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

## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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

## AUTHOR CONTRIBUTIONS

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## Appendix

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

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# Caregiving Consequences Inventory: a measure for evaluating caregiving consequences from the bereaved family member's perspective

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## Abstract

***Objective***: **The aims of this study were to validate an instrument for measuring bereaved family members' perceptions of caregiving consequences and to examine the association between caregiving consequences and psychological distress.**

***Methods***: **Cross-sectional questionnaires were administered to family members of patients who had died in regional cancer centers. We measured the Caregiving Consequences Inventory (CCI), respondent's optimism, overall reward scale, and psychological distress and collected background data. A retest was conducted.**

***Results***: **Bereaved families from two regional cancer centers were surveyed ($N = 189$ and 109; effective response rate, 57 and 80%). By exploratory and confirmatory factor analyses, we identified four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain. Although the four reward domains were highly correlated with each other ($0.47 < r < 0.69$), the 4-domain model was superior. The respondents with less education, strong faith, and less optimism reported fewer perceived rewards, thus demonstrating known group validity. In addition, perceived reward had little or no correlation with psychological distress. The psychometric properties of this scale were good ($\alpha = 0.78$–$0.93$, $\mathrm{ICC} = 0.60$–$0.73$) and construct validity was supported ($\mathrm{GFI} = 0.929$; $\mathrm{AGFI} = 0.819$; $\mathrm{CFI} = 0.749$; $\mathrm{RMSEA} = 0.097$).**

***Conclusions***: **The CCI is valid for measuring caregiving consequences from the bereaved family member's perspective in Japan. Furthermore, it is important to use perceived rewards and burdens as a measure of caregiving consequences for improving the quality of the caregiving and bereavement experience.**

**Keywords: caregiver; palliative care; neoplasms; measures; reward; burden**

## Introduction

The World Health Organization concept of palliative care includes attention to the health and well-being of the family members caring for a patient, and it proposes a support system to help caregivers cope during the patient's illness and their own bereavement [1]. Research has shown that caring for severely ill patients can have a negative impact on the mental, physical, and financial well-being of the caregivers [2–5]. In addition, the caregiver's burden is associated with family dissatisfaction and regret in received care [6], depression in family members [7,8], and caregiver mortality [9,10] in the course of caregiving and bereavement. Thus, palliative care specialists and researchers have tried to help reduce the caregiver's burden [11–15].

While past research has clearly documented the negative emotions experienced during caregiving and bereavement, recent research has investigated positive consequences of caregiving [16]. Approximately 60–70% of caregivers have reported that they could recognize positive aspects of the experience [17–19], and psycho-educational interventions have had long-term positive effects on caregiving consequences [20,21]. Although several positive outcomes of caregiving such as appreciation, gratification, mastery, finding meaning and purpose in life, reprioritization, personal growth, and satisfaction [22–26] have been explored, the operational definitions of words used by researchers vary [16] and there is no consensus on what constitutes positive caregiving outcomes.

In Japan, cancer is the leading cause of death. Although enhancement of palliative care for Japanese cancer patients and family caregivers is a priority in Japan, we found only a few studies that investigated in detail caregiving for severely ill cancer patients. To deliver appropriate support for family caregivers, it is important to evaluate both positive and negative caregiving outcomes. There are a few scales that evaluate both positive and negative caregiving outcomes [27,28]. However, in these scales, various positive aspects are measured in 1 domain only, and it is difficult to understand the positive aspects of caregiving in detail. Moreover, surveys of families of patients at the end of life are not culturally appropriate in Japan. Thus, for considering how to provide care to the families, it is necessary to assess caregiving consequences, that is, the positive and negative experiences of the caregivers from the bereaved family's viewpoint. It is difficult to use the scale with many items (more than 20 items) for vulnerable bereaved families in Japan. Today, however, there are a few brief scales.

The aim of this study was to develop a brief measure for evaluating caregiving consequences from the bereaved family member's perspective and to measure the validity and reliability of this new measure in Japan.

## Methods

This survey was made up of two cross-sectional anonymous mailed surveys of the bereaved family members of cancer patients in two regional cancer centers in Ibaraki Prefecture (Part 1) and Shizuoka Prefecture (Part 2). Both centers have general wards and inpatient palliative care units (PCU).

### Measurements

#### Caregiving Consequences Inventory (CCI)

To evaluate the consequences of caring for incurable cancer patients from the bereaved family's perspective, we pooled items found through a systematic literature review of studies that described the positive aspects of caregiving [22–25,29–31], caregiver burden [2–5], caregiving-related concepts [16,26,32–38], stress-related growth [39–41], and discussions about the similarity of the concepts. Reviewers were a research nurse specializing in palliative care, a palliative care specialist, and a researcher specializing in clinical psychology. Then, we hypothesized a factor structure prior to psychometric testing of 5 domains of perceived rewards: personal growth, mastery, appreciation for others, meaning in life, and reprioritization, and 1 domain of perceived burden. In Japan and overseas, both a Caregiving Burden Scale with a clear domain structure [42,43] and one without a clear structure [44,45] are used. However, we used 1 domain for the caregiving burden in this survey for the following reasons: (1) the size of the contribution of the first factor is very large compared with the second factor42 and (2) the caregiving burden in Japan can be assumed to be included in 1 domain [46,47]. We also discussed the content validity for the items using the following selection criteria: (1) easily understood and completed, (2) potentially applicable to both caregiving and bereavement, (3) comprising hypothesized dimensions, and (4) comprising three or more items for each domain. We then selected 19 items as perceived reward domains and 5 items as perceived burden domains. All of the authors were in agreement on these items and factors. This process ensured the content validity of the initial 24-item version of the CCI (available from the authors). These items were rated using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used the initial 24-item version in Part 1 of the survey and the 16-item shortened version in Part 2.

