

**Financial support:** Mitsunori Miyashita, Satoru Tsuneto, Yasuo Shima  
**Administrative support:** Mitsunori Miyashita, Kazuki Sato  
**Provision of study materials or patients:** Tatsuya Morita, Mitsunori Miyashita, Kazuki Sato  
**Collection and assembly of data:** Takuya Shinjo, Mitsunori Miyashita, Kazuki Sato

**Data analysis and interpretation:** Takuya Shinjo, Tatsuya Morita, Kei Hirai, Mitsunori Miyashita  
**Manuscript writing:** Takuya Shinjo, Tatsuya Morita  
**Final approval of manuscript:** Takuya Shinjo, Tatsuya Morita, Kei Hirai, Mitsunori Miyashita, Kazuki Sato, Satoru Tsuneto, Yasuo Shima

## REFERENCES

1. WHO: Palliative care. <http://www.who.int/cancer/palliative/en/>
2. Adam J: ABC of palliative care: The last 48 hours. *BMJ* 315:1600-1603, 1997
3. Ellershaw J, Smith C, Overill S, et al: Care of the dying: Setting standards for symptom control in the last 48 hours of life. *J Pain Symptom Manage* 21:12-17, 2001
4. Furst CJ, Doyle D: The terminal phase, in Doyle D, Hanks G, Cherny N, et al (eds): *Oxford Textbook of Palliative Medicine* (ed 3). New York, NY, Oxford University Press, 2004, pp 1119-1133
5. Hallenbeck J: Palliative care in the final days of life: "They were expecting it at any time." *JAMA* 293:2265-2271, 2005
6. Heyland DK, Dodek P, Rocker G, et al: What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ* 174:627-633, 2006
7. Lynn J, Teno JM, Phillips RS, et al: Perceptions by family members of the dying experience of older and seriously ill patients: SUPPORT investigators—Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Ann Intern Med* 126:97-106, 1997
8. Redinbaugh EM, Baum A, DeMoss C, et al: Factors associated with the accuracy of family caregiver estimates of patient pain. *J Pain Symptom Manage* 23:31-38, 2002
9. Plonk WM Jr, Arnold RM: Terminal care: The last weeks of life. *J Palliat Med* 8:1042-1054, 2005
10. Woof R, Carter Y, Harrison B, et al: Terminal care and dying, in Faull C, Carter Y, Woof R (eds): *Handbook of Palliative Care*. Oxford, United Kingdom, Blackwell Science, 1998, pp 307-332
11. Wilkinson S, Mula C: Communication in care of the dying, in Ellershaw J, Wilkinson S (eds): *Care of the Dying*. New York, NY, Oxford University Press, 2003, pp 74-89
12. Kristjanson LJ: Caring for families of people with cancer: Evidence and interventions. *Cancer Forum* 28:123-127, 2004
13. Wilkes L, White K, O'Riordan L: Empowerment through information: Supporting rural families of oncology patients in palliative care. *Aust J Rural Health* 8:41-46, 2000
14. Sykes N: End of life issues. *Eur J Cancer* 44:1157-1162, 2008
15. Teno JM, Claridge BR, Casey V, et al: Family perspectives on end-of-life care at the last place of care. *JAMA* 291:88-93, 2004
16. Hanson LC, Danis M, Garrett J: What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 45:1339-1344, 1997
17. Cherlin E, Fried T, Prigerson HG, et al: Communication between physicians and family caregivers about care at the end of life: When do discussions occur and what is said? *J Palliat Med* 8:1176-1185, 2005
18. Fried TR, Bradley EH, O'Leary J: Prognosis communication in serious illness: Perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc* 51:1398-1403, 2003
19. Miyashita M, Morita T, Tsuneto S, et al: The Japan HOspice and Palliative Care Evaluation study (J-HOPE study): Study design and characteristics of participating institutions. *Am J Hosp Palliat Care* 25:223-232, 2008
20. Morita T, Hirai K, Sakaguchi Y, et al: Measuring the quality of structure and process in end-of-life care from the bereaved family perspective. *J Pain Symptom Manage* 27:492-501, 2004
21. Morita T, Akechi T, Ikenaga M, et al: Communication about the ending of anticancer treatment and transition to palliative care. *Ann Oncol* 15:1551-1557, 2004
22. Morita T, Ikenaga M, Adachi I, et al: Family experience with palliative sedation therapy for terminally ill cancer patients. *J Pain Symptom Manage* 28:557-565, 2004
23. Morita T, Akechi T, Ikenaga M, et al: Terminal delirium: Recommendations from bereaved families' experiences. *J Pain Symptom Manage* 34:579-589, 2007
24. Steinhilber KE, Christakis NA, Clipp EC, et al: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 284:2476-2482, 2000
25. Singer PA, Martin DK, Kelner M: Quality end-of-life care: Patients' perspectives. *JAMA* 281:163-168, 1999
26. Miyashita M, Sanjo M, Morita T, et al: Good death in cancer care: A nationwide quantitative study. *Ann Oncol* 18:1090-1097, 2007
27. Grbich C, Parker D, Maddocks I: Communication and information needs of care-givers of adult family members at diagnosis and during treatment of terminal cancer. *Prog Palliat Care* 8:345-350, 2000
28. Vachon ML: Psychosocial needs of patients and families. *J Palliat Care* 14:49-56, 1998
29. Kristjanson L, Hudson P, Oldham L: Working with families in palliative care, in Aranda S, O'Connor M (eds): *Palliative Care Nursing: A Guide to Practice* (ed 2). Melbourne, Australia, AUSMED Publications, 2003, pp 271-283
30. Morita T, Ichiki T, Tsunoda J, et al: A prospective study on the dying process in terminally ill cancer patients. *Am J Hosp Palliat Care* 15:217-222, 1998

## Care for the Bodies of Deceased Cancer Inpatients in Japanese Palliative Care Units

Takuya Shinjo, M.D.,<sup>1</sup> Tatsuya Morita, M.D.,<sup>2</sup> Mitsunori Miyashita, R.N., Ph.D.,<sup>3</sup>  
Kazuki Sato, R.N., M.Hlth.Sci.,<sup>3</sup> Satoru Tsuneto, M.D., Ph.D.,<sup>4</sup> and Yasuo Shima, M.D.<sup>5</sup>

### Abstract

**Objectives:** The aim of this study is to clarify the actual experiences and preferences of the bereaved family for the care of their deceased family member.

**Methods:** At 95 palliative care units in Japan, a cross-sectional nationwide survey of the bereaved families of cancer patients was performed in 2007.

