 12 (4%) preferred the hospital for care and death, respectively.

### Differences among preference of place for end-of-life cancer care and death: results of univariate analyses

For end-of-life cancer care and preference of place: gender of patient ( $p = 0.046$ ), gender of primary family caregiver ( $p = 0.000$ ), presence of other caregivers ( $p = 0.027$ ), GDI ( $p = 0.001$ ), overall satisfaction ( $p = 0.118$ ), and each reward domain of CCI ( $p = 0.011 \sim 0.087$ ) differed among groups. For place of death: gender of patient ( $p = 0.111$ ), gender of primary family caregiver ( $p = 0.007$ ), length of home hospice care ( $p = 0.114$ ), presence of other caregivers ( $p = 0.072$ ), GDI ( $p = 0.012$ ), and each reward

**Table 1** Characteristics of participants (*N*=294)

	Number	Percentage
<b>Patients</b>		
Age, in years (mean ± SD)	72±13	
<49	17	6
50~59	30	10
60~69	58	20
70~79	99	34
>80	90	30
<b>Sex</b>		
Male	181	61
Female	111	38
<b>Length of home hospice care, in days (mean ± SD)</b>		
≤60	181	62
>60	113	38
<b>Origin of cancer</b>		
Lung and bronchiolar	63	21
Esophagus and stomach	44	15
Liver and pancreas	50	17
Intestinal	54	19
Others	83	28
<b>Bereaved family members</b>		
Age, in years (mean ± SD)	61±12	
<49	50	17
50~59	88	30
60~69	83	28
70~79	57	20
>80	16	5
<b>Sex</b>		
Male	60	20
Female	230	78
<b>Health status</b>		
Good	76	26
Moderately good	157	53
Moderately poor	40	14
Poor	7	2
<b>Relationship</b>		
Spouse	166	56
Child	79	27
Child-in-law	34	12
Parent	4	1
Sibling	6	2
Other	4	1
<b>Frequency of attending patient</b>		
Every day	274	93
4–6 days/week	12	4
Less than 3 days/week	6	2
<b>Presence of other caregivers</b>		
Present	200	68
Absent	93	32

**Table 1** (continued)

	Number	Percentage
<b>Cost of medicine for the month before death (thousand yen)</b>		
<99	114	39
100–199	78	27
200–399	59	20
400–599	14	5
>600	16	65
<b>Time since patient's death, in years (mean ± SD)</b>		
<1	132	45
1–2	117	40
>3	45	15
<b>Good Death Inventory (mean ± SD)</b>		
	4.79	0.80
<b>Care Evaluation Scale (mean ± SD)</b>		
	82.04	13.81
<b>Satisfaction*</b>		
Satisfaction	266	90
Dissatisfaction	16	5
<b>Caregiver Consequence Inventory</b>		
<b>Appreciation for others (mean ± SD)</b>		
	5.88	0.97
<b>Meaning in life (mean ± SD)</b>		
	5.23	1.21
<b>Reprioritization (mean ± SD)</b>		
	5.72	1.14
<b>Mastery (mean ± SD)</b>		
	5.04	1.33
<b>Burden (mean ± SD)</b>		
	3.82	1.55

PCU palliative care unit

Several total *N* and percentage do not equal 294 and 100% due to missing values

\*Evaluated using a Likert scale with scoring ranging from 1 to 6

Score from one to three were indicative of dissatisfaction, and score from four to six were indicative of satisfaction

domain of CCI ( $p=0.021\sim0.049$ ) differed among groups (Table 2).

Related factors for preference of home care and home death: results of multivariate logistic regression

Multivariate logistic regression identified four factors ( $p < 0.2$ ) for those who were more likely to prefer home as their choice for end-of-life cancer care: (1) male participants (OR, 3.44; 95% CI, 1.69, 7.03); (2) availability of other caregivers (OR, 1.56; 95% CI, 0.90, 2.71); (3) higher good death concept (OR, 1.45; 95% CI, 1.00, 2.10), and (4) experience of mastery as a consequence of caregiving (OR, 1.21; 95% CI, 0.97, 1.52). Male participants (OR, 3.10; 95% CI, 1.44, 6.67), who had other caregivers (OR, 1.51; 95% CI, 0.86, 2.68), and experienced reprioritization as a consequence of caregiving (OR, 1.47; 95% CI, 1.15, 1.88) and were enrolled in home hospice services for more than 60 days (OR, 1.62; 95% CI, 0.92, 2.86) were more likely to prefer to die at home (Table 3).

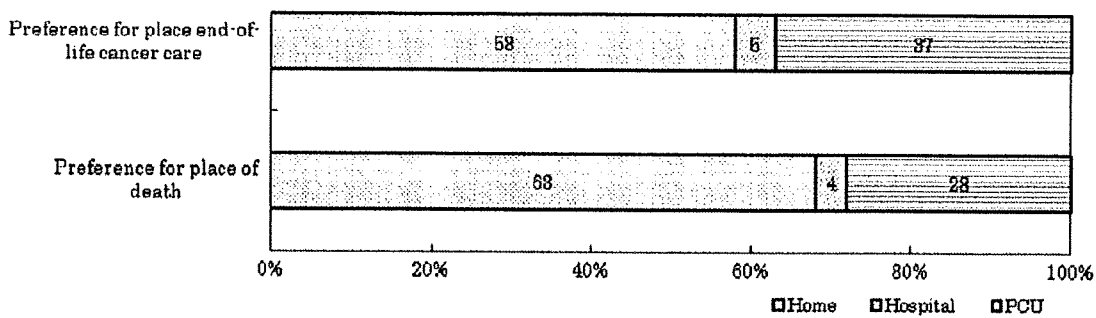


Fig. 1 Preference of place for end-of-life cancer care and death for participants ( $N=294$ )

## Discussion

This study was conducted to investigate the preferences of place for end-of-life care and death and related factors. We elicited information from the primary family caregiver who had a loved one who died of cancer at home. We used outcome measurements of hospice services. We found that 58% of participants preferred home for end-of-life care and 68% preferred to die at home. Gender of participants and the presence of other caregivers were related to preference of location for care and place of death. A good death concept and mastery as a caregiver consequence were related to the preference of place of cancer care only. For place of death, reprioritization as a caregiver consequence and length of home hospice care were related. There are differences in related factors for preferences for cancer care location and place of death. Agar et al. reported that "place of care" and "place of death" are not synonymous, suggesting that these are related to different concepts and needed to be asked separately [22].

Among our sample, preference for home as the place for end-of-life cancer care and place of death was higher in comparison with the non-bereaved general population of Japan. Forty-six percent of the non-bereaved general population preferred the home for cancer care and 55% preferred to die at home [1]. And the bereaved family who was familiar with PCU care was likely to prefer PCU as the cancer care location and place of death [1]. Preferences for place of care and death are influenced by the experience and the quality of service not the kind of service. The general Japanese public assumes that home death is impossible, because of uncontrollable symptoms, anxiety about the progressive worsening of illness, and concern about the burden for the family. Even though there are few home hospices or PCUs in Japan, there is a need to decrease anxiety and misunderstanding about home hospice services and home death. Therefore, active dissemination of information to the general public about home hospice and the available support resources is needed to increase the public's awareness of options.

We found that males were more likely than females to prefer home for end-of-life care and place of death. This finding is in accordance with other studies [4, 23–27]. Generally, in Japan, a male would expect his wife to provide care, but a female would not expect her husband to assume a caregiver role or to take on the housework and also would not want to be a burden for the children. This suggests that home hospice should include family care and respite care. For those who preferred home, another person was likely to be available to assist with care. A sufficient number of caregivers, living with relatives, and frequent contact with healthcare professionals are important elements for improving the quality of home hospice care [4, 25, 28, 29]. Therefore, respite care and family care are needed to empower family caregivers and reduce caregiver burden, which would increase the possibility of home death.