#### Overall perceived rewards

We asked about overall perceived rewards with the statement: 'It was a good experience for me to care for my family member' using a 7-point Likert scale (1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree). We used this scale to examine the concurrent validity of the CCI in Part 2 of the survey. We did not have scales to examine details of positive aspects of caregiving consequences when the survey was conducted. We therefore used a single item to measure concurrent validity, the best method in such a situation [48].

#### The Life Orientation Test—Revised (LOT-R)

Research has shown that optimism is associated with positive aspects of difficult situations [18,49]. We hypothesized that the perceived reward domain score is positively correlated with optimism of the respondents. The LOT-R is a 10-item (six target items and four fillers) self-report scale measuring expectations about positive outcomes in general, using a 5-point scale from 0 (strongly disagree) to 4 (strongly agree) [49]. The validity and reliability of the Japanese version have been confirmed, and Sakamoto proposed a two-factor model consisting of optimism and pessimism [50]. Responses are scored from 0–12 with higher scores on the three optimism items representing greater dispositional optimism, while higher scores on the three pessimism items represent greater dispositional pessimism. We used this scale to examine the known group validity of the CCI in Part 1 of the survey.

#### The General Health Questionnaire-12-item version (GHQ-12)

The GHQ-12 is a screening instrument covering a range of psychiatric symptoms (e.g. anxiety and depression) as well as somatic symptoms and social dysfunction [51]. We used the GHQ-12 to measure the degree of psychological distress of the respondents and to examine the discriminate validity of the CCI in Part 2 of the survey.

#### Background data of caregivers and patients

The patient's age, sex, and number of hospital days, time since patient's death, and care settings were extracted from medical databases. The caregiver's background data included the bereaved family member's age, sex, relationship with the patient, and frequency of attending the patient.

In Part 1, we also asked the respondents about health status during the caregiving period, presence of other caregivers, whether the caregiver lived with the patient, and caregiver's faith, education, and household income during the caregiving period. Research has shown that caregivers with less education and strong faith reported fewer perceived rewards [52,53]. Thus, we used these data to examine the known group validity of the CCI.

### Participants and procedures

To find potential participants for Part 1 of the survey, we identified from medical records bereaved family members of patients who died from lung or gastrointestinal cancer from September 2004–February 2006 on the general ward in a regional health center in Ibaraki Prefecture and patients who died from all forms of cancer in PCUs in the same regional health center during the same period. We mailed questionnaires to potential respondents in October 2006 and a reminder was sent in November 2006 to those who did not respond. The respondents were asked to report the level of agreement on the initial 24-item CCI and LOT-R and to supply background data. To examine test–retest reliability, we sent the same questionnaire one month later.

For Part 2 of the survey, we identified from medical records bereaved family members of patients who died from April 2005–April 2006 in PCUs of regional cancer centers in Shizuoka Prefecture. We mailed questionnaires to potential respondents in March 2007 and a reminder was sent in April 2007 to those who did not respond. The respondents were asked to report their level of agreement with the final 16 items of the shortened version of the CCI, their overall perceived rewards, responses to the GHQ-12, and background data.

The inclusion criteria were the same in both surveys and were as follows: (1) patient was aged 20 years or more and (2) patient was hospitalized at least 3 days. The exclusion criteria were the same in both surveys: (1) participant was recruited for another survey for bereaved family members, (2) participant would have suffered serious psychological distress as determined by the primary physician, (3) cause of death was treatment related or due to injury, (4) there was no bereaved family member who was aged 20 years or more, (4) participant was incapable of replying to a self-reported questionnaire, and (5) participant was not aware of the diagnosis of malignancy.

### Ethical consideration

The protocols were approved by the institutional review board of each institute. In both Part 1 and Part 2, if the respondents did not want to participate in the survey they were asked to return the questionnaire with 'no participation' indicated, and a reminder was not mailed to them.

### Statistical analyses

#### Scale development

For item reduction, we first deleted items with data missing for 20% or more of the respondents, or highly skewed distributions of the ratings defined as 'mean ± standard deviation' beyond the scope of the variable. We then used exploratory factor analysis using the maximum likelihood method [54] with a promax rotation for perceived reward domains and perceived burden domains, separately. According to the results of the exploratory factor analysis, attributes with factor loadings less than 0.3 (standardized regression coefficient) were deleted. Among several models tested, we adopted the model that showed sufficient fitness to the factor structure based on the hypothesized concepts and clinical validity based on full agreement of the authors. The items that were finally adopted for the CCI are described in the appendix. The domain score was calculated by summing the items in each domain. The total reward score was calculated by summing the 12 items in all perceived reward domains, although we did not provide the CCI total score, which was calculated by summing the 16 items, including 12 perceived reward items and four burden items.

### Scale validation

*Validity*: To examine concurrent validity, we calculated the Pearson's correlation coefficients between each domain of the CCI and one item overall for perceived rewards using data from Part 2. In addition, to examine construct validity of the final 16 items of the CCI, we calculated the Pearson's correlation coefficients between each domain score of the CCI using data from Part 1, and conducted a confirmatory factor analysis using data from Parts 1 and 2, separately. Known group validity was examined using a $t$ test to compare the reward domain scores of respondents who had more faith compared with those with less faith, scores of respondents who had more education compared with those with less education, and scores of respondents who were more optimistic compared with those who were less optimistic.

Faith responses were grouped into a group with less faith (1: none at all and 2: slightly strong) and a group with more faith (3: moderately strong and 4: very strong). In addition, responses about education level were grouped into a group with less education (1: finished junior high school and 2: finished high school) and a group with more education (3: junior college graduate and 4: college graduate). As for optimism and set the threshold value for optimism was established at 6/7.

In addition, to examine discriminate validity, we calculated the Pearson's correlation coefficients between each domain score of the CCI and psychological distress. We used GHQ scoring (0-0-1-1), and set the threshold for psychological distress at 2/3 [55]. We divided the score into binary variables whether the score exceeded a cutoff value or not, and used it as a dependent variable.