**Results:** Of the 670 questionnaires sent to bereaved families, 492 were returned (response rate of 76%). The overall requirement to improve the end-of-life care was rated as follows: improvement needed (42.7%) and no improvement needed (58%). In total, 9.4% of the families reported that they experienced problems with the deceased body after leaving the hospital, including a change in the facial appearance (8.5%), stains on the body (8%), and an odor emanating from the body (4%). Regarding the preferences for treatment procedures, over half the families preferred not to have traditional procedures performed in which the deceased's hands are joined with a band, the jaws are tied with a band around the face to close the mouth, and the body is wrapped in a sheet. The most preferable treatment procedure was to have makeup applied lightly and moderately. Maintaining the appearance of the deceased body was related to the overall care evaluation of end-of-life care.

**Conclusions:** As the preferences for the care of deceased bodies are changing, end-of-life care needs to be improved with respect to culture, religious views, and the wishes of the patient and their family.

### Introduction

**I**N JAPAN, approximately 1 million people die per year. In 2003, the main causes of death due to disease were neoplasms (30.5%), heart disease (15.7%), and stroke (13.0%). Patient death at hospitals reached over 80% in 2003, and of these over 90% were patients with cancer.<sup>1</sup> This fact indicates that many patients and their families experience death at hospitals in Japan. The same tendency was reported in the United States, the United Kingdom, and Canada.<sup>2-4</sup>

As the number of deaths in hospital is increasing, the care for the deceased patient, called "last offices" in United Kingdom and Australia,<sup>4-7</sup> has been developed and has spread widely to Japanese hospitals.<sup>8,9</sup> Several texts describe both the respectful administration and associated practical procedures of care by nurses after the death of the patient.<sup>6-11</sup> The care of

the deceased body could be stressful particularly if the patient died from an infectious disease.<sup>4,6</sup> In Japan, nursing textbooks and postgraduate education address the care for the deceased patient with regard to both clinical procedures and Japanese rituals.<sup>8,9</sup> Indeed, Japanese nurses have taken a major role in the care of the patient's body after death. Some Japanese experts have stressed the potential role of the care of a deceased body from a bereavement and mourning point of view for the lost patient.<sup>9</sup>

After the confirmation of the patient's death by the doctor, nurses usually clean up, dress, apply make-up, and maintain the deceased body and face, sometimes before learning any family preferences. These procedures also include Japanese rituals (Table 1). The care of the deceased body is, thus, considered as the end-of-life care and the beginning of the funeral preparation. In recent times, the bereaved family often entrust

<sup>1</sup>Palliative Care Unit, Shakaihoken Kobe Central Hospital, Kobe, Hyogo, Japan.

<sup>2</sup>Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara General Hospital, Hamamatsu, Shizuoka, Japan.

<sup>3</sup>Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

<sup>4</sup>Department of Palliative Medicine, Osaka University Graduate School of Medicine, Osaka, Japan.

<sup>5</sup>Department of Palliative Medicine, Tsukuba Medical Center Hospital, Tsukuba, Ibaraki, Japan.

Accepted August 4, 2009.

TABLE 1. THE MEANING OF TRADITIONAL PROCEDURES FOR THE DECEASED BODY IN JAPAN

<i>Traditional procedures</i>	<i>Ritual meaning</i>	<i>Practical meaning</i>
The deceased's hands are joined with a band	To prevent the deceased body from moving as a result of being possessed by evil spirits	To prevent the arms from dropping from the stretcher during transport
The orifices are blocked with cotton	To prevent evil spirits entering the deceased body through the mouth	To prevent the body and clothes of the deceased from soiling from vomit and secretions
The jaws are tied with a band around the face to close the mouth	N/A	To maintain the facial appearance
The face is covered with a piece of white cloth	Same meaning as 'the orifices are blocked with cotton'	To avoid the attention of others
The deceased body is wrapped in a white sheet	N/A	To avoid the attention of others when transporting the deceased through the hospital

N/A, not available.

a funeral director to coordinate the funeral. They can organize everything from transferring the body from the hospital to the wake (almost same meaning to vigil), the funeral hall arrangements, and conducting the funeral itself. If there is enough room at home for the wake and the funeral ceremony for the viewing, either the family members or a funeral director can take the deceased to the family's own home.

The principal religions in Japan are Buddhism, Shinto, and Christianity. Statistics show that only a minority of Japanese people are deeply devoted to a specific religion.<sup>12</sup> Most funerals are Buddhist despite the fact most Japanese are non-believers. Buddhist funeral ceremonies include a wake on the first night after death, a funeral ceremony usually on the day after the wake, cremation of the deceased immediately after a funeral ceremony, a burial in a family grave around 49 days after cremation, and a periodic memorial service. The Buddhist priest chants a section from a sutra during the ceremony while incense is offered. Worldwide, Buddhist funerals are quite different from Japanese Buddhist funerals due to the influence of ethnicity and the rituals of different countries (e.g., Tibet, Thai, Bhutan, Myanmar, China, and Sri Lanka). Additionally, the treatment of the deceased body in Japan is influenced by the various religions including Buddhist and Shinto as well as traditional rituals. Thus, modern Japanese funerals and the treatment of the deceased body may be unique to the Japanese.

Although the care of the deceased body is a widespread practice as part of the end-of-life care at both palliative care units and general hospitals in Japan, there has been no systematic research from the perspective of the bereaved family. Thus, the aim of this study is to clarify (1) the actual experiences of and (2) the preferences of the bereaved family for the care of their deceased family member.

## Methods

### Subjects

These data were part of a large cross-sectional anonymous nationwide survey of the bereaved families of cancer patients called the Japan Hospice and Palliative care Evaluation study (J-HOPE study).<sup>13</sup>

Inclusion criteria for survey participants were: (1) the patient died at a palliative care unit, (2) the deceased patient was aged 20 years or more, and (3) the bereaved family member

was aged 20 years or more. Exclusion criteria for the survey were: could not identify the bereaved family member's address, the participant was incapable of replying to a self-questionnaire and the participant would have suffered serious psychological distress as determined by a primary physician. The final criterion was adopted to comply with ethical standards. Since a primary physician at a palliative care unit in Japan generally attends to the patient and their family almost daily, they would be able to identify families who would suffer a serious psychological impact from this survey. No formal criteria or psychiatric screening were applied.

We conducted a cross-sectional questionnaire survey in June 2007, and again in August 2007 to any nonresponding families. In this survey, we selected 670 respondents who died from November 2004 to October 2006 at 95 palliative care units in random order. Five palliative care units were excluded as they provided specific care based on the Christianity religion. The institutional ethics review board of each participating institution approved the ethical and scientific validity of this study.

### Questionnaire

A questionnaire was developed as there was a lack of a similar survey on the subject. We initially pooled items from a systematic literature review<sup>4-11</sup> and several multidisciplinary focus-group discussions. Subsequently, an expert panel consisting of 10 palliative care specialists categorized the items. The face validity was confirmed by a pilot test and an external review by 12 palliative care specialists not involved in this study.

To confirm their intention to participate, families agreed to respond by checking the box in the front page of the questionnaire. The families reported their demographic characteristics, age, gender, and the relationship to the patient and the time interval from patient death to the study.