Bereaved family members who preferred home for their place for end-of-life care were likely to have higher evaluations of decedent's death as good and mastery of life as a consequence of the caregiving experience. Bereaved family members who did not prefer the home presented low in good death inventory and each domain of the caregiving consequence inventory by univariate analysis. Yao et al. reported that a home-death group had higher good-death assessment than a hospice-death group [30]. These results suggest that improving the quality of dying is an important factor in the preference of the home for cancer care, and the caregiver can experience feelings of control over life by overcoming difficulties.

Those who had reprioritization of life as a positive caregiving consequence and had more than 60 days of home hospice service preferred the home for place of death. While past research has documented the dichotomous negative [5] and positive effects of caregiving [21, 31–33], there has been little research into the details of caregiving consequences and the influence on preference for place of care and death. Concerns about being a burden to others is reported as the major consideration in decision-making regarding the place of death [34], but, in our study, preference for home is likely to be associated with the

**Table 2** Differences in demographic characteristics and clinical characteristics of participants for preference of place ( $N=294$ )

Variable	Place for end-of-life cancer care			Place of death		
	No. of participants (%)		<i>p</i> value	No. of participants (%)		<i>p</i> value
	Home	Facilities		Home	Facilities	
<b>Patients</b>						
Age, in years (mean $\pm$ SD) <sup>a</sup>						
<49	9 (56)	7 (43)	0.640	11 (73)	4 (27)	0.520
50~59	16 (55)	13 (45)		18 (62)	11 (38)	
60~69	32 (57)	24 (43)		37 (66)	19 (34)	
70~79	55 (57)	41 (43)		62 (65)	33 (35)	
>80	51 (60)	34 (40)		61 (73)	23 (27)	
Sex <sup>b</sup>						
Male	93 (53)	83 (47)	0.046*	111 (64)	63 (36)	0.111
Female	68 (65)	36 (35)		76 (74)	27 (26)	
Length of home hospice care, in days (mean $\pm$ SD) <sup>b</sup>						
$\leq 60$ days	98 (56)	77 (44)	0.458	111 (64)	62 (36)	0.114
>60 days	65 (61)	42 (39)		78 (74)	28 (26)	
Site of cancer <sup>c</sup>						
Stomach and esophageal	24 (59)	17 (41)	0.894	28 (70)	12 (30)	0.613
Lung	38 (61)	24 (39)		44 (72)	17 (28)	
Liver, pancreas	23 (47)	26 (53)		28 (58)	20 (42)	
Intestinal	32 (60)	21 (40)		37 (70)	16 (30)	
Others	46 (60)	31 (40)		52 (68)	25 (32)	
<b>Bereaved family members</b>						
Age, in years (mean $\pm$ SD) <sup>a</sup>						
<49	27 (56)	21 (44)	0.400	36 (77)	11 (23)	0.968
50~59	47 (55)	38 (45)		50 (60)	33 (40)	
60~69	46 (59)	32 (41)		55 (70)	23 (30)	
70~79	32 (57)	24 (43)		36 (64)	20 (36)	
>80	11 (73)	4 (27)		12 (80)	3 (20)	
Sex <sup>b</sup>						
Male	45 (79)	12 (21)	0.000**	47 (83)	19 (17)	0.007*
Female	115 (52)	106 (48)		139 (64)	79 (36)	
Relationship <sup>b</sup>						
Spouse	97 (59)	67 (41)	0.626	109 (67)	54 (33)	0.795
Others	66 (56)	52 (44)		80 (69)	36 (31)	
Presence of other caregivers <sup>b</sup>						
Present	120 (62)	73 (38)	0.027*	136 (71)	55 (29)	0.072
Absent	42 (48)	46 (52)		52 (60)	35 (40)	
Cost of Medicine for the month before death (thousand yen) <sup>a</sup>						
<99	65 (60)	44 (40)	0.854	77 (71)	31 (29)	0.741
100~199	42 (58)	31 (42)		46 (63)	27 (37)	
200~399	27 (47)	30 (53)		37 (65)	20 (35)	
400~599	10 (41)	4 (29)		11 (79)	3 (21)	
>600	10 (62)	6 (38)		10 (67)	5 (33)	
Time since patient's death, in years (mean $\pm$ SD) <sup>a</sup>						
<1	71 (56)	55 (44)	0.666	80 (64)	46 (36)	0.316
1~2	67 (59)	47 (41)		81 (72)	31 (28)	
>3	25 (59)	17 (41)		28 (68)	13 (32)	
GDI <sup>d</sup>	1.72 (1.25~2.35)		0.001*	1.51 (1.09~2.10)		0.013*



**Table 2** (continued)

Variable	Place for end-of-life cancer care			Place of death		
	No. of participants (%)		<i>p</i> value	No. of participants (%)		<i>p</i> value
	Home	Facilities		Home	Facilities	
CES <sup>d</sup>	1.00 (0.99–1.02)		0.784	1.004 (0.99–1.02)		0.670
Overall satisfaction <sup>b</sup>						
Satisfied	157 (59)	109 (41)	0.118	181 (69)	83 (31)	0.258
Dissatisfied	6 (38)	10 (62)		8 (53)	7 (46)	
CCI						
Appreciation for others <sup>d</sup>	1.31 (1.02–1.67)		0.033*	1.31 (1.01–1.68)		0.038*
Meaning in life <sup>d</sup>	1.23 (1.01–1.51)		0.043	1.32 (1.07–1.63)		0.010*
Reprioritization <sup>d</sup>	1.36 (1.08–1.70)		0.008*	1.46 (1.15–1.84)		0.002*
Mastery <sup>d</sup>	1.39 (1.14–1.68)		0.001*	1.38 (1.13–1.67)		0.002*
Burden <sup>d</sup>	0.74 (0.46–1.20)		0.220	0.81 (0.49–1.34)		0.414

Facilities: hospital or palliative care unit

<sup>a</sup> Linear-by-linear association<sup>b</sup> Fisher exact test<sup>c</sup> Chi square test<sup>d</sup> Univariate linear logistic regression\**p*<0.05\*\**p*<0.001

positive consequences and not the burdens. Thus, emotional and psychological support is needed so that caregivers can have a positive point of view about priorities or values. Participants who had more than 60 days of home hospice service were more likely to prefer the home for their place of death. Length of service might be important because it could affect payment and intensity of the experience. While

there are reports about the differences of length of service among care settings [35–37], the preference of place and the relationship to length of service has not been considered. However, short enrollment periods could impede the full benefit of hospice care [37]; therefore, we recommend that short-term enrollment in home hospice is inappropriate because early entry would benefit the patient and family

**Table 3** Independent factors of preference for home evaluated by logistic regression backward elimination

Variable <sup>a</sup>	Place for end-of-life cancer care			Place of death		
	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value
Gender of family member	3.44	1.69–7.03	0.001	3.10	1.44–6.67	0.004
Presence of other caregiver	1.56	0.90–2.71	0.112	1.51	0.86–2.68	0.153
Good death concept	1.45	1.00–2.10	0.050	Not in the model		
CCI, mastery	1.21	0.97–1.52	0.090	Not in the model		
CCI, reprioritization	Not in the model			1.47	1.15–1.88	0.002
Length of home hospice care	Not in the model			1.62	0.92–2.86	0.094
Cox & Snell <i>R</i> <sup>2</sup>	0.114			0.086		
Nagelkerke <i>R</i> <sup>2</sup>	0.153			0.120		

The dependent variable had two categories: home and general hospital or PCU

OR odds ratio; 95% CI confidence interval

Variables with a significance level &lt;0.2 in the univariate analysis of preference place were entered. (These variables are listed in Table 2.)