*Reliability*: To examine the reliability of the CCI, we calculated Cronbach's $\alpha$ coefficients (Cronbach's $\alpha$) and intra-class correlation coefficients (ICC) for test–retest reliability using data for Part 1 of the survey.

All analyses were performed using the statistical package SAS version 9.1 (SAS Institute) and AMOS version 7.0 (SPSS institute). The significance level was set at $P<0.05$ (two-tailed).

## Results

Of 344 and 160 questionnaires sent to bereaved family members in Part 1 and Part 2, respectively, 11 and 23 were undeliverable, and 215 and 121 were returned. Among these, 23 and 12 individuals refused to participate, and 3 and 0 were excluded due to missing data. Thus, 189 and 109 responses were analyzed (effective response rates, 57 and 80%, respectively).

As for follow-up of Part 1, of 175 questionnaires sent to bereaved families who responded during the study period, nine individuals refused to participate, and two responses were excluded due to missing data. Finally, 112 responses were analyzed (effective response rate, 64%). Table 1 summarizes the background of the respondents.

### Item reduction

In accordance with the above-mentioned item reduction procedure, we initially excluded oneitem

**Table 1**. Backgrounds of respondents

| | Part 1($N = 189$) | | Part 2($N = 109$) | |
|---|---|---|---|---|
| | *n* | % | *n* | % |
| *Patients* | | | | |
| Age, y (mean ± SD) | 69 ± 12 | | 73 ± 11 | |
| Sex | | | | |
| Male | 108 | 57 | 47 | 43 |
| Female | 81 | 43 | 62 | 57 |
| Hospital days (mean ± SD) | 41 ± 37 | | 56+/74 | |
| Care setting | | | | |
| General ward | 55 | 29 | 0 | 0 |
| Palliative care unit | 134 | 71 | 109 | 100 |
| *Bereaved family members* | | | | |
| Age, y (mean ± SD) | 57 ± 12 | | 60 ± 12 | |
| Sex | | | | |
| Male | 63 | 33 | 42 | 39 |
| Female | 122 | 65 | 64 | 59 |
| Time since patient's death: months (mean ± SD/range) | 15 ± 5(7–25) | | 17 ± 4(11–24) | |
| Relationship | | | | |
| Spouse | 87 | 46 | 47 | 43 |
| Child | 64 | 34 | 42 | 39 |
| Child-in-law | 20 | 11 | 8 | 7 |
| Other | 15 | 9 | 10 | 10 |
| Health status | | | | |
| Good | 48 | 25 | — | — |
| Moderate | 106 | 56 | — | — |
| Fair | 28 | 15 | — | — |
| Poor | 5 | 3 | — | — |
| Presence of other caregivers | | | | |
| Present | 131 | 69 | — | — |
| Absent | 54 | 29 | — | — |
| Living status | | | — | — |
| Living together | 157 | 83 | — | — |
| Not living together | 30 | 16 | — | — |
| Religiousness | | | | |
| Much | 14 | 7 | — | — |
| Moderate | 34 | 18 | — | — |
| Fair | 46 | 24 | — | — |
| None | 85 | 45 | — | — |
| Education | | | | |
| Junior high school | 34 | 18 | — | — |
| High school | 82 | 43 | — | — |
| College | 40 | 21 | — | — |
| University | 31 | 16 | | |
| Household income (thousand yen) | | | | |
| 000–249 (–2500$) | 31 | 16 | — | — |
| 250–499 (2500–4990$) | 74 | 39 | — | — |
| 500–749 (5000–7490$) | 37 | 20 | — | — |
| 750–999 (7500–9990$) | 21 | 11 | — | — |
| 1000- (10 000$-) | 16 | 8 | - | - |

Several total percents do not equal 100% due to missing values.

**Table 2**. Exploratory factor analysis of Caregiving Consequence Inventory

| | | Standardized regression coefficients | | | | Communality |
|---|---|---|---|---|---|---|
| | | F1 | F2 | F3 | F4 | |
| *Perceived reward domain* | | | | | | |
| 1 Mastery (mean = 4.9, SD = 1.2) | | | | | | |
| Q1 | I feel confident enough to manage future life changes | **0.91** | 0.05 | −0.06 | 0.04 | 0.86 |
| Q2 | I have learned to cope better with my life | **0.83** | −0.10 | 0.05 | 0.18 | 0.85 |
| Q3 | I came to accept some of the changes in my life | **0.75** | 0.11 | 0.14 | −0.18 | 0.64 |
| 2 Appreciation for others (mean = 5.5, SD = 1.0) | | | | | | |
| Q4 | I came to have more appreciation for others | −0.04 | **0.96** | −0.03 | 0.04 | 0.90 |
| Q5 | I became more aware of love from other people | 0.06 | **0.84** | −0.01 | 0.07 | 0.81 |
| Q6 | I came to place greater value on relationships | 0.06 | **0.71** | 0.10 | −0.06 | 0.58 |
| 3 Meaning in life (mean = 4.9, SD = 1.2) | | | | | | |
| Q7 | I came to find purpose and sense of meaning in my life | −0.04 | 0.04 | **1.00** | −0.06 | 0.94 |
| Q8 | I have a better outlook on my life | 0.19 | 0.00 | **0.64** | 0.07 | 0.66 |
| Q9 | I came to believe that there was a meaning in life no matter what happened | 0.19 | −0.05 | **0.63** | 0.15 | 0.69 |
| 4 Reprioritization (mean = 5.6, SD = 1.0) | | | | | | |
| Q10 | I came to understand of the brevity of life and appreciate each day | −0.02 | −0.01 | 0.01 | **0.99** | 0.96 |
| Q11 | I came to notice what is really important in my life | 0.21 | 0.17 | 0.09 | **0.50** | 0.66 |
| Q12 | I have learned the importance of being alive | −0.09 | 0.14 | 0.42 | **0.43** | 0.61 |
| *Perceived burden domain* | | | | | | |
| Burden (mean = 3.7, SD = 1.6) | | | | | | |
| Q13 | I felt a physical burden | | | **0.96** | | 0.58 |
| Q14 | I sacrificed my own time and schedule | | | **0.76** | | 0.92 |
| Q15 | I felt a mental burden | | | **0.67** | | 0.44 |
| Q16 | I felt a financial burden | | | **0.33** | | 0.11 |