The questionnaire examined whether end-of-life care needed to be improved, the problems experienced with the deceased body, and the preferences for treatment procedures of the bereaved body. First, the question whether improvement was required for hospital care was evaluated by the answer to, "How much improvement do you think is required for the end-of-life care that you received at the palliative care unit?" The answer was rated on a 4-point scale: 1, no need for improvement; 2, need for some improvement; 3, need for con-

siderable improvement; and 4, need for much improvement. Second, problems with the deceased body as experienced by the bereaved family were evaluated by the response to, "Did you experience problems with the patient's deceased body after leaving the hospital?" The families who reported problems with the deceased body were further requested to report on the actual problems experienced. Finally, all families were requested to rate the preference of traditional procedures for the bereaved body, which involved ritual procedures and make-up to maintain the appearance. The answers were recorded as either "preferred," "not preferred," or "neutral, either is acceptable." The meaning of each traditional procedure is shown in Table 1.

#### Chart review data

Primary physicians recorded the patient demographic characteristics (age, gender, primary tumor site, and admission period).

#### Statistical analysis

To describe the estimated frequency of the observed phenomenon, we calculated the 95% confidence intervals (CI) for the overall levels of a family-reported requirement for improvement. To compare between demographic characteristics (age, gender) and preferences for traditional procedures for the bereaved body, univariate analyses were performed using Student's *t* test and  $\chi^2$  test, where appropriate. Each preference for traditional procedures for the bereaved body was preliminarily scored as follows: "preferred" to 2, "neither" to 1, and "not preferred" to 0. We reported the variables when statistical significance achieved  $p < 0.05$ . All statistical analyses were performed using the Statistical Package for Social Sciences (version 16.0; SPSS Inc., Chicago, IL).

#### Results

Of the 670 questionnaires sent to bereaved family members, 492 family members returned the questionnaires (response rate, 76%). 20 were undeliverable due to an incorrect address. Of the 492 family members, 40 family members returned the questionnaires, expressing their refusal to participate. Seventeen responses were excluded due to missing data. Thus, 435 responses were finally analyzed (effective response rate, 65%). The demographic characteristics of patients and bereaved families are summarized in Table 2.

#### The family-reported requirement for improvement

The overall requirement to improve end-of-life care, as rated by family members, was recorded as follows: much improvement needed (1.4%, 95% confidence interval [CI], 0.6%–3.0%,  $n = 6$ ), considerable improvement needed (4.3%, 95% CI, 2.8%–6.8%,  $n = 19$ ), some improvement needed (37%, 95% CI, 32%–41%,  $n = 159$ ), and no improvement needed (58%, 95% CI, 53%–62%,  $n = 251$ ).

#### Problems experienced with the deceased body

The requirement to improve care had a weak but significant correlation with the problems experienced ( $\rho = 0.20$ ,  $p < 0.001$ ). In total, 86% of the families ( $n = 375$ ) reported no problems with the deceased body after leaving the hospital,

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF THE PATIENT AND THEIR BEREAVED FAMILIES

	n (%)
Patients	435
Age, mean (SD)	71 (11)
Gender	
Male	227 (52)
Female	208 (48)
Primary tumor sites	
Lung	118 (27)
Stomach	52 (12)
Colon, rectum	51 (12)
Liver	26 (6.0)
Bile duct, pancreas	45 (10)
Esophagus	17 (3.9)
Breast	24 (5.5)
Prostate, kidney, bladder	35 (8.0)
Head and neck	12 (2.8)
Uterus, Ovary	25 (5.8)
Others	30 (6.8)
The period from first visit to death	
Mean (SD), days	46 (61)
Bereaved families	435
Age, mean (SD)	59 (13)
Gender	
Male	150 (35)
Female	280 (64)
Relationship	
Spouse	192 (44)
Child	141 (32)
In-laws	44 (10)
Siblings	31 (7.1)
Parents	3 (0.7)
Others	19 (4.4)
Period from patient death to survey	
Mean (SD), months	12 (4)

Some of the data do not add up to 100% due to missing data. SD, standard deviation.

while 9.4% ( $n = 41$ ) reported some problems with the patient's deceased body (Table 3). Problems with the facial appearance were reported by 8.5% of the families ( $n = 37$ ). Of these 37, the most frequent problem was the change in facial appearance due to edema (6.0%,  $n = 26$ ). Problems with stains on the body

TABLE 3. FAMILY-REPORTED PROBLEMS CONCERNING THE DECEASED PATIENT'S BODY

Problems	n (%)
Any problems experienced	41 (9.4)
Body	
Stained with excrement or blood	8 (1.8)
Bad odor	4 (0.9)
Face	
Facial appearance changed due to edema	26 (6.0)
Facial appearance changed due to unnatural make-up	8 (1.8)
Facial appearance changed due to cotton blocking the orifices	11 (2.4)

More detailed answers were requested from the families who reported problems with the deceased body. Multiple answers were allowed.

TABLE 4. FAMILY-REPORTED PREFERENCES FOR TRADITIONAL PROCEDURES FOR THE DECEASED BODY

Traditional procedures	n (%)		
	Preferred	Not preferred	Neutral
<b>Ritual procedures</b>			
The deceased's hands were joined with a band	29 (6.7)	249 (57)	119 (27)
The orifices were blocked with cotton	86 (20)	118 (27)	190 (44)
The jaws were tied with a band around the face to close the mouth	51 (12)	248 (57)	95 (22)
The face was covered with a piece of white cloth	174 (40)	85 (20)	142 (33)
The deceased body was wrapped in a white sheet	26 (6.0)	250 (58)	111 (26)
<b>Makeup procedures</b>			
Lightly and moderately	268 (62)	25 (5.7)	108 (25)
Close to the former appearance	191 (44)	57 (13)	149 (34)
Vividly	61 (14)	164 (38)	164 (38)
Make up on the male deceased face	53 (12)	188 (43)	147 (34)
Use of cosmetics belonging to the deceased	106 (24)	46 (11)	232 (53)

Some of the data do not add up to 100% due to missing data.

caused by excrement or blood and a bad odor were low in frequency. There was no significant correlation between the primary cancer sites, the occurrence of changing of the facial appearance due to edema ( $p = 0.10$ ), the stain ( $p = 0.78$ ), and the site of the bad odor ( $p = 0.93$ ).

#### Preferences for traditional procedures for the deceased body

Table 4 shows the family-reported preferences for traditional procedures. Over half the families preferred not to have the deceased's hands joined with a band, the jaws tied with a band around the face to close the mouth, and the body wrapped in a sheet. The most preferable make-up was applied lightly and moderately. The older survey participants were significantly more likely to prefer to have the face covered with a piece of white cloth ( $p = 0.001$ ). Female survey participants were significantly less likely to prefer to have the deceased's hands joined with a band ( $p = 0.031$ ). There was no statistical correlation between the relationship concerning the patient and the bereaved family and the preferences for traditional procedures for the deceased body ( $p = 0.068$ ).