Good death concept and CCI-Mastery are only in the logistic regression model of place for end-of-life cancer care

Length of home hospice care and CCI Reprioritization are only in the logistic regression model of place of death

<sup>a</sup> Variables with a significant correlation with preference place (*p*<0.20) are listed

who desire home death. There are, however, a number of problems that remain to be explored, such as the complex structures of delivery and payment systems which differ greatly. Our research offers evidence that a good death is important for place of care, and length of service influences the preference for place of death. Further research is needed to explain these findings.

### Limitations and future perspectives

Currently, there is no registered home hospice system in Japan; therefore, we selected participant home hospice agencies as a convenience sample. The participating agencies are staffed by home hospice experts; thus, our findings may not be entirely representative of care received by bereaved families in home care settings throughout Japan. In future studies, we would like to conduct a nationwide survey of preferences for place of care and place of death from a sample of patients and bereaved families who use general home care services. We plan to investigate factors that influence the decision-making process of cancer care and place of death.

### Conclusions

To our knowledge, our report is the first to investigate the relationship of the experience of a loved one's death in a home hospice setting to the family caregiver's preference of place for end-of-life care and death. We identified predictors of preference of place for end-of-life care and death: good death concept, quality of structure and process of service, and caregiver consequences. Home hospice care and home death are currently difficult to achieve in Japan, but the desire for home death is linked to the increased availability and increased public awareness of home hospice services; therefore, it is important for the public to be informed. In addition to early entry into home hospice services, quality improvement of specialized clinics, adequate application of nursing care insurance, and a family support system will empower caregivers.

**Acknowledgments** This research was supported by the Japan Hospice Palliative Care Foundation.

**Conflict of interest** There is no conflict of interest.

### References

- Sanjo M, Miyashita M, Morita T, Hirai K, Kawa M, Akechi T, Uchitomi Y (2007) Preferences regarding end-of-life cancer care and associations with good-death concepts: a population-based survey in Japan. *Ann Oncol* 18:1539–1547
- Bruera E, Sweeney C, Russell N (2003) Place of death of Houston area residents with cancer over a two-year period. *J Pain Symptom Manage* 26:637–643
- Foreman LM, Hunt RW, Luke CG, Roder DM (2006) Factors predictive of preferred place of death in the general population of South Australia. *Palliat Med* 20:447–453
- Gomes B, Higginson IJ (2006) Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 4:515–521
- Heide A, Vogel-Voogt E, Visser AP, Rijt CCD, Maas PJ (2007) Dying at home or in an institution: perspectives of Dutch physicians and bereaved relatives. *Support Care Cancer* 15:1413–1421
- Tang ST, McCorkle R (2001) Determinants of place of death for terminal cancer patients. *Cancer Invest* 19:165–180
- Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y (2007) Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 18:1090–1097
- Miyashita M, Morita T, Hirai K (2008) Evaluation for end-of-life cancer care from the perspective of bereaved family members: the Japanese experience. *J Clin Oncol* 26:3845–3852
- Aranda SK, Hayman-White K (2001) Home caregivers of the person with advanced cancer: an Australian perspective. *Cancer Nurs* 24:300–307
- Hudson P, Aranda S, McMurray N (2002) Intervention development for enhanced lay palliative caregiver support—the use of focus groups. *Eur J Cancer Care* 11:262–270
- Singer Y, Bachner YG, Shvartzman P, Carmel S (2005) Home death—the caregivers' experiences. *J Pain Symptom Manage* 30:70–74
- Carlsson M, Rollison B (2003) A comparison of patients dying at home and patients dying at a hospice: sociodemographic factors and caregivers' experiences. *Palliat Support Care* 1:33–39
- Curtis JR, Patrick DL, Engelberg RA, Norris K, Asp C, Byock I (2002) A measure of the quality of dying and death: initial validation using after-death interviews with family members. *J Pain Symptom Manage* 24:17–31
- Higginson IJ, Sen-Gupta GJ (2000) Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *J Palliat Med* 3:287–300
- Teno JM, Clarridge BR, Casey V, Welch T, Wetle T, Shield R, Mor V (2004) Family perspectives on end-of-life care at the last place of care. *JAMA* 291:88–93
- Aoun SM, Kristjanson LJ (2005) Caregiving for the terminally ill: at what cost? *Palliat Med* 19:551–555
- Thomas C, Morris SM, Clark D (2004) Place of death: preferences among cancer patients and their carers. *Soc Sci Med* 58:2431–2444
- Miyashita M, Morita T, Tsuneto S, Sato K, Shima Y (2008) The Japan Hospice and Palliative care Evaluation study (J-HOPE Study): study design and characteristics of participating institutions. *Am J Hosp Palliat Care* 25:223–232
- Miyashita M, Morita T, Sato K, Hirai K, Shima U, Ucheyomi Y (2008) Good death inventory: a measure for evaluating good death from the bereaved family member's perspective. *J Pain Symptom Manage* 35:486–498
- Morita T, Hirai K, Sakaguchi Y (2004) Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage* 27:492–501
- Sanjo M, Morita T, Miyashita M, Shiozaki M, Sato K, Hirai K, Shima Y, Uchitomi Y (2008) Caregiving consequences inventory: a measure for evaluation caregiving consequences from the bereaved family member's perspective. *Psychooncology* 24: Epub ahead of print
- Agar M, Currow D, Shelby-James T, Plummer J, Sanderson C, Abemethy A (2008) Preference for place of care and place of

- death in palliative care: are these different questions? *Palliat Med* 22:787–795
23. Choi KS, Chae YM, Lee CG, Kim SY, Lee SW, Heo DS, Kim JS, Lee KS, Hong YS, Yun YH (2005) Factors influencing preference for place of terminal care and of death among cancer patients and their families in Korea. *Support Care Cancer* 13:565–572
  24. Gomes B, Higginson IJ (2008) Where people die (1974–2030): past trends, future projections and implications for care. *Palliat Med* 22:33–41
  25. Grande GE, Addington-Hall JM, Todd CJ (1998) Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 47:565–579
  26. Izquierdo-Porrera AM, Trelis-Navarro J, Gomes-Batiste X (2001) Predicting place of death of elderly cancer patients followed by a palliative care unit. *J Pain Symptom Manage* 21:481–490
  27. McNamara B, Rosenwax L (2007) Factors affecting place of death in Western Australia. *Health & Place* 13:356–367
  28. Fukui S, Fukui N, Kawagoe H (2004) Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: a nationwide survey. *Cancer* 101:421–429
  29. Hu WY, Chiu TY, Cheng YR, Chuang RB, Chen CY (2004) Why Taiwanese hospice patients want to stay in hospital: health-care professional's beliefs and solutions. *Support Care Cancer* 12:285–292
  30. Yao CA, Hu WY, Lai YF, Cheng SY, Chen CY, Chiu TY (2007) Does dying at home influence the good death of terminal cancer patients? *J Pain Symptom Manage* 34:497–504
  31. Hudson PL (2006) How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support? *J Palliat Med* 9:694–703
  32. Kim Y, Schulz R, Carver C (2007) Benefit-finding in the cancer caregiving experience. *Psychosom Med* 69:283–291
  33. Sano T, Maeyama E, Kawa M, Shirai Y, Miyashita M, Kazuma K, Okabe T (2007) Family caregiver's experiences in caring for a patient with terminal cancer at home in Japan. *Palliat Support Care* 5:389–395
  34. Tang ST (2003) When death is imminent. *Cancer Nurs* 26:245–251
  35. Han B, McAuley W, Remsburg R (2007) Agency ownership, patient payment source, and length of service in home care. *Gerontologist* 47:438–446
  36. Miller S (2004) Hospice care in nursing homes: is site of care associated with visit volume? *J Am Geriatr Soc* 52:1331–1336
  37. Stevenson D, Huskamp H, Grabowski D, Keating N (2007) Differences in hospice care between home and institutional settings. *J Palliat Med* 10:1040–1047