**Table 3**. Concurent validity of Caregiving Consequence Inventory

| | Oveall perceived |
|---|---|
| *Perceived reward domains* | |
| Mastery | 0.37*** |
| Appreciation for others | 0.30*** |
| Meaning in life | 0.39*** |
| Reprioritization | 0.43*** |
| Total reward score | 0.44*** |

Figures are Pearson's correlation coefficients. $^{*}P<0.05$, $^{**}P<0.01$, $^{***}P<0.001$.

due to skewed responses from the initial CCI. According to the results of the exploratory factor analysis, 12 items for perceived rewards and 4 items for perceived burden were selected. The following 4 domains were extracted as perceived rewards: (1) mastery, (2) appreciation for others, (3) meaning in life, and (4) reprioritization. The result of the exploratory factor analysis of the CCI is shown in Table 2.

## Scale validation

### Validity

Table 3 shows the concurrent validity. The correlation of each reward domain of the CCI and the one-item overall perceived reward was moderate and ranged from $r = 0.30$ to 0.43.

Table 4 shows the known group validity and demonstrates significant differences in each reward domain of the CCI according to the hypothesized respondent's characteristics (i.e. the respondent's faith, education, and optimism).

Figure 1 shows the result of confirmatory factor analysis using data from Part 1 of the survey. This solution has the most interpretable factors and showed sufficient fitness to the factor structure, consistency with the hypothesized concepts, and clinical validity. Although we hypothesized a model with five perceived rewards including a personal growth domain at first, exploratory factor analysis revealed that the three items we hypothesized as personal growth were due to an improper solution and no convergence could be attained. Therefore, we adopted 12 items for four perceived reward domains and 4 items for the burden domain. The fit indices for this final model were acceptable ($\chi^2$ 262.333 [df = 99], $P<0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094) (see Figure 1). The confirmatory factor analysis using Part 2 data reproduced acceptable fit indices with one correlated error term ($\chi^2$ 191.6 [df = 98], $P<0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097) (see Figure 2).

**Table 4.** Known-group validity of Caregiving Consequence Inventory

| | Faith | | | | *P*-value | Education | | | | *P*-value | Optimism | | | | *P*-value |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Less faith | | More faith | | | Less educated | | More educated | | | Less optimistic | | More optimistic | | |
| | Means | SD | Means | SD | | Means | SD | Means | SD | | Means | SD | Means | SD | |
| *Perceived reward domains* | | | | | | | | | | | | | | | |
| Mastery | 4.8 | 1.2 | 5.2 | 1.0 | 0.02* | 5.1 | 1.1 | 4.6 | 1.3 | 0.01* | 4.8 | 1.1 | 5.2 | 1.2 | 0.03* |
| Appreciation for others | 5.5 | 1.1 | 5.6 | 1.0 | 0.63 | 5.6 | 1.0 | 5.4 | 1.2 | 0.32 | 5.5 | 1.0 | 5.7 | 1.1 | 0.15 |
| Meaning in life | 4.8 | 1.2 | 5.4 | 0.9 | <0.001*** | 5.2 | 1.0 | 4.6 | 1.3 | 0.001** | 4.9 | 1.1 | 5.1 | 1.3 | 0.13 |
| Reprioritization | 5.4 | 1.1 | 5.8 | 0.8 | 0.03* | 5.7 | 0.9 | 5.4 | 1.2 | 0.06 | 5.4 | 1.0 | 5.9 | 1.1 | 0.003** |
| Total reward score | 5.1 | 1.0 | 5.5 | 0.7 | 0.01* | 5.4 | 0.8 | 5.0 | 1.0 | 0.01* | 5.1 | 0.9 | 5.5 | 1.0 | 0.03* |

$^{*}P<0.05$, $^{**}P<0.01$, $^{***}P<0.001$.

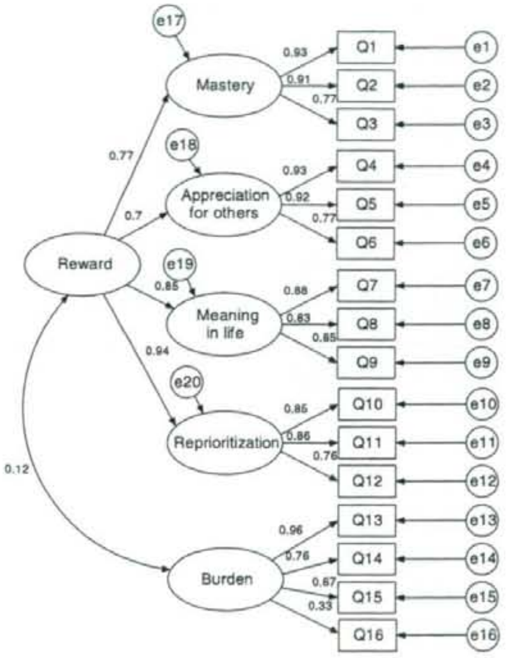

**Figure 1.** Confirmatory factor analysis of Caregiving Consequence Inventory (Part 1). $\chi^2$262.333 (DF = 99), $P<0.001$; GFI = 0.919; AGFI = 0.848; CFI = 0.792; RMSEA = 0.094

The four reward domain scores were highly correlated with each other ($0.47<r<0.69$) (Table 5). We tested the factor structure of reward further by conducting confirmatory factory analyses, comparing the 4-reward domain and 1-reward domain approaches. The analysis revealed that the 4-reward domain model fit the data significantly better than the 1-reward domain model ($\chi^2$ 699.4 [df = 103], $P<0.001$; GFI = 0.692; AGFI = 0.652; CFI = 0.541; RMSEA = 0.186).