#### Discussion

This is the first study to evaluate the experiences of bereaved families and their preferences for the care of the deceased body in Japan. Our study had two major findings.

First, our study revealed that a very small number of bereaved families experienced problems with the deceased body. Thus, most were generally satisfied with the end-of-life care provided in the inpatient palliative care unit. The problems experienced with the deceased patient's body were, however, correlated with the family-reported requirement for improvement of the end-of-life care. The main problems reported by bereaved families in this study included the changing of the facial appearance and/or the presence of body stains. These results suggest that maintaining the appearance and preventing stains and odors are essential for end-of-life care.

It is important to clarify the contributing factor for the changing of the facial appearance, stains, and odors of the deceased body because prevention may be a possible treatment to avoid problems with the body after death. Our study

revealed no significant correlation between changing facial appearance due to edema, body stains, and odors after death and primary cancer sites. Also, no empirical research has examined the contributing factors behind the stains and bad odors of a deceased body. This may be due to the small sample size. Therefore, a case control study is appropriate to identify the risks, particularly for body stains and odors after death.

After death, viewing the deceased person by families and friends is still customary in many countries.<sup>14</sup> Viewing helps bring families and friends together to celebrate the life and mourn the passing of a person.<sup>14</sup> This cultural perspective and our study reconfirm that maintaining the patient's appearance after death for viewing purposes is not only an issue in Japan but is also an issue universally.

Second, our study revealed that the preferences for traditional procedures for the deceased body are changing. Some procedures have been practiced to prevent evil spirits entering the deceased body, and soiling the body and clothes by vomit and secretions. In our study, most survey participants did not request the procedures, such as joining the deceased's hands with a band and blocking the orifices with cotton. These results suggest that the perspective about death rituals is considerably changing. From a practical point-of-view, a novel gel-forming water absorptive polymer agent<sup>15</sup> has been developed to prevent infection and the outflow of vomit, secretions, and feces after death. From the universal perspective, practices relating to how the deceased body is treated will vary and be dependent on each patient's cultural background and religious practices.<sup>5,8,11</sup> Consultation with the individual and the families is required to avoid offering care in a stereotypical way.<sup>16</sup> Care workers should confirm the patient or families' wishes before caring for the deceased body. Therefore, to achieve a consultation at the appropriate time before a patient's death, care workers are required to detect imminent death using common signs (e.g., deterioration in consciousness, terminal delirium, retained respiratory secretions, audible respirations with mandibular movement, cyanosis of the extremities, and no palpable pulse).<sup>17</sup>

#### Limitations

Although this study has several strengths, including successfully obtaining a large sample size with more than a 70%

response rate, this study has some limitations. First, due to its retrospective nature, there may be a recall bias. Second, as all patients received specialized palliative care, adherence levels to recommended care practices were generally high, and may result in statistical analyses with a low sensitivity. Thus, the findings could not be automatically generalized to other situations. Third, the postmortem care is strongly related to culture, religion, ethics, and ritual issues. Therefore, the findings may not be applicable to other cultures or ethnic groups. Finally, there are little data regarding religious and ethnicity preferences to compare to the results of our study.

### Conclusions

Almost all the bereaved families experienced acceptable end-of-life care of their deceased relative. Maintaining the appearance of the deceased body was related to the overall care evaluation of end-of-life care. Procedures for maintaining the appearance of the deceased and preventing stains are vital to achieve a better end-of-life care. The preferences for the care of the deceased body are changing and this care may be refined by the consideration of the culture, religious views, and wishes of both the patient and their family.

### Acknowledgments

This research project was supported by a Grant-in-Aid from the Japan Hospice Palliative Care Foundation. We would like to thank Michiyo Mukai, R.N., from the Palliative Care Unit, Shakaihoken Kobe Central Hospital; Yumi Sakuma, R.N., and Emi Kiyohara, R.N., from the Seirei Hospice, Seirei Mikatahara General Hospital; Miki Namba, R.N., and Koji Fujimoto, R.N., from the Palliative Care Team, Seirei Mikatahara General Hospital; Chizuru Imura, R.N., from the Seirei Hospice, and the Seirei Mikatahara General Hospital, Shizuoka, Japanese Nursing Association, Tokyo for developing the questionnaire; Mitsue Kobayashi, R.N., "Angel Make" Study Group, Tokyo and Yumi Ohmori, R.N., from the Komatsu Hospital, Osaka for providing specialist advice.

### Author Disclosure Statement

No competing financial interests exist.

### References

1. The Japanese Ministry of Health, Labor, and Welfare: Statistics and other data. 2005; updated April 10, 2009. [www.mhlw.go.jp](http://www.mhlw.go.jp) (Last accessed April 15, 2009).
2. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88-93.
3. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, Shortt S, Tranmer J, Lazar N, Kutsogiannis J, Lam M, Canadian Researchers End-of-Life Network (CARENET): What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ* 2006;174:627-633.
4. Higgins D: Carrying out last offices. Part 1—Preparing for the procedure. *Nurs Times* 2008;104:20-21.
5. Higgins D: Carrying out last offices. Part 2—Preparation of the body. *Nurs Times* 2008;104:24-25.
6. Dougherty L, Lister S: Last offices. In: *The Royal Marsden Hospital Manual of Clinical Nursing Procedures, 7th ed.* Oxford: Blackwell Publishing, 2008, pp. 444-458.
7. Quedstedt B, Rudge T: Nursing care of dead bodies: A discursive analysis of last offices. *J Adv Nurs* 2003;41:553-560.
8. Kobayashi Y: Review of postmortem care [in Japanese]. *Bull Niigata Seiryu Univ* 2005;5:291-303.
9. Kobayashi M: *Care toshitenno shigesyuu* [in Japanese]. Tokyo: Nihon Kango Kyokai Syuppan Kai, 2007.
10. Blum CA: 'Til death do us part?' The nurse's role in the care of the dead a historical perspective: 1850-2004. *Geriatr Nurs* 2006;27:58-63.
11. Quedstedt B, Rudge T: Nursing care of dead bodies: A discursive analysis of last offices. *J Adv Nurs* 2003;41:553-560.
12. Japan Technical Information Services Co., Ltd.: *Nippon: The Land and its People, 8th ed.* Tokyo: Gakuseisya, 2006.
13. Miyashita M, Morita T, Tsuneto S, Sato K, Shima Y: The Japan HOspice and Palliative Care Evaluation study (J-HOPE study): Study design and characteristics of participating institutions. *Am J Hosp Palliat Care* 2008;25:223-232.
14. Gonzalez F, Hereira M: Home-based viewing (el velorio) after death: A cost-effective alternative for some families. *Am J Hosp Palliat Care* 2008;25:419-420.
15. Humex Co., Ltd.: Safety set: Disposable anti-contagious pluggings. 2008. [www.hum.co.jp/Product2/Appli\\_ura.pdf](http://www.hum.co.jp/Product2/Appli_ura.pdf) (Last accessed April 15, 2009).
16. Speck P: Spiritual/religious issues in care of the dying. In: Ellershaw J, Wilkinson S (eds): *Care of the Dying. A Pathway to Excellence.* New York: Oxford University Press, 2003, pp. 90-105.
17. Morita T, Ichiki T, Tsunoda J, Inoue S, Chihara S: A prospective study on the dying process in terminally ill cancer patients. *Am J Hosp Palliat Care* 1998;15:217-222.