## 9576 General Poster Session (Board #K13), Mon, 8:00 AM - 12:00 PM

**Code status documentation in the outpatient electronic medical records of patients with metastatic cancer.** *J. Greer, J. Temel, S. Admane, J. Solis, T. Lynch, W. Pirl; Massachusetts General Hospital, Boston, MA*

**Background:** Advanced care planning is an essential component of cancer care for patients with incurable malignancies. However, the extent to which clinicians clearly document end-of-life care discussions and code status preferences in ambulatory medical records is unknown. The goal of the study was to investigate the rate of code status documentation in the electronic longitudinal medical record (LMR) of patients with metastatic cancers. **Methods:** We conducted a retrospective review of outpatient medical records of 2498 patients with metastatic solid tumors seen at an academic cancer center from 10/1/06 through 2/29/08. An electronic database was used to gather information on patient demographics, cancer type, and visits to the cancer center. The sample consisted of patients with metastatic breast, colorectal, non-colorectal gastrointestinal (GI), bladder/kidney, ovarian, prostate, and lung cancers. For the study endpoints, we queried the LMR to determine completion and designation of code status, which could be documented as follows: full code, do not resuscitate (DNR)/do not intubate (DNI), or DNR/DNI with specific resuscitation requests. Multiple logistic regression was used to identify independent predictors of code status completion and resuscitation preference. **Results:** Among the 2498 patients, 508 (20.3%) had a documented code status. Code status was documented more frequently in patients with metastatic non-colorectal GI (193/609, 31.7%) and lung (179/583, 30.7%) cancers compared to patients with genitourinary malignancies (bladder/kidney [4/89, 4.5%], ovarian [4/93, 4.3%] and prostate [7/365, 1.9%] cancers). Independent predictors of having documented code status included cancer type and a greater number of visits to the cancer center. Younger patients and black patients were less likely to be designated as DNR/DNI. **Conclusions:** Despite the incurable nature of metastatic cancers, a minority of patients had a code status documented in the outpatient medical record. Given the importance of advanced care planning for those with terminal illness, interventions are needed to encourage discussion and documentation of end-of-life care preferences in patients with advanced cancer.

## 9578 General Poster Session (Board #K15), Mon, 8:00 AM - 12:00 PM

**Exploration of hereditary cancer and feasibility of genetic services at the end of life.** *J. M. Quillin, J. N. Bodurtha, L. A. Siminoff, T. J. Smith; Virginia Commonwealth University, Richmond, VA*

**Background:** For families, optimal hereditary cancer assessment begins with an affected relative. End of life could be the last chance for testing or DNA banking. Many palliative care oncologists do not feel qualified to offer genetic services and are rarely doing so (NSGC, 2008). The genetic burden of cancer in palliative care is unknown. **Methods:** We investigated prevalence of hereditary cancer among dying cancer patients, previous genetic testing or DNA banking, and awareness and intentions regarding these services. In spring/summer 2008 we recruited and interviewed patients (or surrogate decision makers) from the VCUHS Palliative Care Unit. Genetic risk was characterized as "strong" using classification criteria developed by Scheuner et al. (1997) or other consensus diagnostic criteria. Statistics were assessed using SAS 9.1.3. **Results:** 43 (47%) patients (including 9 surrogates) agreed to participate. The most common diagnoses were leukemias/lymphomas (n=9), and cancers of the lung (n=8), colon (n=5), and breast (n=4). 8 of 43 (18.6%, 95% CI = 7.0% to 30.2%) patients had "strong" genetic risk. Currently available genetic tests could have addressed risk for several patients, especially for HNPCC and hereditary breast/ovarian cancer. None had previous testing or DNA banking. Of strong-risk patients (or surrogates), 7 (87.5%) had heard/read "almost nothing" or "relatively little" about testing. All had heard/read little or nothing about DNA banking. 83% would "probably get tested" if offered, and 72% would "probably" or "definitely" bank DNA. There were no significant differences by race/ethnicity, nor by genetic risk. **Conclusions:** The genetic burden of cancer may be at least as high in the palliative care population as in other clinical settings and is not being discovered upstream. Patient interest in genetic services is high, but awareness is low.

## 9577 General Poster Session (Board #K14), Mon, 8:00 AM - 12:00 PM

**J-HOPE study: Evaluation of end-of-life cancer care in Japan from the perspective of bereaved family members.** *M. Miyashita, T. Morita, K. Sato, S. Tsuneto, Y. Shima; The University of Tokyo, Tokyo, Japan; Seirei Mikatahara Hospital, Hamamatsu, Japan; Osaka University, Suita, Japan; Tsukuba Medical Center Hospital, Tsukuba, Japan*

**Background:** The Japan Hospice and Palliative Care Evaluation (J-HOPE) study was conducted in 2007 and 2008. The aim of the study was to evaluate the quality of end-of-life care at regional cancer centers (CCs), inpatient palliative care units (PCUs), and home hospices (HHs) in Japan from the perspective of bereaved family members. **Methods:** A nationwide cross-sectional mail survey was conducted in 2007 and 2008. The survey was sent to bereaved families 6-18 months after the death of a patient at 56 CCs, 100 PCUs, or 14 HHs. Outcome measures were the good death inventory, the care evaluation scale, and overall satisfaction with care. The protocol of this study was approved by the institutional review boards of each participating institution. **Results:** Of the 13,181 bereaved family members that received the survey, 8,163 (62%) participants returned their responses. Among bereaved family members, significantly fewer responded that patients were free from physical distress at CCs (50%) than PCUs (80%) and HHs (73%) ( $P < 0.0001$ ). Significantly fewer patients trusted the physicians at CCs (79%) when compared with PCUs (83%) and HHs (88%) ( $P < 0.0001$ ). Significantly fewer patients were valued as people at CCs (83%) than PCUs (93%) and HHs (95%) ( $P < 0.0001$ ). In addition, significantly fewer participants felt physicians should have worked to improve the patients' symptoms more quickly at CCs (55%) when compared with PCUs (78%) and HHs (77%) ( $P < 0.0001$ ). Significantly fewer participants felt nurse should improve their knowledge and skills regarding end-of-life care at CCs (51%) when compared with PCUs (76%) and HHs (78%) ( $P < 0.0001$ ). A total of 51% of participants reported that nurses should improve their knowledge and skills regarding end-of-life care. Finally, significantly fewer participants were satisfied with the end-of-life care provided by CCs (80%) when compared with PCUs (93%) and HHs (94%) ( $P < 0.0001$ ). **Conclusions:** Overall, the bereaved family members appreciated the end-of-life care provided by CCs, PCUs, and HHs in Japan. However, in some situations, the quality of end-of-life care provided by CCs was lower than that provided by PCUs and HHs.

## 9579 General Poster Session (Board #K18), Mon, 8:00 AM - 12:00 PM

**Correlates of hospice use in elders with cancer.** *C. Owusu, S. Koroukian, E. Madigan; Case Western Reserve University, Cleveland, OH*

**Background:** Use of hospice has remained relatively low. We aim to identify correlates of hospice in elders with cancer, hypothesizing that the presence of functional limitations and geriatric syndromes are associated with hospice use, independently of age and comorbidities. **Methods:** The study population included Ohio residents age 65 years or older, diagnosed with breast (n=774), prostate (n=271), or colorectal cancer (n=1,011) during the period 07/1999-12/2001, receiving care through the Medicare fee-for-service system, and first receiving home health care (HHC) in the 30 days before or after cancer diagnosis. This strategy was aimed at obtaining clinical data at baseline, as documented in the HHC Outcome Assessment Information Set (OASIS). Our data source consisted of records from the Ohio Cancer Incidence Surveillance System (OCISS) linked with Medicare data, and the OASIS. In addition to descriptive analyses, multivariable logistic regression analysis was conducted to evaluate the association between hospice use, comorbidity, functional limitations, and geriatric syndromes, after adjusting for patient and tumor attributes. **Results:** Respectively across the anatomic cancer sites, hospice was used by 9.8%, 22.5%, and 25.1%, of patients. Hospice use increased significantly with age, and was higher among men than women. No differences in hospice use were observed by race, Medicaid status, or the presence of comorbidities. Conversely, hospice use was significantly higher ( $p < 0.001$ ) among patients with functional limitations (24.0% vs. 16.5% in all others), and those with geriatric syndromes (23.8% vs. 15.3% in all others). Results from the multivariable logistic regression analysis indicated that comorbidities and functional limitations were not associated with hospice use, whereas patients with geriatric syndromes were 1.5 times as likely as those without geriatric syndromes to use hospice (adjusted odds ratio (AOR): 1.5, 95% confidence interval (1.2-1.9). **Conclusions:** The findings highlight the importance of clinical data that extend beyond comorbidities, when analyzing hospice use. Given marked differences in the disease trajectory across the anatomical cancer sites, future studies should analyze these associations separately in breast, prostate, and colorectal cancer patients.

