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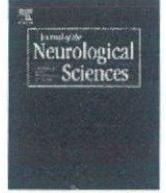
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Care burden and depression in caregivers caring for patients with intractable neurological diseases at home in Japan[☆]

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ABSTRACT

Objectives: The aims of this study are to describe the care burden on caregivers of individuals with intractable neurological diseases and to clarify the prevalence of depression in caregivers and factors related to the presence of depression.

Methods: A cross-sectional survey was conducted among caregivers who provide home care to patients with neurological diseases such as Parkinson disease (PD), spinocerebellar degeneration (SCD), multiple system atrophy (MSA), and amyotrophic lateral sclerosis (ALS), using a mailed, self-administered questionnaire. We used the Burden Index of Caregivers to measure multi-dimensional care burden and the Center for Epidemiologic Studies Depression scale to determine the presence of depression among caregivers.

Results: A total of 418 questionnaires were analyzed. Although several domains of care burden for caregivers were significantly different among the four diseases, the intensity of caregiving and hours spent caregiving were the main definitive variables. In addition, we described different aspects of the care burden using the multi-dimensional care burden scale. The prevalence of depression in caregivers was high (PD, 46%; SCD, 42%; MSA, 63%; ALS, 61%). Hours required for close supervision of the patient ($P=0.015$), intensity of caregiving ($P=0.024$), and low household income ($P=0.013$) were independently-related variables for depression in caregivers.

Conclusions: The care burden of caregivers was mainly explained by the intensity of caregiving and hours spent caregiving per day, not only according to the disease. The high prevalence of depression indicates the need for effective interventions, especially for caregivers of patients with MSA and ALS.

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1. Introduction

The concept of burden of care was defined in 1980 by Zarit, an American gerontologist, as the physical, psychological, financial, and social discomfort and disruption experienced by the principal caregiver of an older family member [1]. In 1999, Shultz showed in a prospective study in the United States that care burden is an independent risk factor for mortality among elderly spousal caregivers [2]. Since then, many studies focusing on care burden have been

conducted and numerous instruments measuring care burden have been developed [1,3–12]. In addition, it has been shown that many caregivers experience depression during the caregiving period and care burden is correlated with depression in caregivers [13–20].

Japanese health policy now provides various preferential treatment conditions to patients with certain neuromuscular diseases, including Parkinson disease (PD), spinocerebellar degeneration (SCD), multiple system atrophy (MSA), and amyotrophic lateral sclerosis (ALS), under the framework of “intractable diseases.” Despite increased subsidization of costs, however, the heavy burden of home care for these patients has remained [21,22]. However, a quantitative evaluation of the care burden and depression among caregivers of individuals with intractable neurological disease has not been conducted in Japan. In addition, although the care burden and quality of life of caregivers for patients with PD [13,14,23,24] and ALS [25–29] have been well investigated worldwide, little research has

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been done on caregivers for patients with SCD and MSA until now [30,31].

Therefore, we conducted a cross-sectional study using a multi-dimensional instrument to clarify the care burden and depression among caregivers of patients with intractable neurological diseases including PD, SCD, MSA, and ALS in Japan. The aims of this study are (1) to clarify the care burden of caregivers of patients with such intractable neurological diseases, (2) to explore factors related to the multiple dimensions of the care burden of caregivers, (3) to clarify the prevalence of depression in caregivers of such intractable neurological diseases, and (4) to explore factors related to depression in caregivers.

2. Methods

2.1. Participants and procedures

Participants were caregivers providing home health care to patients with intractable neurological diseases between November 2003 and May 2004. A self-rating questionnaire was mailed to all caregivers of patients registered as having PD, SCD, MSA, and ALS in Mie Prefecture, Japan. The participants were asked to complete the questionnaire and return the answer sheets.

2.2. Measurements

2.2.1. Burden Index of Caregivers (BIC-11) [32]

The BIC-11 is a multi-dimensional scale that measures the care burden on caregivers. The BIC-11 was developed through qualitative research and a validation study in accordance with Japanese cultural characteristics. The BIC is composed of 10 questions with 5 domains, "time-dependent burden," "emotional burden," "existential burden," "physical burden," and "service-related burden." Each domain consisted of two questions. Each question was assessed using a 5-point Likert scale (0: never, 1: almost never, 2: sometimes, 3: often, 4: always) and one item for overall burden, i.e., "How burdensome do you think providing care is to you?" The validity and reliability of the BIC-11 have been confirmed [32].