Address correspondence to:

Takuya Shinjo, M.D.

Palliative Care Unit

Shakaihoken Kobe Central Hospital

2-1-1 Souyama-cho

Kita-ku

Kobe

Hyogo 6511145

Japan

E-mail: [shinjo@doctor.email.ne.jp](mailto:shinjo@doctor.email.ne.jp)

**This article has been cited by:**

1. Charles F. von Gunten . 2010. Editor's PerspectiveEditor's Perspective. *Journal of Palliative Medicine* 13:1, 5-6. [Citation] [Full Text] [PDF] [PDF Plus]

## Discharge from a Palliative Care Unit: Prevalence and Related Factors from a Retrospective Study in Japan

Mitsunori Miyashita, R.N., Ph.D.,<sup>1</sup> Kazuko Arai, M.D.,<sup>2</sup> Yosuke Yamada, M.D., Ph.D.,<sup>3</sup>  
Machiko Owada, R.N.,<sup>3</sup> Tomoyo Sasahara, R.N., Ph.D.,<sup>1,4</sup>  
Masako Kawa, R.N., Ph.D.,<sup>1</sup> and Taketo Mukaiyama, M.D.<sup>5</sup>

### Abstract

**Purpose:** Selecting a place for end-of-life care is an important issue for patients with cancer. In this study we conducted a retrospective analysis on the prevalence of discharge from a palliative care unit (PCU) and explored factors related to discharge based on individual-level data from 5 years of experience at the Tokyo Metropolitan Toshima Hospital PCU.

**Methods:** We retrospectively collected information on patients and families from the admission database of the PCU. We calculated the prevalence of patients discharged from the PCU and explored the factors related to discharge using bivariate and multivariate analysis.

**Results:** The subjects were 498 terminal patients with cancer. The overall discharge rate was 33%. For subjects who were admitted for symptom control, the discharge rate was 54%. The duration of the period from referral to death (odds ratio [OR] = 4.98,  $p < 0.001$ ), Eastern Cooperative Oncology Group Performance States [ECOG PS]\_OR = 0.51,  $p = 0.003$ ), problems with oral intake (OR = 0.41,  $p = 0.048$ ), presence of nausea (OR = 0.41,  $p = 0.046$ ), experience of radiation therapy (OR = 0.27,  $p = 0.003$ ), and patient's anxiety for family (OR = 0.35,  $p = 0.029$ ) were independent related factors for discharge from the PCU, according to logistic regression.

**Conclusion:** Early referral to the PCU and development of alleviation methods for symptoms such as nausea and anxiety and depression are important for promoting discharge and would contribute to the patient's quality of life at the end of life.

### Introduction

SELECTING A PLACE for end-of-life care is an important issue for patients with cancer. Japanese good-death studies revealed that it is important for patients to stay in a favorite place at the end of life in order to achieve a good death.<sup>1,2</sup> In addition, studies in Western and Asian countries have found that many patients with cancer wanted to stay at home at the end of life.<sup>3-7</sup> In a recent Japanese population-based survey, 46% of the general public preferred that end-of-life cancer care be given at home.<sup>8</sup> There is sufficient evidence that discharge from the hospital will improve the quality of life for end-of-life patients with cancer, and many Japanese patients with cancer desire to be at home during the advanced stage. In Japan, patients are not discharged at

the end of aggressive treatment. This practice may be the result of insufficient discharge planning, the medical practitioner's reluctance to relinquish treatment, or the social factors of the patient or family.

The Japanese Ministry of Health, Labour, and Welfare has strongly supported the provision of specialized palliative care services, and palliative care units (PCUs) for cancer and acquired immune deficiency syndrome (AIDS) patients. This service has been covered by National Medical Insurance since 1990. The number of PCUs has dramatically increased from just 5 in 1990 to 175 in 2007. PCUs for patients with cancer are certified by the prefecture authorities based on several criteria.<sup>9</sup> The growth of home-care hospice has been slow in comparison, and the proportion of home cancer deaths has gradually decreased to only 6% in 2006. Most pa-

<sup>1</sup>Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.

<sup>2</sup>Department of Cancer Palliative Care, Center Institution Hospital of Japanese Foundation for Cancer Research, Tokyo, Japan.

<sup>3</sup>Palliative Care Unit, Tokyo Metropolitan Toshima Hospital, Tokyo, Japan.

<sup>4</sup>Graduate School of Comprehensive Human Sciences, University of Tsukuba, Tsukuba, Japan.

<sup>5</sup>Department of Cancer Palliative Care, Center Institution Hospital of Japanese Foundation for Cancer Research, Tokyo, Japan.



tients with cancer do not receive home hospice care because there are too few home hospices in Japan. The usage rate of home hospice services for home death is much lower than in the United States or the United Kingdom.<sup>10</sup> According to the above-mentioned statistics, more than 80% of patients with cancer died in a general hospital ward in 2006. In 2002, the Japanese health insurance system established Palliative Care Team (PCT) services for an additional fee for patients with cancer on general medical wards. This system provided financial support to certified PCTs based on several criteria. However, the number of certified palliative care teams was only approximately 60 in 2007. In contrast, there were approximately 8000 hospitals, including 288 regional cancer centers and 1113 teaching hospitals in Japan in 2007. PCT services covers only a small proportion of cancer deaths. This system is clearly insufficient as a single source of specialized palliative care for patients with cancer. Therefore, the most common type of specialized palliative care service in Japan is the PCU. The Japanese health care system for terminally ill patients focused on cancer and AIDS patients. Other diseases were covered under conventional health care provision.

Japanese inpatient PCUs have two primary roles. One is end-of-life care (providing palliative care at place of death) and the other is symptom control for advanced cases, when death is not imminent. Although some Japanese would like to stay in a PCU at the end of life, many others would like to stay at home. To that end, the PCU should palliate a patient's distressing symptoms appropriately with the goal of discharge to enhance the patient's quality of life. However, the current status of discharge from the PCU in Japan is unclear. At some PCUs, all admitted patients died there without being discharged, and at other PCUs, 40% of admitted patients were discharged at least once during the dying process. According to national hospice data, the average discharge rate is estimated to be from 15% to 20% (unpublished data). However, the factors influencing discharge from the PCU have not been investigated in Japan. Literature review indicates that there are no reports from other countries regarding discharge from inpatient palliative care units.