# Value of religious care for relief of psycho-existential suffering in Japanese terminally ill cancer patients: the perspective of bereaved family members

Michiyo Ando<sup>1\*</sup>, Ryo Kawamura<sup>2</sup>, Tatsuya Morita<sup>3</sup>, Kei Hirai<sup>4,5</sup>, Mitsunori Miyashita<sup>6</sup>, Takuya Okamoto<sup>7</sup> and Yasuo Shima<sup>8</sup>

<sup>1</sup>Faculty of Nursing, St. Mary's College, Fukuoka, Japan

<sup>2</sup>Graduate School of Human Sciences, Osaka University, Osaka, Japan

<sup>3</sup>Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka, Japan

<sup>4</sup>Center of the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences, Osaka University, Osaka, Japan

<sup>5</sup>Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

<sup>6</sup>Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo, Japan

<sup>7</sup>Palliative Care Unit, Toya Onsen Hospital, Hokkaido, Japan

<sup>8</sup>Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki, Japan

\*Correspondence to:

Michiyo Ando, St. Mary's College, Tsubuku Honmachi 422, Kurume, Fukuoka, Japan. E-mail: andou@st-mary.ac.jp

## Abstract

**Objective:** This study aimed to clarify the experience of bereaved family members of cancer patients regarding the usefulness of religious care (perceived usefulness). The value of this care to palliate psycho-existential suffering in future patients was also examined (predicted usefulness).

**Methods:** A questionnaire was sent to 592 bereaved family members of cancer patients who were admitted to certified palliative care units in Japan. Responses were obtained from 378 families, indicating whether the patient received religious care, the perceived usefulness of the care, and its predicted usefulness for palliation of psycho-existential suffering.

**Results:** About 25% ( $N = 83$ ) indicated that the patient had received religious care, whereas 75% ( $N = 255$ ) had not received it. Families of patients who had received religious care evaluated pastoral care workers (86%), religious services (82%), and religious music (80%) as 'very useful' or 'useful'. Families predicted usefulness of religious care for future patients: attending a religious service (very useful or useful, 56%; not useful or harmful, 44%), a religious atmosphere (48%, 52%), meeting with a pastoral care worker (50%, 50%), and religious care by physicians (26%, 74%), and nurses (27%, 73%). Families with a religion were significantly more likely to rate religious care as useful for future patients.

**Conclusions:** Families of patients who received religious care generally evaluated this care to be very useful or useful. For future patients, some families felt that religious care would be useful, but some did not. In Japan, religious care is more likely to provide benefits to patients who have a religion.

Copyright © 2009 John Wiley & Sons, Ltd.

**Keywords:** religious care; Japanese bereaved family; palliative care; cancer; oncology

Received: 4 February 2009

Revised: 23 June 2009

Accepted: 17 July 2009

## Background

The World Health Organization has stated that palliative care should be spiritual as well as physical, social, and psychological [1]. Spirituality has been identified as one of the key concerns of dying patients who require support, and spiritual care has been shown to contribute to patient comfort at the end of life. Koenig *et al.* highlighted both the

considerable overlap and distinct characteristics of religion and spirituality [2]. The National Cancer Institute defines religion as a set of beliefs and practices associated with a religion or denomination, and spirituality as the search for ultimate meaning through religion or other paths. In the current work, we use similar definitions of 'religion' and 'spirituality'. We consider that a religious service such as prayer in Christianity has a role in spiritual care.

As many as 50% of cancer patients report becoming 'more religious', or that their 'illness has strengthened their faith', and religion and spirituality are positively associated with better quality of life, psychological adjustment, and well-being [3]. Previous studies have shown that the spirituality of patients who participate in clinical research is positively associated with quality of life and that they trust in both God and medicine [4]. Religious and spiritual beliefs provide patients with a framework for ascribing meaning to the illness and answers to existential questions [5]. Religious resources may serve multiple functions in long-term adjustment to cancer, including maintaining self-esteem, giving emotional comfort, and providing a sense of meaning and purpose [6]. Religious/spiritual coping, which is defined as the use of cognitive and behavioral techniques that arise out of one's religion or spirituality, in the face of stressful life events [7] may serve similar purposes and provide a sense of hope [8]. These studies show the importance of the religious and spiritual aspects of care for cancer patients.

Chaplaincy provides a kind of spiritual care in palliative care. Kernohan *et al.* [9] examined the spiritual needs of 62 patients in Northern Ireland and found that 92% had faith in God or a Higher Being. The majority of the participants (82%) felt their spiritual needs had been addressed and viewed their interaction with the chaplaincy service as positive. Alferi *et al.* [10] found differences in religious coping strategies between Catholic and Evangelical women, including the need for social support from church members, attending church meetings, talking to a priest or minister, and taking comfort in religion. Moreover, Dann *et al.* [11] demonstrated a preference of religious care based on Sacred Gathering, with 80% or more subjects agreeing that music, prayer, and scripture were important in care. Astrow *et al.* [12] found that many patients wanted to be asked about their religion or spirituality in a study of outpatients in the Northeastern United States.

In Japan, Miyashita *et al.* [13,14] have examined the concept of 'good death' in the general population and among bereaved families. Bereaved families were chosen as participants since many terminally ill cancer patients are too physically and mentally vulnerable to participate in such studies [15]. As a consequence, surveys of terminally ill patients are likely to be unrepresentative and/or biased [16]. Family members are potential proxies for terminally ill patients and surveys of bereaved relatives may therefore be of value. Thus, postbereavement evaluations of end-of life care have been conducted worldwide [14]. Miyashita *et al.* found that bereaved families in Japan identified 'religious and spiritual comfort' as a factor in achieving a good death at the end of life [13]. However, cultural differences were also

apparent in this study, since Steinhäuser *et al.* [17] showed that 89 and 85% of American patients emphasized 'being at peace with God' and 'prayer', respectively, whereas the corresponding figures were 37 and 52% in the Japanese subjects in Miyashita *et al.* [13]. Moreover, 96% of American subjects [17] but only 50–69% of Japanese subjects [13] emphasized the importance of 'knowing what to expect about one's physical condition' in achieving a good death.

Thus, it is unclear if the results of studies of religious care in Western countries would also be obtained in Japan. Therefore, to clarify views on religious care and improve spiritual care in Japan, we examined these issues from the perspective of bereaved families. The aim of the study was to clarify (1) the perceived value of religious care performed in certified palliative care units and (2) the potential value of this care for palliating psycho-existential suffering for future patients.

## Subjects and methods

### Participants

The most common type of specialized palliative care service in Japan is the Palliative Care Unit. Therefore, we chose bereaved family members of patients in Palliative Care Units as the subjects of the study. All these units provide palliative care through a multidisciplinary team including attending physicians, nurses, psychiatrists, clinical psychologists, and medical social workers. Some Palliative Care Units provide regular religious care by pastoral care workers or priests. The details of the service contents have been given in a previous study [18].