Table 1
Participant characteristics (N=418)

	n (%)
Patient age, years (mean+/-SD)	70+/-9
Patient gender (female)	218 (52)
Diagnosis	
Parkinson disease	273 (65)
Spinocerebellar degeneration	77 (18)
Multiple system atrophy	39 (9)
Amyotrophic lateral sclerosis	29 (7)
Intensity of caregiving ^a	
0	117 (30)
1	90 (23)
2	84 (22)
3	77 (20)
4	54 (14)
5	56 (14)
Caregiver age, years (mean+/-SD)	65+/-11
Caregiver gender (female)	253 (61)
Relationship to patient (spouse)	315 (76)
Caregiver's chronic illness	331 (80)
Working caregivers	103 (25)
Household income (yen, millions)	
<=3	186 (47)
<=5	113 (29)
<=7	46 (12)
<=9	29 (7)
>9	21 (5)
Duration of caregiving, years (mean+/-SD)	5.6+/-4.6
Hours spent caregiving per day (mean+/-SD)	5.4+/-5.7
Hours required for close supervision of the patient (mean+/-SD)	4.8+/-6.3
Number of other persons who help with caregiving (mean+/-SD)	1.1+/-1.0

^a Japanese intensity of caregiving grading for the long-term care insurance system.

Table 2

Care burden among caregivers of patients with intractable neurological diseases (Burden Index of Caregivers)

	PD		SCD		MSA		ALS		P value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Time-dependent burden	2.4	(1.1)	2.2	(1.1)	2.5	(1.0)	2.4	(1.2)	0.356
Emotional burden	1.4	(1.0)	1.2	(1.0)	1.6	(1.4)	1.6	(1.2)	0.153
Existential burden	1.4	(1.0)	1.3	(1.0)	1.7	(1.1)	1.9	(1.2)	0.046
Physical burden	1.6	(1.1)	1.2	(1.0)	1.6	(1.1)	1.9	(1.2)	0.017
Service-related burden	0.9	(0.9)	0.9	(0.9)	1.1	(1.0)	1.2	(1.0)	0.489
Total care burden	2.0	(1.1)	1.6	(1.0)	2.2	(1.2)	2.0	(1.1)	0.047
BIC total	1.6	(0.8)	1.3	(0.8)	1.8	(0.9)	1.8	(1.0)	0.015

Each question was rated 0: never, 1: almost never, 2: sometimes, 3: often, or 4: always. P values were calculated by analysis of variance.

PD, Parkinson disease; SCD, spinocerebellar degeneration, MSA, multiple system atrophy; ALS, amyotrophic lateral sclerosis.

2.2.2. The Center for Epidemiologic Studies Depression scale (CES-D) [33,34]

The CES-D, developed by the National Institute of Mental Health, USA, is a self-report scale to identify individuals at risk for depression. It has been translated into Japanese by Shima. It is a self-assessment of 20 symptoms associated with depression. The responses to the questions indicate the number of days per week the subject is affected by the symptoms (0 days with a score of 0, 1 to 2 days with a score of 1, 3 to 4 days with a score of 2, and 5 or more days with a score of 3). Scores can range from 0 to 60, with a higher score representing a stronger tendency toward depressive feelings. A score of 16 or higher indicates depression [34].

2.2.3. Participant demographics

Regarding demographic factors, we collected information on patient's age, gender, diagnosis, intensity of caregiving, caregiver's age, gender, relationship to patient, presence of chronic illness, working status, household income, duration of caregiving, hours spent caregiving per day, hours required for close supervision of the patient, and number of other persons who help with care. The intensity of caregiving score was determined according to the Japanese intensity of caregiving grading for the long-term care insurance system (0: none or needs only social support, 1: needs part-time caregiving, 2: needs slight caregiving, 3: needs moderate caregiving, 4: needs frequent caregiving, and 5: needs constant caregiving). The intensity of caregiving score was determined by local authorities in accordance with the needs of caregiving and the opinion of the primary physician. In the Japanese long-term care insurance system, the medical and welfare services, including financial support, were defined by the intensity of caregiving score.