Although many studies have been conducted on the barriers to admission to hospice,<sup>11-17</sup> there have been few regarding discharge from the PCU. Hu et al.<sup>18</sup> investigated patient-related barriers and their resolution in the discharge planning to palliative home care in Taiwan, and reported that the barriers were: inability to manage emergent medical conditions; patient beliefs that the quality of hospital care is better than home care; and an insufficient number of caregivers. In addition, the effective solutions that correlated significantly with the above factors were ranked as follows: to reassure the patient about the possibility of smooth readmission; to arrange palliative home care programs; and to educate family members about taking care of the patient at home. However, Hu's previous work was based on expert medical practitioners' opinions. An individual-based analysis has not been conducted worldwide.

The Tokyo Metropolitan Toshima Hospital opened its PCU in 1999. In this PCU, the administration's philosophy is based on the World Health Organization's definition of palliative care—that is, that palliative care should be provided from the early phase of advanced disease.<sup>19</sup> The Toshima Hospital covers patients with cancer from the en-

tire area of the Tokyo Metropolis. The home care system in Tokyo varies among regions; however, there are very few home hospices. The conventional home care clinics and visiting nursing programs provide home care for patients with cancer; however, Toshima Hospital is the most frequent place of death for most patients. Appropriate discharge planning would allow these patients to be at home according to individual preferences. This PCU has emphasized symptom control using an interdisciplinary team approach and proactive discharge planning to achieve a seamless transition to home care. In addition, this PCU collected individual patient data from 1999 to 2004 from admission to discharge. We conducted a retrospective analysis regarding the prevalence of discharge from a PCU and explored factors related to discharge based on individual-level data from 5 years of experience with the Tokyo Metropolitan Toshima Hospital PCU.

## Methods

### Subjects

The number of patients admitted to the PCU was 546 from July 1999 to March 2004. We excluded patients transferred to other acute care wards or other hospitals ( $n = 19$ ) and the patients who were alive on March 1, 2004 ( $n = 29$ ). Our analysis included 498 patients.

### End point

The end point of this study was the patient's discharge from the PCU during the dying process. In principle, a discharge marked a transition in the place of care from the PCU to home. We did not include brief times that the patient was away from the hospital, such as weekends.

### Data collection

We collected the data on patients and caregivers from the admission database. The following data were collected on patients: age, gender, cancer site, symptoms (pain, fatigue, appetite loss, dry mouth, nausea, vomiting, constipation, diarrhea, cough, dyspnea, abdominal swelling, edema, anxiety, and depression), treatment experience (surgery, radiation, chemotherapy, hormone therapy, immunotherapy, and alternative therapy), duration from referral to death, Eastern Cooperative Oncology Group Performance Status (ECOG PS), cognitive disorder, oral intake, marital status, patient anxiety about treatment and psychosocial factors, and patient desire for treatment and psychosocial factors. For the family caregivers, we collected the following data: age, gender, relationship to the patient, family caregiver anxiety about treatment and psychosocial factors, family caregiver desire for treatment and psychosocial factors. Information about the patient's and family's anxieties regarding treatment and psychosocial factors was obtained at admission using a questionnaire. The questionnaire included 10 dichotomous items about anxieties and desire of patients and caregivers.

At patient admission, the PCU staff (physicians, nurses, and medical social workers) determined the aim of admission to be either symptom control or end-of-life care (providing palliative care at the place of death) and recorded it in the admission database. Categorization was based on life expectancy and patient and family preferences. If the pa-

TABLE 1. PATIENT CHARACTERISTICS (n = 284)

	n	%
Age, y		
<40	9	3
40-49	20	7
50-59	75	27
60-69	88	31
70-79	69	25
≥80	19	7
Gender		
Female	162	57
Male	122	43
Cancer site		
Lung	49	17
Breast	37	13
Stomach/esophagus	55	19
Liver/gallbladder/pancreas	44	15
Colon/rectum	37	13
Ovary/uterus	28	10
Others	34	12
Symptoms		
Pain	218	78
Fatigue	157	56
Appetite loss	177	63
Dry mouth	78	28
Nausea	100	36
Vomiting	50	18
Constipation	125	45
Diarrhea	52	19
Cough	52	19
Dyspnea	87	31
Abdominal swelling	96	34
Edema	64	23
Insomnia	93	33
Anxiety	113	40
Depression	108	39
Treatment experience		
Surgery	175	63
Radiation	121	43
Chemotherapy	168	60
Hormone therapy	28	10
Immunotherapy	19	7
Alternative therapy	122	44
Others	37	13
Duration from referral to death, days		
<7	1	0
7-13	7	3
14-27	21	8
28-55	60	21
56-111	86	31
112-223	62	22
≥224	43	15
ECOG PS		
0	6	2
1	50	18
2	76	27
3	100	36
4	49	17
Cognitive disorder	10	4
Oral intake		
No problem	145	53
Some problem	99	36
No oral intake	28	10
Marital status		
Married	208	76
Unmarried	25	9
Other (divorced, etc.)	40	15

TABLE 1. PATIENT CHARACTERISTICS (n = 284) (CONT'D)

	n	%
Family caregiver age		
<30	8	3
30-39	42	16
40-49	56	21
50-59	84	31
60-69	48	18
≥70	31	12
Family caregiver gender		
Female	159	57
Male	120	43
Relationship to patient		
Spouse	132	49
Child	100	37
Sibling	20	7
Parent	4	1
Others	14	5

Data are for patients admitted to control their symptoms.  
ECOG PS, Eastern Cooperative Oncology Group Performance States.

patient's life expectancy was a few weeks, the patient was categorized as "end-of-life care." In addition, if the patient and family desired hospitalization with a life expectancy under one month, the patient was also categorized as "end-of-life care." If the patient needed symptom control and end-of-life care, we classified the patient as "end-of-life care."

### Analysis

First, we calculated the prevalence of discharge with three denominators: overall, for patients where the aim of admission was symptom control, and for patients where the aim was end-of-life care. Second, we explored factors related to discharge from the PCU by bivariate analyses such as the  $\chi^2$  test and Cochran-Armitage trend test, as appropriate. Finally, we conducted a multiple logistic regression analysis with backward variable selection method ( $p < 0.2$ ) to determine the independent factors contributing to discharge. The analytic sample regarding the related factors was limited to the patients who were admitted for symptom control only. All statistical analyses were two-tailed and the significant value was set at 0.05. We used the statistical package SAS version 9.1 (SAS Institute, Cary, NC,) for all analyses.