Primary physicians identified potential participants based on the following inclusion criteria: (1) bereaved family members of an adult cancer patient (one family member was selected for each patient), (2) aged 20 years old or more, (3) capable of replying to a self-reported questionnaire, (4) aware of the diagnosis of malignancy, and (5) no serious psychological distress recognized by the primary physicians. The last criterion was adopted on the assumption that primary physicians could identify families who might suffer a serious psychological burden due to this survey. Completion and return of the questionnaire was regarded as consent to participate in this study. The ethical and scientific validity of the study were confirmed by the institutional review board of each hospital.

### Questionnaire

The questionnaire was developed following previous studies of religious services in palliative care [11,12,19]. Families rated whether they did or did not receive religious care on a three-point scale ('received in the hospital', 'received outside the

hospital', 'not received'). If 'not received' was chosen, the reasons were selected from four choices: 'Patients did not need this care or had a bad image of religion', 'Consciousness or physical condition became too bad to receive religious care', 'Patients did not know how to obtain religious care, although they wanted this care', and 'other reasons'. Also, families indicated whether the patient did or did not have a religion (Christianity, Buddhism, or Shinto) at the time of diagnosis as 'Yes' or 'No'. The family was asked to rate the perceived usefulness of religious care received by the patient in a palliative care unit on a four-point scale ('very useful', 'useful', 'not so useful', 'harmful'). The categories of care included 'Attending a religious service', 'Reading books or watching videos about religion', 'Listening to reading of Buddhist scriptures or the Bible', 'Listening to religious music', 'Religious atmosphere in hospitals', 'Reading religious periodicals published by hospitals', 'Meeting with a pastoral care worker', 'Physicians talking about religious topics and praying', 'Nurses talking about religious topics and praying', and 'Physicians or nurses with a religion'. In addition, families were asked to report whether the patient had expressed an opinion regarding the usefulness of religious care, using a five-point scale ('very useful', 'useful', 'not so useful', 'harmful', 'did not express').

The families were also asked to report whether they had an experience in which they wished for a religious service, but were rejected to receive such a service due to a hospital regulation (e.g. a religious group was not allowed to visit the patients). All families also rated the usefulness of religious care for future patients (predicted usefulness) on a four-point scale ('very useful', 'useful', 'not so useful', 'harmful') in the categories of 'Attending religious events (such as religious services, prayer, sermons, worship)', 'Religious atmosphere in hospitals', 'Meeting with a pastoral care worker', 'Physicians talking about religious topics and praying', 'Nurses talking about religious topics and praying', and 'Physicians or nurses with a religion'.

### Procedure

The study was performed as part of a large cross-sectional anonymous nationwide survey of bereaved families of cancer patients who had been admitted to 100 palliative care units in Japan. The structure of the Palliative Care Unit has been described in a previous study [18]. Questionnaires were mailed to bereaved families in June 2007, and again to nonresponding families in August 2007. This study was permitted from the Ethical committee of St. Mary's College.

### Analysis

The differences in predicted usefulness were classified based on the absence or presence of a religion,

with the significance of differences determined using a  $\chi^2$  test.

## Results

### Perceived usefulness of religious care

The survey was conducted for 592 bereaved family members of cancer patients who were admitted to palliative care units in Japan. Responses were obtained from 378 families, and 281 of these responses were suitable for analysis. Table 1 summarizes the background of the participants (bereaved family members). Of the responses, 25% ( $N = 83$ ) indicated that the patient had received religious care and 75% ( $N = 255$ ) had not received this care. From the families' perspective, patients did not receive religious care because 'Patients did not need this care or had a bad image of religion' ( $n = 113$ , 44%), 'Consciousness or physical condition became too bad to receive religious care' ( $n = 97$ , 38%), 'Patients did not know how to obtain religious care where there were religious resources, although they wanted this care' ( $n = 10$ , 4%), and other reasons ( $n = 36$ , 14%). Two families among all respondents ( $n = 2$ , 1%) reported that they were denied religious care due to hospital regulations, although they actually wanted this care.

Table 2 summarizes the perceived usefulness of religious care received by patients in palliative care units. Families of patients with religious beliefs at the time of diagnosis (which we refer to as families with religion) regarded the following activities to be 'very useful' or 'useful': 'Attending a religious service' (82%), 'Reading books or watching videos about religion' (64%), 'Listening to reading Buddhist scriptures or the Bible' (68%), 'Listening to religious music' (80%), 'A religious atmosphere in hospitals' (78%), 'Reading religious periodicals published by hospitals' (38%), 'Meeting with a pastoral care worker' (86%), 'Physicians talking about religious topics and praying' (54%), 'Nurses talking about religious topics and praying' (64%),

**Table 1.** Characteristics of bereaved family members

Characteristics	%	Number
Mean age (years)		60.0 ± 12.7
Gender	30.2	114
Male	69.8	264
Female		
Relationships to the patient:		
Spouse of patient	50.5	142
Children of patient	30.6	86
Son-in law/wife	6.4	18
Parent of patient	2.1	6
Brother or sister of patient	6.8	19
Others	3.6	10
Religion		
Present	37.3	114
None	62.7	192

**Table 2.** Perceived-usefulness for the religious care, which bereaved family members received in palliative care unit

	Very useful		Useful		Very useful+useful		Not so useful		Harmful		Total
	No.	%	No.	%	No.	%	No.	%	No.	%	
Attending a religious service	13	30	23	52	36	82	7	16	1	2	44
Reading books or watching videos about religion	6	17	17	47	23	64	12	33	1	3	36
Listening to reading Buddhist scriptures or the Bible	9	22	19	46	28	68	11	27	2	5	41
Listening to religious music	16	36	19	43	35	80	8	18	1	2	44
Religious atmosphere in hospitals	15	27	28	45	43	78	12	22	0	0	55
Reading religious periodical published by hospitals	2	6	10	31	12	38	19	59	1	3	32
Meeting with a pastoral care worker (Buddhist priest, priest, chaplain father, sister)	17	35	25	51	42	86	6	12	1	2	49
Physicians talking about religious topics and praying	10	29	9	26	19	54	15	43	1	3	35
Nurses talking about religious topics and praying	7	19	16	44	23	64	12	33	1	3	36
Physicians or Nurses have a religion	14	33	15	36	29	69	13	31	0	0	42

and 'Physicians or nurses with a religion' (69%). Moreover, based on families who reported that the patient expressed an opinion regarding religious care, patients found this care to be 'very useful' or 'useful' ( $n = 39$ , 98%), 'not so useful' ( $n = 1$ , 1%) and 'harmful' ( $n = 1$ , 1%).

#### Usefulness of religious care for future patients

Table 3 summarizes the predicted usefulness of religious care for future patients based on experiences of bereaved families. The following religious care was predicted to be 'useful' ('very useful' or 'useful') or 'not useful' ('not so useful' or 'harmful'): 'Attending religious events' (56% useful, 44% not useful), 'A religious atmosphere in hospitals' (48%, 52%), 'Meeting with a pastoral care worker' (50%, 50%), 'Physicians talking about religious topics and praying' (26%, 74%), 'Nurses talking about religious topics and praying' (27%, 73%), and 'Physicians or nurses having a religion' (40%, 60%). In particular, religious care offered by physicians or nurses was considered 'harmful' by 20–21% of families.

Table 4 summarizes the differences in the predicted usefulness of religious care for future patients for those with and without a religion. Families with a religion felt that religious care was much more useful than those without a religion: 'Attending religious events' ( $p = 0.001$ ), 'Religious atmosphere in hospitals' ( $p = 0.082$ ), 'Meeting with a pastoral care worker' ( $p = 0.000$ ), 'Physicians talking about religious topics and praying' ( $p = 0.146$ ), 'Nurses talking about religious topics and praying' ( $p = 0.112$ ), and 'Physicians or nurses with a religion' ( $p = 0.01$ ).