2.3. Statistical analysis

We first described the mean values of the BIC and compared them among diseases by analysis of variance. Second, we explored factors related to each domain of the BIC using multiple regression analysis. The dependent variables were the mean score of each domain of the BIC, total care burden, and the total BIC score (mean of 11 questions); explanatory variables were participant characteristics. The multiple regression analyses were conducted with a backward variable selection method ($P < 0.05$). We included the diagnosis in the models. Third, we calculated the prevalence of depression among caregivers and compared its presence among the four diseases by the chi-square test. Finally, we explored factors related to the prevalence of depression by logistic regression analysis. The dependent variable was the presence of depression in caregivers and explanatory variables were participant characteristics. Logistic regression analysis was also conducted with the backward variable selection method ($P < 0.05$). We included the diagnosis in the model. The significance level was set at 0.05 and two-sided tests were conducted. All analyses

were carried out with the statistical package SAS Version 9.1 (SAS Institute, Cary, NC).

2.4. Ethical considerations

Before implementing this study, the ethical and scientific validity was approved by ethics committees at Mie University Hospital in

Table 3
Factors related to the domains and total score of the Burden Index of Caregiver

	Regression coefficient	Standard error	P value
Time-dependent burden ($R^2=0.442$)			
PD (reference)	–	–	–
SCD	–0.06	0.13	0.615
MSA	–0.06	0.18	0.725
ALS	–0.13	0.21	0.536
Hours spent caregiving per day	0.05	0.01	<0.0001
Hours required for close supervision of the patient	0.04	0.01	0.001
Intensity of caregiving	0.19	0.04	<0.0001
Emotional burden ($R^2=0.133$)			
PD (reference)	–	–	–
SCD	–0.12	0.16	0.443
MSA	0.04	0.22	0.874
ALS	0.13	0.25	0.620
Hours spent caregiving per day	0.03	0.01	0.008
Intensity of caregiving	0.16	0.05	0.001
Existential burden ($R^2=0.171$)			
PD (reference)	–	–	–
SCD	–0.08	0.15	0.592
MSA	0.06	0.21	0.774
ALS	0.40	0.24	0.099
Caregiver's age	0.01	0.01	0.021
Hours spent caregiving per day	0.04	0.01	0.001
Intensity of caregiving	0.10	0.04	0.028
Physical burden ($R^2=0.425$)			
PD (reference)	–	–	–
SCD	–0.23	0.13	0.086
MSA	–0.21	0.19	0.273
ALS	–0.01	0.22	0.948
Caregiver's age	0.01	0.01	0.013
Duration of caregiving	0.03	0.01	0.021
Hours spent caregiving per day	0.05	0.01	<0.0001
Hours required for close supervision of the patient	0.03	0.01	0.019
Patient gender (male)	0.46	0.10	<0.0001
Intensity of caregiving	0.15	0.04	0.000
Relationship to patient (spouse)	–0.29	0.14	0.037
Service-related burden ($R^2=0.056$)			
PD (reference)	–	–	–
SCD	0.01	0.13	0.941
MSA	0.22	0.20	0.291
ALS	0.52	0.22	0.019
Hours spent caregiving per day	0.02	0.01	0.016
Total care burden ($R^2=0.379$)			
PD (reference)	–	–	–
SCD	–0.16	0.15	0.265
MSA	–0.23	0.21	0.257
ALS	0.04	0.24	0.860
Hours spent caregiving per day	0.03	0.01	0.022
Hours required for close supervision of the patient	0.04	0.01	0.001
Patient gender (male)	0.23	0.11	0.039
Intensity of caregiving	0.20	0.04	<0.0001
BIC total ($R^2=0.399$)			
PD (reference)	–	–	–
SCD	–0.12	0.10	0.251
MSA	–0.14	0.15	0.348
ALS	0.03	0.16	0.838
Hours spent caregiving per day	0.05	0.01	<0.0001
Intensity of caregiving	0.13	0.03	<0.0001
Caregiver gender (male)	–0.18	0.08	0.025

The analyses were conducted by the multiple regression analysis with backward variable selection method ($P<0.05$). PD, Parkinson disease; SCD, spinocerebellar degeneration, MSA, multiple system atrophy; ALS, amyotrophic lateral sclerosis.