### Results

Of 498 patients, 164 (33%) were discharged from the PCU to home care. Of the 284 patients admitted for symptom control, 153 (54%) were discharged, and 13 of 214 (6%) admitted for end-of-life care were discharged.

Characteristics of patients admitted for symptom control are shown in Table 1. The proportion of patients over 60 years old was 63%, and 57% were women. The symptoms on admission were pain (78%), fatigue (56%), and appetite loss (63%). Time from referral until death for 89% of these patients was over 4 weeks, and 53% had an ECOG PS of over 3. The percentage of family over 60 years old was 30%, and 57% were women. Spouses made up 49% of the family members.

The results of bivariate analyses for patients admitted for symptom control are shown in Table 2. The significant barriers to discharge were: short duration from referral to death ( $p < 0.001$ ), higher ECOG PS ( $p < 0.001$ ); problems with oral intake ( $p = 0.018$ ); married ( $p = 0.032$ ); presence of symptoms on admission such as appetite loss ( $p = 0.01$ ), dry mouth ( $p = 0.002$ ), nausea ( $p = 0.02$ ), constipation ( $p = 0.03$ ), edema ( $p = 0.02$ ), anxiety ( $p = 0.02$ ), and depression ( $p = 0.02$ ); family caregiver with older age ( $p = 0.022$ ); patient anxiety as to "whether distress could be alleviated" ( $p = 0.002$ ); "future treatment strategy" ( $p = 0.025$ ); patient desire "to alleviate psychological symptoms" ( $p = 0.001$ ); family caregiver anxiety over "whether distress could be alleviated" ( $p = 0.005$ ); family caregiver desire "to alleviate physical symptoms" ( $p = 0.009$ ); and family caregiver desire "to alleviate psychological symptoms" ( $p = 0.002$ ).

The results of multiple logistic regression analysis are shown in Table 3. A significant independent factor for discharge to home care was longer length of time from referral to death (odds ratio [OR] = 4.98, 95% confidence interval [CI]: 3.11-7.97,  $p < 0.001$ ). On the other hand, a high ECOG PS score (OR = 0.51, 95% CI: 0.33-0.80,  $p = 0.003$ ), no oral intake (OR = 0.41, 95% CI: 0.17-0.99,  $p = 0.048$ ), nausea (OR = 0.41, 95% CI: 0.17-0.99,  $p = 0.046$ ), history of radiation therapy (OR = 0.27, 95% CI: 0.12-0.64,  $p = 0.003$ ), and patient anxiety about family (OR = 0.35, 95% CI: 0.14-0.90,  $p = 0.029$ ) were significant independent barriers to discharge to the home. The coefficient of determination for the statistical model ( $R^2$ ) was 0.51 and the adjusted coefficient of determinant (Max-rescaled  $R^2$ ) was 0.68.

### Discussion

This is the first study to clarify the discharge rate from the PCU to home care in Japan. We also explored the factors promoting and inhibiting discharge from the PCU. We found that 33% of the patients who were admitted were discharged.

TABLE 2. FACTORS RELATED TO DISCHARGE FROM THE PCU (BIVARIATE ANALYSIS) (n = 284)

	Proportion of patients discharged, %	p value
Duration from referral to death, days		<0.001 <sup>a</sup>
<7	0	
7-13	0	
14-27	5	
28-55	20	
56-111	57	
112-223	77	
≥224	95	
ECOG PS		<0.001 <sup>a</sup>
0	100	
1	78	
2	66	
3	47	
4	18	
Oral intake		0.02 <sup>b</sup>
No problem	59	
Some problem	49	
No oral intake	36	
Marital status		0.03 <sup>b</sup>
Married	50	
Unmarried	56	
Other (divorced, etc.)	73	
Symptom: appetite loss		0.01 <sup>b</sup>
Absent	63	
Present	48	
Symptom: dry mouth		0.002 <sup>c</sup>
Absent	59	
Present	44	
Symptom: nausea		0.02 <sup>b</sup>
Absent	59	
Present	44	
Symptom: constipation		0.03 <sup>b</sup>
Absent	59	
Present	46	
Symptom: edema		0.02 <sup>b</sup>
Absent	57	
Present	41	
Symptom: anxiety		0.02 <sup>b</sup>
Absent	59	
Present	45	
Symptom: depression		0.02 <sup>b</sup>
Absent	59	
Present	44	
Patient Anxiety: whether distress could be alleviated		0.002 <sup>c</sup>
Absent	66	
Present	46	
Patient Anxiety: future treatment strategy		0.02 <sup>b</sup>
Absent	63	
Present	49	
Patient desire to alleviate anxiety		0.001 <sup>c</sup>
Absent	64	
Present	45	
Family caregiver age		0.02 <sup>b</sup>
<30	63	
30-39	69	
40-49	48	
50-59	54	
60-69	52	
≥70	35	
Family caregiver anxiety: whether distress could be alleviated		0.005 <sup>c</sup>
Absent	65	
Present	47	

TABLE 2. FACTORS RELATED TO DISCHARGE FROM THE PCU (BIVARIATE ANALYSIS) ( $n = 284$ ) (CONT'D)

	Proportion of patients discharged, %	p value
Family caregiver desire to alleviate physical symptoms		0.009 <sup>c</sup>
Absent	83	
Present	51	
Family caregiver desire to alleviate psychological symptoms		0.002 <sup>c</sup>
Absent	70	
Present	48	

<sup>a</sup> $p < 0.001$ .<sup>b</sup> $p < 0.05$ .<sup>c</sup> $p < 0.01$ .We displayed only variables with  $p < 0.05$ .

Data are for patients admitted to control their symptoms. PCU, palliative care unit.

Of the patients admitted for symptom control, 54% were discharged. This figure is very high compared to other PCUs in Japan. This is because this institute had worked on discharge planning. In addition, we explored factors related to discharge from the PCU to home care. We were therefore able to clarify which tasks promoted transition from the PCU to home care. The coefficient of determinant and the adjusted coefficient were high ( $R^2 = 0.51$ , Max-rescaled  $R^2 = 0.68$ ) by multiple logistic regression analysis. The model constructed with this data represents a sufficient explanation regarding discharge from the PCU for patients admitted for symptom control.