## Discussion

### Perception of religious care received by patients in palliative care units

Over 80% of the families of patients who received religious care felt that attending a religious service,

listening to religious music, a religious atmosphere, and meeting with a pastoral care worker was 'very useful' or 'useful'. In particular, the perceived usefulness of meeting with a pastoral care worker (86%) and attending a religious service (82%) was high in this study. The importance of meeting with a pastoral care worker is in accord with the study of Kernohan *et al.*, in which 82% of patients felt their spiritual needs had been addressed and viewed their interaction with the chaplaincy service in a positive manner [9]. The usefulness of music and a religious atmosphere is also in accord with a previous study, in which Dann *et al.* demonstrated that services (music, ritual, and prayer) in sacred gatherings were helpful for cancer patients [12]. On the other hand, the reason for the low percentage of families who felt that reading periodicals published by hospitals was useful (38%) may be that the contents of the periodicals are designed for general patients, rather than focusing on psycho-existential care for terminally ill cancer patients. It is also possible that patients near to the end of life do not have the strength to read and may prefer religious care that has a lower physical burden. Overall, families of patients who received religious care generally felt that the care was useful. In addition, 95% ( $N = 39$ ) of patients who expressed an opinion on religious care ( $n = 41$ ) felt that the care was 'very useful' or 'useful'. Considering these evaluations, the results indicate that both families and patients who received religious care were generally satisfied with the care.

About 75% of patients did not receive religious care, with the major reason being that the patients did not want this kind of care. These results differ from those in a Western study, in which over two-thirds of 53 admitted patients (70%,  $n = 37$ ) were visited by a chaplain within two days. In addition, 14% of families reported that the patient did not receive religious care because their religion differed from that of the care offered by hospitals. Considering these results and those from other studies that suggest that patients want religious or



## Religious care for relief of psycho-existential suffering

**Table 3.** Estimated-usefulness of religious care for future patients from bereaved family members' perspective

	Very useful		Useful		Very useful+		Not so useful		Harmful		Not so useful+		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Attending religious events	32	11	136	45	168	56	116	39	14	8	130	44	298	100
Religious atmosphere in hospitals	32	11	111	38	143	48	119	40	34	12	153	52	296	100
Meeting with a pastoral care worker (Buddhist priest, priest, chaplain father, sister)	36	12	112	38	148	50	114	39	31	11	145	50	293	100
Physicians talking about religious topics and praying	15	5	57	21	72	26	149	54	57	20	206	74	278	100
Nurses talking about religious topics and praying	15	5	62	22	77	27	145	52	58	21	203	73	280	100
Physicians or Nurses have a religion	28	10	85	30	113	40	136	47	38	13	174	60	287	100

**Table 4.** Estimated-usefulness of religious care for future patients separated by presence or absence of a religious belief

Item	Families with a religion						Families without a religion						$\chi^2$	p
	Very use- ful/useful		Not so useful		Harmful/ nuisance		Very use- ful/useful		Not so useful		Harmful/ nuisance			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%		
Attending religious events	67	74	22	24	2	2	84	50	73	44	10	6	13.4	0.001
Religious atmosphere in hospitals	56	60	29	31	8	9	75	46	69	42	20	12	5.0	0.082
Meeting with a pastoral care worker	67	71	22	23	5	5	66	41	70	44	24	15	21.8	0.000
Physicians talking about religious topics and praying	29	34	44	52	12	14	39	25	82	52	36	23	3.8	0.146
Nurses talking about religious topics and praying	31	36	44	51	12	14	41	26	79	50	37	24	4.4	0.112
Physicians or nurses with a religion	51	55	33	36	9	10	56	35	82	52	21	13	9.3	0.010

spiritual care [12,20], it may be important to develop medical facilities in which religious care is available in the form desired by patients.

### Usefulness of religious care for future patients

About half of the families felt that the following care would be 'very useful' or 'useful' for future patients: 'Attending religious events', 'There is a religious atmosphere' and 'Meeting with a pastoral care worker'. However, about 70% families felt that 'physicians (or nurses) talking about religious topics and praying' was 'Not so useful' or 'harmful'. These results seem to be inconsistent with findings in Western culture that patients require physicians to participate in their religious care, with studies showing that most patients want physicians to consider their spiritual needs in the overall plan of care [21] and that over 50% of patients thought it appropriate for physicians to inquire about their religious belief [12]. One reason for this difference may be that only about 30% of the Japanese population has a religion, and most people want physicians or nurses to act principally as medical professionals without a religious element in their work. The finding that families with a religion were more likely to find this activity more useful strengthens this interpretation, and we believe that religious care in Japan is likely to be more beneficial to patients with a certain religion.

### Limitations

This study has several limitations. First, data were obtained from bereaved family members, and it thus uncertain if the same view would be obtained from terminally ill cancer patients. Although we investigated whether patients expressed an opinion about the usefulness of religious care, an investigation of religious care given to terminally ill cancer patients in certified palliative care units would be useful. Second, all subjects received specialized palliative care service, and some of these services are funded by religious foundations (mainly Christian) in Japan. Therefore, the results might not be applicable to other patients and families.

### Conclusion

The families and patients who received religious care generally evaluated the religious care as very useful or useful. For future patients, some families thought religious care would be useful, but many thought that such care provided by physicians and nurses was not so useful or even harmful. Religious care may be more beneficial for patients who desire this care and for those with a religion. For patients without a religion, general psycho-existential care [22-24] may be preferable as an alternative.

## Acknowledgements

This research was supported by a Japan Hospice Palliative Care Foundation.

## References

1. WHO. *National Cancer Control Program, Policies and Managerial Guidelines*, (2nd edn), WHO: Geneva, 2002.
2. Koenig HGM, McCullough ME, Larson DB. *Handbook of Religion and Health*. Oxford University Press: Oxford, 2001.
3. Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including spirituality in quality of life measurement in oncology. *Psycho-Oncology* 1999;8:417–428.
4. Daugherty CK, Fitchett G, Murphy P et al. Trusting God and medicine: spirituality in advanced cancer patients volunteering for clinical trials of experimental agents. *Psycho-Oncology* 2005;14:135–146.
5. Holland J, Passik S, Kash K et al. The role of religious and spiritual beliefs in coping with malignant melanoma. *Psycho-Oncology* 1999;8:14–26.
6. Jenkins RA, Pargament KI. Religion and spirituality as resources for coping with cancer. *J Psychosoc Oncol* 1995;13:51–74.
7. Tix AP, Fraser PA. The use of religious coping during stressful life events: main effects, moderation, and meditation. *J Consult Clin Psychol* 1998;66:411–422.
8. Thune-Boyle IC, Stygall JA, Keshtgar MR, Newman SP. Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Soc Sci Med* 2006;63:151–164.
9. Kernohan WG, Waldron M, McAfee C, Cochrane B, Hasson F. An evidence base for a palliative care chaplaincy service in Northern Ireland. *Palliat Med* 2007;21:519–525.
10. Alferi S, Culver J, Carver C, Arena PL, Antoni MH. Religiosity, religious coping and distress—a prospective study of Catholic and evangelical Hispanic women in treatment for early-stage breast cancer. *J Health Psychol* 1999;4:343–356.
11. Dann NJ, Higby DJ, Mertens WC. Can a cancer program-sponsored spiritual event meet with acceptance from patients and other attendees? *Integrat Cancer Ther* 2005;4:230–235.
12. Astrow A, Wexler A, Teixeira K, He MK, Sulmasy DP. Is failure to meet spiritual need associated with cancer patients' perceptions of quality of care and their satisfaction with care? *J Clin Oncol* 2007;25:5753–5757.
13. Miyashita M, Morita T, Hirai K, Uchitomi U. Good death in cancer care: a nationwide quantitative study. *Ann Oncol* 2007;18:1090–1097.
14. Miyashita M, Morita T, Hirai K. Evaluation of end-of-life cancer care from the perspective of bereaved family members: the Japanese experience. *J Clin Oncol* 2008;26:3845–3852.
15. Addington-Hall JM, MacDonald LD, Anderson HR et al. Randomized controlled trial of effects of co-ordinating care for terminally ill cancer patients. *BMJ* 1992;305:1317–1322.
16. Addington-Hall J, Clark D, Corner J. Survey research in palliative care using bereaved relatives. In *Researching Palliative Care*, Field D et al. (eds). Open University Press: Buckingham, United Kingdom, 2001; 27–36.
17. Steinhilber KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA* 2000;284:2476–2482.
18. Miyashita M, Morita T, Tsuneto S, Sato K, Shima Y. The Japan Hospice and Palliative care Evaluation Study (J-HOPE) study: study design and characteristics of participating institutions. *Am J Hospice Palliat Care* 2008;25:223–232.
19. Brazil K, Bedard M, Kureger P, Abernathy T, Lohfeld L, Willison K. Service preferences among family caregivers of the terminally ill. *J Palliat Med* 2005;8:69–78.
20. Balloni TA, Vanderwerker LC, Block SD et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol* 2007;25:555–560.
21. King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith healing and prayer. *J Fam Pract* 1994;39:349–352.
22. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005;23:5520–5525.
23. Ando M, Morita T, Okamoto T, Ninosaka Y. One week short-term life review interview can improve spiritual well-being of terminally ill cancer patients. *Psycho-Oncology* 2008;17:885–890.
24. Duggleby WD, Degner L, Williams A et al. Living with hope: initial evaluation of a psychosocial hope intervention for older palliative home care patients. *J Pain Symptom Manage* 2007;33:247–257.