Table 6 shows the known group validity and shows that no significant correlation exists between each domain score and psychological distress, except for a slight correlation with mastery ($r=-0.19$, $P=0.05$) and burden ($r=0.24$, $P=0.01$).

### Reliability

Table 7 shows the internal consistency and test–retest reliability. Cronbach's $\alpha$ ranged from 0.78 to 0.93. The Cronbach's $\alpha$ coefficient of the total reward domain was 0.93 and of the burden domain was 0.78. The ICC ranged from 0.60 to 0.73. The ICC of the total reward domain was 0.73 and of the burden domain was 0.60.

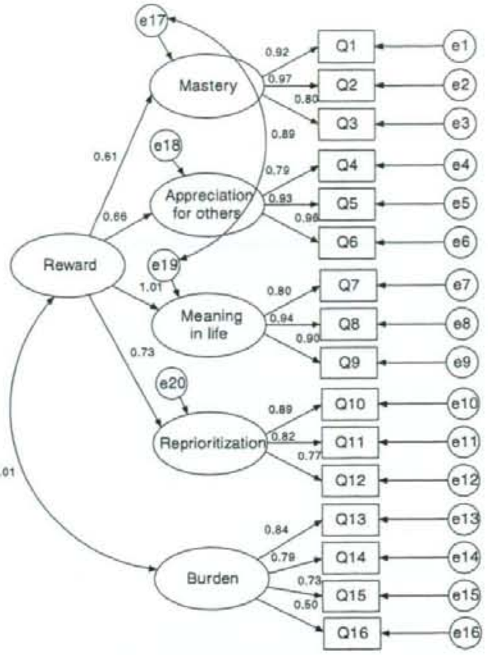

**Figure 2.** Confirmatory factor analysis of Caregiving Consequence Inventory (Part 2). $\chi^2$191.6 (DF = 98), $P<0.001$; GFI = 0.929; AGFI = 0.819; CFI = 0.749; RMSEA = 0.097

**Table 5.** The association with each other domain score of CCI

| | Mastery | Appreciation for others | Meaning in life | Reprioritization |
|---|---|---|---|---|
| Mastery | 1.00 | | | |
| Appreciation for others | $0.47^{***}$ | 1.00 | | |
| Meaning in life | $0.63^{***}$ | $0.49^{***}$ | 1.00 | |
| Reprioritization | $0.60^{***}$ | $0.60^{***}$ | $0.69^{***}$ | 1.00 |
| Burden | 0.07 | 0.06 | 0.12 | 0.07 |

Figures are Pearson's correlation coefficients. $^{*}P<0.05$, $^{**}P<0.01$, $^{***}P<0.001$.

**Table 6.** The association between caregiving consequence and psychological distress

| | Psychological distress |
|---|---|
| *Perceived reward domains* | |
| Mastery | $-0.19^{*}$ |
| Appreciation for others | 0.11 |
| Meaning in life | $-0.13$ |
| Reprioritization | $-0.01$ |
| Total reward score | $-0.07$ |
| *Perceived burden domain* | |
| Burden | $0.24^{*}$ |

Figures are Pearson's correlation coefficients. $^{*}P<0.05$, $^{**}P<0.01$, $^{***}P<0.001$.

## Discussion

The most important result of this study was the development of an instrument to measure the bereaved family's perceptions about the caregiving experience in Japan. The instrument showed good internal consistency and test–retest reliability, and known group validity was also consistent with a previous study [52,53]. The CCI is 16 items and takes less than 10 min to complete. Plain terms are used for these items, so the deficit rate is low 2% or less. Thus, we believe that this scale can assess caregiving consequences with few demands placed on the bereaved family.

Exploratory factor analysis and confirmatory factor analysis revealed 5 domains consisting of 4 sub-domains of perceived rewards and 1 domain of perceived burden: mastery, appreciation for others, meaning in life, reprioritization, and burden. The themes of the domains are consistent with our prior hypothesized concepts.

Items selected for the 'mastery' domain represented the extent to which the respondent felt in control over his or her life [35,36,56]. Although the operationalization of 'meaning' varied widely across studies and sometimes represented overall

**Table 7.** Reliability of Caregiving Consequence Inventory

| | α | ICC |
|---|---|---|
| *Perceived reward domains* | | |
| Mastery | 0.90 | 0.73 |
| Appreciation for others | 0.90 | 0.60 |
| Meaning in life | 0.89 | 0.62 |
| Reprioritization | 0.86 | 0.67 |
| Total reward score | 0.93 | 0.73 |
| *Perceived burden domain* | | |
| Burden | 0.78 | 0.60 |

α, Cronbach's alpha coefficient; ICC, intra-class correlation coefficient.

positive aspects of caregiving [34,57], items selected for 'meaning' in life domains assessed the sense of purpose in life and task [57]. The 'appreciation for others' domain included items about gratitude for relationships and compassion [52], and the 'reprioritization' domain assessed changes in values and attitudes about living life to the fullest [23,52]. These 4 reward domains are similar to those identified in other studies of post-traumatic growth [39,40], and the burden domain included the items identified important for assessing caregiver burden [2,3,12,14]. Thus, content validity is assured.

It was not surprising that the 4 reward domain scores were highly correlated with each other because a sense of mastery may occur through the development of new capabilities and finding a sense of meaning or purpose [32]. In addition, caregivers described their deeper appreciation for relationships for one of the changes in values [31]. On examining concurrent validity, each reward domain of the CCI and overall perceived rewards were only moderately correlated, and the comparisons between the 4-domain and 1-domain models of perceived rewards revealed the superiority of the 4-domain model. We thus believe that a comprehensive assessment of rewards by one overall item is difficult and evaluation of every domain is recommended.