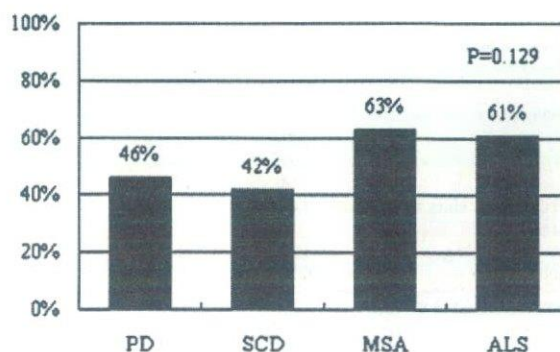


Fig. 1. Prevalence of depression (CES-D). PD, Parkinson disease; SCD, spinocerebellar degeneration; MSA, multiple system atrophy; ALS, amyotrophic lateral sclerosis.

accordance with the Helsinki Declaration. Each subject was informed in writing that participation in the study was voluntary and that privacy would be strictly protected.

3. Results

3.1. Participant characteristics

The questionnaire was sent to all 1577 families of patients with intractable neurological diseases and answer sheets were received from 785 (50%). The 1577 families included caregivers of patient who did not need caregiving. Therefore, we asked families to return the questionnaire only if the patient needed caregiving. Therefore, the nominal response rate was underestimated. The number of total respondents (analysis set) who provided valid final responses was 418 (PD, 273; SCD, 77; MSA, 39; ALS, 29).

We show participant characteristics in Table 1. The mean age of the patients was 70+/-9 years and 52% were female. As for level of caregiving, 48% was equal to or greater than grade 3. The mean age of caregivers was 65+/-11 years and 61% were female. The proportion of caregivers who were spouses was 76%. Annual household income was less than 3 million yen (US \$25,000) for 47% of the respondents. Average duration of caregiving was 5.6+/-4.6 years, and average time spent on care was 5.4+/-4.7 h daily.

3.2. Care burden among caregivers of patients with intractable neurological diseases (BIC-11)

We show the care burden among caregivers of patients with intractable neurological diseases according to the BIC-11 score in Table 2. The time-dependent burden was high for all the diseases (PD, 2.4; SCD, 2.2; MSA, 2.5; ALS, 2.4). As for comparison among diseases, the existential burden ($P=0.046$), physical burden ($P=0.017$), total care burden ($P=0.047$), and BIC total ($P=0.015$) were significantly different. The existential and physical burdens tended to be higher for MSA and ALS compared to PD and SCD. In addition, the total care burden and BIC total were higher for PD, MSA, and ALS compared to SCD.

3.3. Factors related to the domains and total score of the BIC-11

In Table 3, we show factors related to each domain and total score of the BIC-11. The intensity of caregiving and hours spent caregiving per day were related to the care burden domains. In addition, all participant characteristics were related to the different domains. As for the BIC total, hours spent caregiving per day ($P<0.0001$), intensity of caregiving ($P<0.0001$), and caregiver's gender (male, $P=0.025$) were significant variables affecting care burden. Moreover, after adjustment for participant characteristics, the diagnoses were not related to domains of the BIC-11 and total score of the BIC-11. However, for time-dependent burden, physical burden, total care

Table 4
Factors related to depression in caregivers (CES-D)

	Odds ratio	95% confidence interval	P value
PD (reference)	–	–	–
SCD	0.85	0.42–1.71	0.645
MSA	2.20	0.78–6.23	0.139
ALS	3.14	0.87–11.36	0.081
Hours required for close supervision of the patient	1.06	1.01–1.12	0.015
Intensity of caregiving	1.26	1.03–1.55	0.024
Household income	0.76	0.61–0.94	0.013

$R^2=0.127$, max-rescaled $R^2=0.169$.

PD, Parkinson disease; SCD, spinocerebellar degeneration, MSA, multiple system atrophy; ALS, amyotrophic lateral sclerosis.

burden, and BIC total, the R^2 s were high ($R^2=0.442$, 0.425 , 0.379 , and 0.399 , respectively). The R^2 s for emotional burden and existential burden were low ($R^2=0.133$ and 0.171 , respectively).

3.4. Depression among caregivers of patients with intractable neurological diseases (CES-D)

In Fig. 1, we show the prevalence of depression among caregivers of patients with intractable neurological diseases measured by the CES-D. The prevalence of depression was high for caregivers of patients with all diseases surveyed (PD, 46%; SCD, 42%; MSA, 63%; ALS, 61%). But there were no statistically significant differences among diseases ($P=0.129$).