# Religious Care Required for Japanese Terminally Ill Patients With Cancer From the Perspective of Bereaved Family Members

Takuya Okamoto, MD, Michiyo Ando, RN, PhD,  
Tatsuya Morita, MD, Kei Hirai, PhD, Ryo Kawamura, MA,  
Miyashita Mitsunori, RN, PhD,  
Kazuki Sato, RN, MHLthSci, and Yasuo Shima, MD, PhD

The aim of this study was to explore the most suitable religious care for Japanese terminally ill patients with cancer based on the opinions of bereaved family members. A multicenter questionnaire survey on palliative care service was sent to 592 bereaved family members of patients with cancer who were admitted to palliative care units in Japan, and 430 responded by mail. In the section of the questionnaire about religious care, 382 responses were used for quantitative analysis, and 71 responses about religious care for qualitative analysis. In the current study, the 71 responses were grouped into families with and without a religion and were analyzed qualitatively. Families with a religion (N = 28) chose answers such as "Instrumental care" such as music or a religious event, "Freedom of choice of kinds for religious care," "Staff

involvement of religious care," "Meeting with a pastoral care workers," and "Burden of offering a different kind of personal religion." In contrast, families without a religion (N = 44) chose answers such as "Instrumental care," "Freedom of choice whether patients receive religious care or not," "Spiritual care," "Not being able to accept religious care," and "Burden of thinking about a religion and nuisance." These findings suggest that Japanese bereaved families with a religion generally regard religious care positively and prefer care through their own religion, whereas some families without a religion require religious care but some do not prefer it.

**Keywords:** religious care; Japanese; bereaved families; terminal; cancer; qualitative study

From the Palliative Care Unit, Toya Onsen Hospital, Abuta-Gun (TO); Faculty of Nursing, St. Mary's College, Kurume (MA); Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka (TM); Center for the Study for Communication Design, Psychology and Behavioral Sciences, Graduate School of Human Sciences & Department of Complementary and Alternative Medicine (KH), Graduate School of Medicine, Graduate School of Human Sciences (RK), Osaka University, Osaka, Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo (MM, KS); and Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki (YS), Japan.

Address correspondence to: Takuya Okamoto, Palliative Care Unit, Toya Onsen Hospital, Touya-Mati54-41, Touyako-Chou, Abuta-Gun, Hokkaido, Japan; e-mail: [t-okamoto@toya-onsen-hospital.or.jp](mailto:t-okamoto@toya-onsen-hospital.or.jp).

## Background

Terminally ill patients with cancer are likely to search for the meaning of life or existence and may have concerns regarding religion. Spirituality consists of 2 main factors, the meaning of life and faith or religious belief,<sup>1</sup> which refer not just to a particular religious belief but also to a higher transcendence. The National Cancer Institute has defined religion as a set of beliefs and practices associated with a religion or denomination, and spirituality as the search for ultimate meaning through religion or other paths. Based on these studies, we define spirituality as the meaning of life and faith for religious belief.

Table 1. Patient Characteristics

Characteristics	Patients %	Data Number
Mean age (years)		60.4 (11.7)
Sex		
Male	38.9	28
Female	61.1	44
Relationship to the patient		
Spouse	55.6	40
Children	26.4	19
Son-in-law/wife	6.9	5
Parent	1.4	1
Brother or sister	6.9	5
Others	2.8	2
Religious care in palliative care unit		
Yes	26.5	18
No	73.5	50
Religion		
Yes	39.4	28
No	60.6	43
Religious background		
Buddhism		7
Shin-Buddhism, Pure Land Buddhism		4
Catholic		2
Shingon Buddhism		2
Nichiren Buddhism		2
Christianity (Anglican-Episcopal)		1
Church of Japan		
Ontakekyo		1
Cosmology		1
Jodo Shu, Honen Buddhism		1
Shinto Religion		1
Shindoukyo		1
Tenrikyo		1
Truthkyo		1
The Rinzai School		1

Previous studies showed that patients report becoming "more religious," or that "their illness has strengthened their faith,"<sup>2</sup> because "religious and spiritual beliefs" provide patients with a framework for ascribing meaning to their illness and an answer to existential questions.<sup>3</sup> Many patients with a variety of cancer diagnoses consider religion to be important in providing them with social support and hope and helping them cope and find meaning in their illness.<sup>4</sup> Religion and spirituality are also positively correlated with a better quality of life, psychological adjustment, and well-being among patients with cancer.<sup>2</sup>

Dann et al<sup>5</sup> showed that patients with cancer and other attendees found a service with music, ritual, and prayer somewhat or very helpful, with distinct preferences and reactions to the service noted for different sexes, patient status, and religious affiliation.

However, 70% of participants had a religion in Dann et al,<sup>5</sup> whereas not as many Japanese patients have a religion. Moreover, patients with and without a religion may have different requirements for kinds of religious care. Therefore, the current study was performed to clarify the kinds of religious services preferred by terminally ill patients with cancer in Japanese, based on a survey of bereaved relatives.

## Methods

### Participants

Primary physicians identified the potential participants in the study based on the following inclusion criteria: (1) bereaved family members of an adult patient with cancer (1 family member was selected for each patient), (2) aged  $\geq 20$  years old, (3) capable of replying to a self-reported questionnaire, (4) aware of the diagnosis of malignancy, and (5) no serious psychological distress recognized by the primary physicians. The last criterion was adopted on the assumption that primary physicians could identify families who would suffer serious psychological burden due to this survey. Completion and return of the questionnaire was regarded as consent to participate in this study. The ethical and scientific validity of the study were confirmed by the institutional review board of each hospital. The background of the participants is shown in Table 1.

### Procedure

The study was performed as part of a large cross-sectional anonymous nationwide survey of bereaved families of patients with cancer who had been admitted to 100 palliative care units in Japan. The detailed methods of this survey have been described elsewhere.<sup>6</sup> Questionnaires about palliative care service were mailed to bereaved families in June 2007 and again in August 2007 to nonresponding families.

### Analysis

In the questionnaire, bereaved families were asked to respond openly to one question: "What kind of religious care do you think is desirable or not desirable." In Japan, relatively few people have a particular religion or conduct religious behavior,<sup>7</sup> and therefore we separated families based on whether they had a religion or were not religious. As a qualitative