As for discriminate validity, almost none of the reward domains correlated with psychological distress. Only mastery and burden showed slight correlation with psychological distress, however these correlations were very weak. Therefore, we believe that mastery and burden were not clinically correlated with psychological distress.

This means that the caregiver considered reward to be an entity distinct from psychological distress, and it is important to use perceived reward as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

Although the domains of the CCI demonstrated sufficient internal consistency, reliability measured by ICC was of moderate value [58]. Possible reasons for the moderate reliability are (1) the test–retest period was longer than 1 month and (2) the family member's assessment of the CCI may have changed over time. However, the sufficient internal consistency as a measure of reliability for a cross-sectional study is appreciated; therefore, these moderate ICCs are not considered critical limitations of the CCI.

### Limitations and future perspectives

The limitations of this study are as follows: first, the response rate in Part 1 of the survey was 57%. We think that this was low because the response rate of the bereaved families receiving care on the general wards was low (47% on general wards vs 62% in PCU). We believe, however, that the effect on this study was not crucial because (1) the objective was to validate a scale, not to survey actual conditions and (2) comparing the backgrounds of respondents and non-respondents revealed no differences in age, gender, the length of patient's hospital stay, or time since patient's death. Second, we identified the bereaved family members of patients who died from lung or gastrointestinal cancer on the general wards in Part 1 of the survey. We believe, however, that the effect on this study was not crucial because (1) the proportion of deceased patients on the general wards who died from other types of cancers was only 12% (23/188) in Part 1 and (2) we identified the bereaved family members of patients who died of all types of cancer on the PCU in Parts 1 and 2 of the survey. Third, we were unable to examine concurrent validity sufficiently in this study because we did not have scales to examine the details of positive aspects of caregiving consequences when this survey was conducted. Fourth, we set only one correlation between errors in the confirmatory factor analysis in Part 2 because of insufficient sample size. However, we believe this is not a fatal flaw because the fit indices for this final model in Part 1 were acceptable. We are going to perform further confirmation with a larger sample size in the next step. Fifth, this validation was executed in Japan, a culturally and ethnically homogeneous country. It is necessary to examine whether the structure of CCI can be reproduced in different cultures.

In the future, we would like to conduct a national survey on the actual positive and negative aspects of caregiving consequences in Japan. To decide the focus of the intervention, it is necessary to clarify factors related to positive and negative experience, and to explore the mechanisms that maintain and increase positive experiences, as well as those that decrease negative experiences. This CCI provides a good base for further exploration of these mechanisms. We also would like to conduct a prospective survey to clarify factors related to the change of perceived rewards using this tool, and hope that this effort will lead to the development of intervention programs that focus on specific aims and examine the effects on caregiver outcomes.

## Conclusions

We validated the CCI in Japanese bereaved family members. The CCI was a valid scale having sufficient factor validity, internal consistency, test–retest reliability, and acceptable construct validity. The CCI comprises four perceived reward domains: 'mastery', 'appreciation for others', 'meaning in life', and 'reprioritization', and one perceived burden domain, evaluating both positive and negative aspects of caregiving consequences from the bereaved family member's perspective. As for discriminate validity, reward has little or no correlation with psychological distress. Thus, it is important to use perceived rewards as a measure for evaluation of caregiving consequences, as well as the caregiving burden, for improving the quality of the caregiving and bereavement experience.

### Acknowledgements

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## Appendix

## Caregiving Consequences Inventory

How do you feel about your caregiving experience with your family member? Please check the appropriate number. 1: absolutely disagree, 2: disagree, 3: somewhat disagree, 4: unsure, 5: somewhat agree, 6: agree, 7: absolutely agree.
Through caring for your family member,

### Mastery

I feel confident enough to manage future life changes.
I have learned to cope better with my life.
I came to accept some of the changes in my life.

### Appreciation for others

I came to have more appreciation for others.
I became more aware of love from other people.
I came to place greater value on relationships.

### Meaning in life

I came to find purpose and sense of meaning in my life.
I have a better outlook on my life.
I came to believe that there was meaning in life no matter what happened.

### Reprioritization

I came to understand the brevity of life and appreciate each day.
I came to notice what is really important in my life.
I have learned the importance of being alive.

### Burden

I felt a physical burden.
I sacrificed my own time and schedule.
I felt a mental burden.
I felt a financial burden.

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*Original Article*

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

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***Abstract***

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

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

*Key Words*

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

## *Introduction*

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

Moreover, patients are concerned about transition to palliative care services based on the perception that palliative care equates to imminent death,[13] and families fear that palliative care shortens the patient's life before determining the use of PCUs.[10] These concerns may impede appropriate referrals. Nonetheless, retrospective surveys of bereaved families who had actually chosen PCUs as a place of end-of-life care and received specialized inpatient palliative care showed that these negative perceptions of PCUs improved markedly after using the service.[10] Given the necessity of providing sufficient and correct information about PCUs, it is important to understand the differences in perceptions of PCUs between the general population and bereaved families who have actually received specialized palliative care (PCU-bereaved families). Although a recent qualitative study suggested that negative perceptions of PCUs, for example, "a place where one dies" and "somewhere from which you can never return," were associated with dissatisfaction with received care among PCU-bereaved families,[14] this association has not yet been quantitatively investigated. Clarifying the association between the perception of PCUs and overall satisfaction with received care can provide valuable clues as to how health care providers should offer information about PCUs and issues that should be addressed when providing end-of-life care.