3.5. Factors related to depression in caregivers

We show factors related to depression in caregivers of patients with intractable neurological diseases in Table 4. Hours required for close supervision of the patient (odds ratio [OR]=1.06, $P=0.015$), intensity of caregiving (OR=1.26, $P=0.024$), and household income (OR=0.76, $P=0.013$) were significant independently-related variables for depression in caregivers. The R^2 was 0.127 and max-rescaled R^2 was 0.169.

4. Discussion

This is the first large-scale quantitative study to investigate the care burden among caregivers of patients with intractable neurological diseases in Japan. This study is unique due to the use of the multi-dimensional care burden scale (BIC-11)[32]. We examined different features of the care burden according to the domains of the BIC-11. In addition, we showed that there is a high prevalence of depression in home caregivers of patients with intractable neurological diseases and we explored the factors related to depression in these caregivers.

Although several care burden domains of the BIC-11 were significantly different among diseases, we found that there were no significant differences after adjustment for participant characteristics (Table 3). The care burden of caregivers was mainly due to the intensity of caregiving and hours spent caregiving per day, not only by the diseases. The results indicated that the intensity of caregiving is different among diseases. Therefore, it is reasonable that the long-term care insurance system is dependent on the intensity of caregiving.

As for emotional and existential burden, the R^2 s were low. The personality of caregivers, which was not measured in this study, might affect these two domains [6]. The caregiver's age was significantly related to the existential care burden. As for the physical burden, the caregiver's age, duration of caregiving, and patient's gender (male) significantly increased the care burden, whereas the relationship to the patient (spouse) significantly decreased the burden. These results were easily interpretable. The multi-dimensional approach of measuring the care burden revealed these different features of caregiving.

We found a high prevalence of depression in caregivers for all the diseases. Although statistically not significant, the prevalence of

depression in caregivers for MSA (63%) and ALS (61%) was very high. Interventions to alleviate depression are needed especially for caregivers of patients with these two diseases. In addition, we showed the factors that were related to depression in caregivers. The significant variables were the hours required for close supervision of the patient, intensity of caregiving, and household income. This is concordant with the results of Edwards's report [24]. The results of multiple logistic regression analysis were adjusted according to the intensity of caregiving and the availability of social financial support by the health authority. Low income is an independent risk factor for depression in caregivers.

The R^2 for the logistic regression exploring factors related to depression was low. This result might be linked with the low R^2 s obtained for the results of multiple regressions to the emotional and existential burdens. The caregiver's personality or depressive characteristics might be related to these outcomes [6,7]. Further research is needed to explore factors related to depression among caregivers.

In addition, previous research has reported on problem behavior, such as delirium, in patients with PD [23], the emotional effect of the heritability of SCD [30], the multitude of different symptoms of MSA DEL id="del69" orig=""; [31], and respirator-dependent patients and burden of caregiving [27]. Further study including these disease-specific topics would be beneficial.

4.1. Limitations and future perspectives

The limitations of this study are as follows. First, the response rate was low (50%). We suspect that this is related to the patient register used, which included a considerable number of people who do not require care. Thus, the true response rate might be greater than the nominal value. However, it is a fact that there is a lack of external validity in this study. Therefore, we compared the patients' characteristics between participants and non-participants. The mean age of non-participants was 67 compared to participants' mean age of 70. In addition, the proportion of females among non-participants was 55% compared to 52% among participants. The participants were slightly older and had a higher proportion of males. Therefore, we assume that older patients require more care and that males could receive care at home from female caregivers. Moreover, we consider that in comparison with the non-participating caregivers, the participating caregivers are slightly older and comprise a higher proportion of females. However, the difference between participants and non-participants was so small that the non-responder bias is not considered to be a serious limitation. Second, we should note that participants in this study were the caregivers in the homes of patients with certain neurological diseases. The results of this study are not generalizable to institutional caregivers of patients or to caregivers of patients with other intractable neurological diseases.

5. Conclusion

We concluded that although several domains of care burden for caregivers of patients with intractable diseases were significantly different among diseases, the intensity of caregiving and hours spent caregiving were the main variables related to the care burden. In addition, the multi-dimensional approach to exploring care burden is effective. The prevalence of depression in caregivers of patients with intractable neurological disease was high. The significant independently-related variables related to depression were hours required for close supervision of the patient, intensity of caregiving, and low household income.