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

## *Methods*

### *Subjects*

This study was part of a nationwide survey, and the protocol has been described in detail previously.[15] We initially identified four target areas to obtain a wide geographic distribution for the nationwide sample; these comprised an urban prefecture (Tokyo) and three mixed urban-rural areas (Miyagi, Shizuoka, and Hiroshima). A cross-sectional questionnaire survey was performed in a sample of the general population selected by stratified two-stage random sampling and a sample of bereaved families who actually received specialized inpatient palliative care at one of 12 PCUs (PCU-bereaved families). We initially identified 5,000 subjects within the general population (that is, the nonbereaved general population and the bereaved general population) using stratified two-stage random sampling of residents in the four areas. We mailed questionnaires to potential participants in March 2004 and sent a reminder postcard two weeks later.

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

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

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

The questionnaire was constructed through an extensive literature review,[4–9,13] expert consensus among the authors, and on the basis of a previous study.[10] We investigated three topics in this survey: 1) public awareness of PCUs, 2) perceptions of PCUs, and 3) overall satisfaction with received specialized inpatient palliative care. In addition, we investigated respondents' age and gender. The general population was asked whether they had been bereaved through cancer within the previous 10 years. PCU-bereaved families were asked about length of hospital stay, time since the patient's death, and the level of the patient's physical distress on a five-point Likert-type scale (1: not distressed at all, 2: not too distressed, 3: unsure, 4: distressed, 5: very distressed). Despite the possibility of a recall bias, we selected 10 years as the limit of experience of bereavement through cancer in the general population, because a limit of five years yielded essentially the same conclusion in this survey.

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

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

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

### *Analyses*

Initially, we clarified public awareness of PCUs using descriptive statistics. Then, we confirmed similar distributions of variables between the four areas sampled, and explored factors associated with public awareness of PCUs using univariate and multivariate regression analyses. The independent variables were age, gender, and experience of bereavement through cancer. Next, perceptions were analyzed using descriptive statistics for the two study groups (the general population and PCU-bereaved families) and compared the mean between two groups using a *t*-test. We explored the factors that affect perceptions of PCUs using *t*-tests, linear regression, and analysis of variance, as appropriate. The independent variables were age and gender (for both groups), levels of awareness of PCUs and experience of bereavement due to cancer (only for the general population), and length of PCU stay, time since the patient's death, institution (as data were collected regarding 12 PCUs), and level of patient's physical distress (only for PCU-bereaved families). These analyses were conducted separately for the general population and PCU-bereaved families. Finally, we explored the correlation between perceptions of PCUs and overall satisfaction with received care using Spearman's rank correlation. As a large sample size may result in an excess of statistically significant results ($P < 0.05$), we have mainly described "clinically significant" results for which the effect size (ES) was over 0.5.[16] This criterion indicates that the mean value difference as an absolute figure between two extreme categories was over half of the pooled standard deviation.

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

## *Results*

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

Among the 866 respondents from PCU-bereaved families considered as potential participants, 72 were excluded due to serious psychological distress ($n = 30$), lack of competent adult family members ($n = 17$), and other reasons. Of 794 questionnaires sent to the remaining bereaved families, 56 were undeliverable and 552 were returned to the authors. Within this group, 27 individuals refused to participate, 12 were excluded due to missing data, and 513 responses were analyzed (effective response rate, 70%). Comparing the backgrounds of respondents and nonrespondents revealed no differences in gender, age, or time since patient's death, but a significant difference in the length of patient's hospital stay (mean = 44 vs. 36 days). Table 1 summarizes the backgrounds of the respondents.

### *Public Awareness of PCUs (Table 2)*

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

### *Perceptions of PCUs (Table 3)*

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

### *Factors Associated with Perceptions of PCUs*

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

*Table 1*
**Demographic Backgrounds of the Respondents**

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

SD = standard deviation; PCUs = palliative care units.

[a] Experience of losing a family member from cancer during the previous 10 years.

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

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

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

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

## *Discussion*

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

*Table 2*
**General Population Awareness of PCUs ($n = 2{,}548$)**

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

PCUs = palliative care units.

*Table 3*
**Perceptions of PCUs**

| | General Population | | | | Bereaved Families from PCUs | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | ($n=2,548$) | | | | ($n=513$) | | | | | |
| | Agree (%) | Somewhat Agree (%) | Mean | SD | Agree (%) | Somewhat Agree (%) | Mean | SD | $P$-Value[a] | ES |
| Supports patients in living peacefully | 37 | 35 | 4.03 | 1.06 | 45 | 30 | 4.12 | 1.23 | 0.067 | 0.09 |
| Supports patients in living with dignity | 32 | 38 | 3.94 | 0.93 | 38 | 38 | 4.12 | 0.84 | <0.0001 | 0.19 |
| Provides care for families | 29 | 38 | 3.90 | 1.32 | 54 | 33 | 4.38 | 1.38 | <0.0001 | 0.53 |
| Provides compassionate care | 28 | 39 | 3.88 | 1.18 | 56 | 30 | 4.36 | 1.21 | <0.0001 | 0.52 |
| Alleviates pain | 32 | 36 | 3.87 | 1.03 | 57 | 30 | 4.40 | 0.85 | <0.0001 | 0.52 |
| Expensive | 30 | 31 | 3.79 | 0.94 | 18 | 23 | 3.14 | 0.98 | <0.0001 | −0.58 |
| Provides no medical treatments | 12 | 20 | 3.00 | 1.03 | 29 | 25 | 3.59 | 1.32 | <0.0001 | 0.49 |
| Isolates patients from the community | 7.5 | 21 | 2.80 | 0.90 | 8.4 | 21 | 2.75 | 0.81 | 0.40 | −0.04 |
| A place where people only wait to die | 11 | 20 | 2.76 | 1.19 | 18 | 22 | 3.03 | 1.24 | <0.0001 | 0.20 |
| Shortens the patient's life | 2.8 | 5.3 | 2.27 | 0.92 | 7.4 | 9.2 | 2.44 | 0.87 | 0.006 | 0.15 |

PCUs = palliative care units; SD = standard deviation; ES = effect size.
[a] $t$-test.

levels of awareness and perceptions of PCUs in Japan. Interpretation of the findings depends first on an understanding of the health care system and palliative care system in Japan.