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

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A B S T R A C T

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

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INTRODUCTION

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

Following pioneering work by Cartwright et al,⁴⁻⁶ the Regional Study of Care for the Dying was conducted in the United Kingdom in 1990.⁷⁻⁹ This study involved 3,696 patients, and many secondary findings were reported.¹⁰⁻¹³ In the United

States, the large-scale Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments began in 1989.¹⁴ Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatments included a follow-up postbereavement study,¹⁵ and the satisfaction of relatives was measured.¹⁶ Several mortality follow-back surveys have also been conducted in the United States.^{17,18} Teno et al¹⁹⁻²² surveyed patient-centered and family-centered outcomes from a random sample of 1,578 representative individuals who died from chronic illnesses in the United States. Moreover, the National Hospice and Palliative Care Organization surveyed more than 29,292 family hospice users in 2004 and evaluated the care provided using a Web-based approach.²³ The Italian Survey of Dying of Cancer, which evaluated the experiences of Italian patients dying from cancer during 2002 and 2003, was based on a random sample of 2,000 individuals taken from death certificates.²⁴⁻²⁶ In addition, numerous surveys have been performed with bereaved family members, including a large-scale survey in the United Kingdom,²⁷ surveys of intensive care units,²⁸⁻³¹ surveys focusing on the place of care,³² home care,³³ community hospitals,³⁴ comparisons

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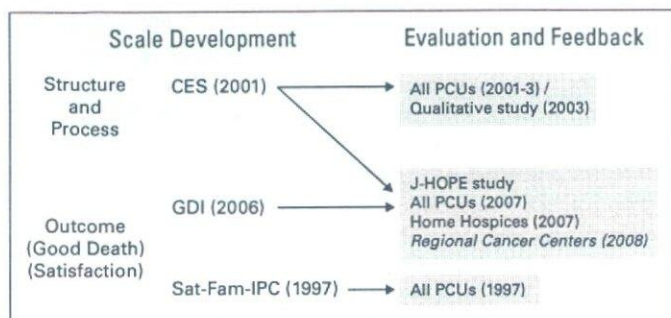


Fig 1. Overview of progress of quality evaluation projects for end-of-life care from the perspective of bereaved family members. CES, Care Evaluation Scale; GDI, Good Death Inventory; PCU, palliative care unit; J-HOPE, Japan Hospice and Palliative Care Evaluation study; Sat-Fam-IPC, Satisfaction Scale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

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

Obtaining valid measures of bereavement from family members is a crucial problem for many surveys. However, the progress made so far in postbereavement surveys has allowed some instruments to be developed. The Views of Informal Carers Evaluation of Services instrument was developed for the Regional Study of Care for the Dying⁴⁰⁻⁴² and was subsequently used in the Italian Survey of Dying of Cancer. The Toolkit Instruments to Measure End of life care instrument was developed by Teno et al^{43,44} and was used in a subsequent mortality follow-back survey. Curtis et al⁴⁵ developed an instrument for assessing the bereaved family members of patients in intensive care units, which is known as the Quality of Dying and Death scale.

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

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

JAPANESE PALLIATIVE CARE SYSTEM FOR PATIENTS WITH CANCER

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

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

Table 1. Summary of Evaluation Studies in Japan

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

NOTE. Italics denote ongoing studies.