In Japan, each person is obligated to enroll in a national health insurance system. The system is designed so that if a person moves, the insured person is expected to pay the same amount for the same amount of care. Medical fees are set and regulated by the government, and the maximum out-of-pocket cost for the patient is 30% of any such fee. In addition, to curb the expense of high-cost care, the government has instituted a monthly cap of 80,100 yen (670 US$) co-payment. Meals and extra charges for private rooms are not covered by the national health insurance system. The system provides the insured person with total freedom to choose any physician, hospital, or clinic.

*Table 4*
**Association Between Overall Satisfaction with Received Care and Perceptions of PCUs**

| | | $n=513$ |
|---|---|---|
| | $R^a$ | $P$-value |
| Provides compassionate care | 0.49 | <0.0001 |
| Provides care for families | 0.49 | <0.0001 |
| Supports patients in living peacefully | 0.43 | <0.0001 |
| Supports patients in living with dignity | 0.40 | <0.0001 |
| Alleviates pain | 0.30 | <0.0001 |
| Isolates patients from the community | −0.27 | <0.0001 |
| A place where people only wait to die | −0.27 | <0.0001 |
| Shortens the patient's life | −0.23 | <0.0001 |
| Expensive | −0.11 | 0.01 |
| Provides no medical treatments | −0.06 | 0.19 |

[a] Spearman's rank correlation coefficient.

Enhancement of palliative care for any Japanese citizen with cancer is a priority in Japan; thus, the Ministry of Health, Labor and Welfare supports dissemination of specialized palliative care services, with services provided by PCUs. PCUs have been covered by national medical insurance since 1991. To be approved as a PCU, institutions must fulfill the ministry's requirements regarding staff numbers, facilities, and equipment.

PCUs provide intensive symptom control and end-of-life care for patients with incurable cancer and their families, and the amount of money paid by national health insurance to medical institutions is fixed, irrespective of the treatment provided to patients. An approved PCU is reimbursed at the rate of 37,800 yen (315 US$) per patient per day by the health insurance system. The maximum out-of-pocket cost for the patient is 30%, 11,340 yen (95 US$). The majority of PCUs belong to general hospitals and have interdisciplinary teams, including attending physicians, nurses, and other specialists.[18]

Consistent with previous findings in Canada in 2004,[9] public awareness of specialized palliative care services has remained insufficient in Japan. Moreover, experience of bereavement due to cancer was not significantly associated with awareness of PCUs, possibly suggesting that health care professionals do not adequately explain PCUs as an option for end-of-life care to patients with cancer and their families.

Of note, the PCU-bereaved families were likely to have better perceptions of PCUs as providers of comprehensive and human-focused care, that is, compassionate care, symptom control, and care for families. They were also less likely to perceive PCUs as being expensive than the general population. These findings highlight the need for a greater effort to inform the general population that the present palliative care system offers comprehensive and human-focused care, and that the cost of its services is covered by the national health insurance system.

In our preceding analysis of the same survey, perceptions of PCUs as "alleviates pain" and "provides care for families" were significantly associated with preferences for PCUs as place of end-of-life care.[19] It is, therefore, particularly important to disseminate adequate information about empirical evidence for effective pain control and the palliative care concept, including treatment of the patient and their family as the unit of care. Future research is needed to clarify the most effective strategy to improve public awareness of palliative care.

On the other hand, the general population is concerned that the PCU is "a place where people only wait to die," and "shortens the patient's life." It is of note that PCU-bereaved families were more likely to agree with both statements than the general population, despite the fact that palliative care aims to help patients live as actively as possible until death and intends neither to hasten nor postpone death,[20] and the reality that patients receive their usual medical treatments in many PCUs.[21]

Moreover, it is important that both perceptions were significantly associated with overall satisfaction with care and differed considerably among institutions. In Japan, there are significant differences in medical and nonmedical care performed in certified PCUs,[21] possibly due to each institution's economic and staffing pressures, and their staff's philosophy of what constitutes palliative care. Recent literature suggests that terminally ill cancer patients choose palliative chemotherapy as a means of maintaining a sense of hope,[22–24] and thus the fact that no anticancer treatments are available at PCUs can make patients and families feel abandoned.[14] This can become a barrier to providing palliative care. More discussion is needed about the most appropriate medical system for a certain group of patients who receive chemotherapy and have difficult symptoms requiring a specialized inpatient palliative care service. That is, because patients and families may have equal access to quality specialized palliative care whether or not they receive anticancer treatment, we believe that PCU administration criteria should change from focusing on disease incurability to degree of need for specialized palliative care, and functional classification of specialized palliative care services (i.e., primary, secondary, and tertiary PCUs) should be established.[25,26] In addition, further efforts to minimize the real differences in provided care among PCUs are essential. This would enable patients receiving anticancer therapy to temporarily receive quality symptom control in PCUs, reflecting a continuum of cancer care.

This study had several limitations. First, because the respondents were not terminally ill cancer patients, results cannot be automatically applied to patients. We believe that this study is valuable, nonetheless, because PCU-bereaved families could provide worthwhile suggestions on the basis of their actual experience. Second, as the response rate among the general population was not high, response bias could exist. Third, we did not explore the possible associations between actual treatment received and perceptions of PCUs among PCU-bereaved families. A more detailed survey is necessary to clarify what kind of care had led to the difference in perceptions and overall satisfaction.

In conclusion, public awareness of PCU remains insufficient in Japan. PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, but both groups shared concerns that the PCU is a place where people only wait to die. More efforts to inform the general population about the actual palliative care system are needed, and it is necessary to reconsider the role of the PCU within the continuum of cancer care.

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