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

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

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

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

Step 1. Initial Nationwide Satisfaction Survey for Inpatient PCUs

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

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

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

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

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

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

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

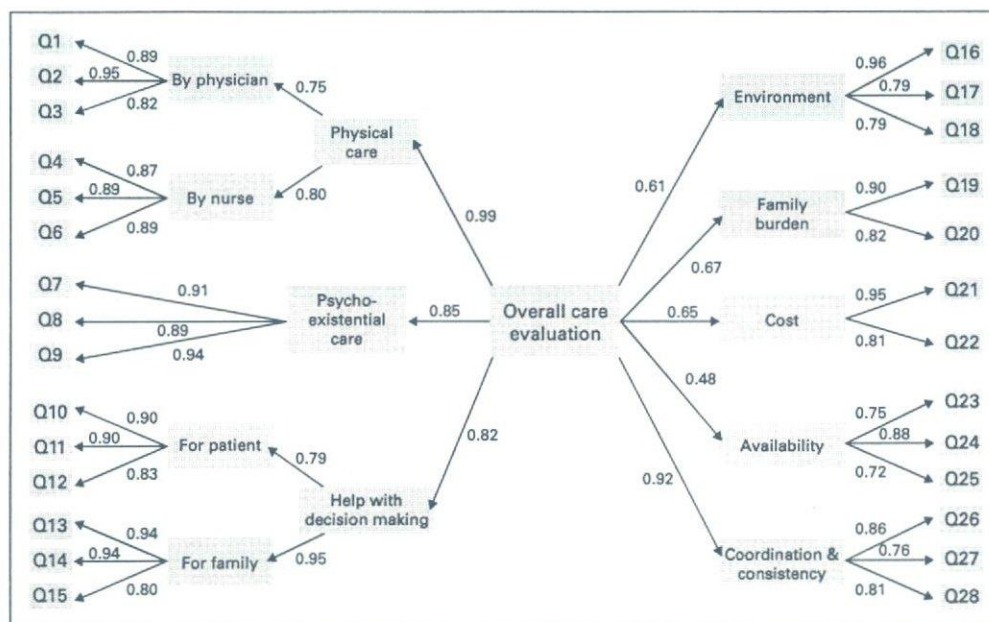


Fig 2. Confirmatory factor analysis of the Care Evaluation Scale.

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

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

Step 3. Development of the Good Death Inventory

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

Table 2. Psychometric Properties of CES and GDI

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

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

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

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

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

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

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

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

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

ADDITIONAL POSTBEREAVEMENT RESEARCH IN JAPAN

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

COMMENTS

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

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

Item and Year	Improvement of Structures and Processes of Care												P
	Highly Necessary		Considerably Necessary		Necessary		Slightly Necessary		Rarely Necessary		Not Necessary		
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	
(1) The doctors dealt promptly with discomforting symptoms of the patient													.0001
2002	35	4.1	31	3.6	52	6.1	109	12.8	356	41.7	233	27.3	
2007	63	1.2	127	2.4	325	6.1	606	11.4	2,151	40.5	1,821	34.3	
(2) The nurses had adequate knowledge and skills													.0001
2002	33	3.9	35	4.1	62	7.3	116	13.6	361	42.3	214	25.1	
2007	49	0.9	135	2.5	378	7.1	664	12.5	2,163	40.7	1,703	32.1	
(3) The doctors sufficiently explained the expected outcome to the patient													.6823
2002	15	1.8	33	3.9	56	6.6	128	15.0	263	30.8	194	22.7	
2007	88	1.7	173	3.3	447	8.4	936	17.6	2,271	42.8	1,111	20.9	
(4) The doctors sufficiently explained the expected outcome to the family													.4204
2002	33	3.9	30	3.5	38	4.5	94	11.0	293	34.3	322	37.7	
2007	69	1.3	159	3.0	377	7.1	729	13.7	2,149	40.5	1,618	30.5	
(5) The staff tried to maintain the patient's hopes													.0001
2002	29	3.4	27	3.2	41	4.8	86	10.1	329	38.6	271	31.8	
2007	45	0.8	105	2.0	300	5.7	472	8.9	2,096	39.5	2,075	39.1	
(6) The patient's room was convenient and comfortable													.0001
2002	34	4.0	28	3.3	60	7.0	127	14.9	307	36.0	267	31.3	
2007	75	1.4	122	2.3	317	6.0	616	11.6	1,786	33.6	2,192	41.3	
(7) The total cost was reasonable													.1270
2002	27	3.2	21	2.5	76	8.9	96	11.3	346	40.6	236	27.7	
2007	88	1.7	160	3.0	459	8.6	748	14.1	1,871	35.2	1,698	32.0	
(8) Admission (use) was possible when necessary without waiting													.9796
2002	51	6.0	54	6.3	71	8.3	138	16.2	251	29.4	249	29.2	
2007	328	6.2	283	5.3	611	11.5	814	15.3	1,341	25.3	1,719	32.4	
(9) There was good cooperation among staff members, such as doctors and nurses													.0001
2002	27	3.2	32	3.8	50	5.9	96	11.3	343	40.2	266	31.2	
2007	63	1.2	132	2.5	275	5.2	569	10.7	2,209	41.6	1,845	34.8	
(10) Consideration was given to the health of the family													.0001
2002	28	3.3	24	2.8	63	7.4	134	15.7	312	36.6	191	22.4	
2007	61	1.1	143	2.7	378	7.1	756	14.2	2,274	42.8	1,461	27.5	

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

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

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

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

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

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