In Japan, patients and families are approached on an individual basis regarding place of death. There is no formal

documentation process. The frequency of meeting with the patient and family varies from facility to facility. This could be a barrier to being discharged from PCU to home. Moreover, many Japanese patients and family members have a negative image of the PCU as "a place where people only wait to die," "that provides no medical treatment," and "that shortens a patient's life."<sup>20, 21</sup> Therefore, some patients and families do not understand that once a patient is admitted to the PCU, he or she can be discharged to home care. The results of this study counter these misconceptions. In this PCU, half of the admissions were for symptom control. Thus, with appropriate symptom control, almost half of the patients could be discharged from the PCU to home care. This suggests not only that appropriate symptom control is im-

TABLE 3. FACTORS RELATED TO DISCHARGE FROM THE PCU (LOGISTIC REGRESSION ANALYSIS) ( $n = 284$ )

	Odds ratio	95% confidence interval	p value
Duration from referral to death	4.98	3.11-7.97	0.001 <sup>a</sup>
ECOG PS	0.51	0.33-0.80	0.003 <sup>b</sup>
Oral intake (reference: no problem)			
Some problems	0.41	0.17-0.99	0.05 <sup>c</sup>
No oral intake	0.52	0.13-2.13	0.37
Marriage status (reference: unmarried)			
Married	0.16	0.04-0.75	0.02 <sup>c</sup>
Other (divorced, etc.)	1.52	0.44-5.29	0.51
Symptom: dry mouth	0.53	0.22-1.30	0.16
Symptom: nausea	0.41	0.17-0.99	0.05 <sup>c</sup>
Treatment experience: radiation	0.27	0.12-0.64	0.003 <sup>b</sup>
Patient anxiety: concerns about family	0.35	0.14-0.90	0.03 <sup>c</sup>
Patient anxiety: concerns about working	3.17	0.92-10.89	0.07
Patient desire to alleviate psychological symptoms	0.50	0.20-1.22	0.13
Family caregiver desire to be informed about progression of disease	0.40	0.15-1.08	0.07
Family caregiver desire to alleviate psychological symptoms	0.37	0.13-1.06	0.06

Data are for patients admitted to control their symptoms.

Odds ratio &gt; 1 indicates factors associated with discharge to home.

The inclusion criterion of logistic regression analysis was  $p > 0.2$ . Therefore, the variables that did not appear in the bivariate analysis (Table 2) were selected.<sup>a</sup> $p < 0.001$ .<sup>b</sup> $p < 0.01$ .<sup>c</sup> $p < 0.05$ .

PCU, palliative care unit.

portant but also that effective discharge planning by an interdisciplinary team contributes to the patient's quality of life.<sup>22,23</sup> We should note that this result is from one institute. In the future, Japanese PCUs should offer not only end-of-life care but also appropriate symptom control and support for keeping the patient in his or her favorite place. In addition, an increase in the discharge rate would contribute to improving the shortage of PCU beds and the long wait for admission.

In this study, 6% of patients who were admitted for end-of-life care were discharged from the PCU to home care. In Japan, the national home death rate of patients with cancer was 6% in 2006. The home care system for patients with cancer is insufficient. In addition, the burden on the family caregivers and the shortage of visiting physicians are barriers to home care of patients with cancer. Consequently, the PCU should function as the place for end-of-life care and dying.

As for factors related to discharge, bivariate analysis showed that short duration from referral to death, high ECOG PS score, problems with oral intake, and presence of symptoms such as appetite loss, dry mouth, nausea, constipation, anxiety, and depression were barriers to discharge. Multiple logistic regression showed similar results. Early referral to the PCU could stabilize symptoms and would make discharge to home more likely. The high ECOG PS is also a reasonable result. When referral to the PCU occurs earlier, it is easier to select the place of care in accordance with the patient's preference; therefore contributing to the patient's quality of life. In Japan, the timing of referrals to palliative care units is generally late.<sup>20</sup>

Appetite loss, dry mouth, nausea, and edema were barriers to discharge. These symptoms are difficult to alleviate. Dry mouth and problems with oral intake are terminal symptoms. Also, patients with nausea often have difficulty moving, causing anxiety in both patient and family. Control of nausea would be an important factor in promoting discharge from the PCU to home care. Development of a method for nausea control at home is important for the future. On the other hand, pain was not a barrier to discharge. Recent developments in pain control can palliate pain at home. Symptom control at home is a crucial issue.

Psychological symptoms such as anxiety and depression were also barriers to discharge. In the multiple logistic analysis, "patient desire to alleviate psychological symptoms" ( $p = 0.13$ ) and "family desire to alleviate psychological symptoms" ( $p = 0.06$ ) were included in the final model. These results might be confounded by the presence of psychological symptoms. However, these results suggest that alleviation of psychological symptoms such as anxiety and depression is an important factor. Early intervention by a psychiatrist or medical psychologist might be effective. In Japan, psycho-oncologists are uncommon. It is therefore important to promote this profession.<sup>24</sup>

According to multiple logistic regression analysis, patient anxiety about working ( $p = 0.07$ ) tended to promote discharge. This results from the patient's desire to fulfill a social role and complete their life's work. These are important factors in a good death for Japanese individuals.<sup>2</sup> Discharge from the PCU could contribute to achievement of a good death. The medical professionals working at the PCU should support the patient's desires including social and psycho-existential factors in achieving a good death for all end-of-life

patients. In our analysis, being married was a barrier to discharge from the PCU. We could not find an explanation for this result. Further study is needed on this point.

### Limitations

There are several limitations in this study. First, this study was conducted at a PCU. Therefore it is difficult to generalize the results to other settings. Second, data on patients and caregivers were based only on the admission database. Therefore, we could not analyze in detail the patient's condition after admission. As each patient's disease trajectory is different it is difficult to analyze fluctuating conditions from a retrospective medical chart review. Finally, the details about family caregivers, the home care system, and economic status might be barriers to discharge from the PCU to home care, but we could not obtain this information in this study.

### Conclusions

This study is the first to clarify the discharge rate from the PCU to home care and to explore the factors promoting and inhibiting discharge from the PCU in Japan. We found that 33% of admitted patients could be discharged home. Of patients admitted for symptom control, 54% were discharged. Short duration from referral to death, high ECOG PS score, physical symptoms such as dry mouth, nausea, and problems with oral intake, and psychological symptoms were barriers to discharge from the PCU to home care. Early referral to the PCU, development of symptom alleviation methods for home care and alleviation of psychological symptoms such as anxiety and depression are important to promote discharge and would contribute to the patient's quality of life.

### Author Disclosure Statement

No competing financial interests exist.

### References

- Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y: Good death in Japanese cancer care: A qualitative study. *J Pain Symptom Manage* 2006;31:140-147.
- Miyashita M, Sanjo M, Morita T, Hirai K, Uchitomi Y: Good death in cancer care: A nationwide quantitative study. *Ann Oncol* 2007;18:1090-1097.
- Townsend J, Frank AO, Fermont D, Dyer S, Karran O, Walgrove A, Piper M: Terminal cancer care and patients' preference for place of death: A prospective study. [see comment]. *BMJ* 1990;301:415-417.
- Brown D, Roberts JA, Elkins TE, Larson D, Hopkins M: Hard choices: The gynecologic cancer patient's end-of-life preferences. *Gynecol Oncol* 1994;55(3 Pt 1):355-362.
- Choi KS, Chae YM, Lee CG, Kim SY, Lee SW, Heo DS, Kim JS, Lee KS, Hong YS, Yun YH: Factors influencing preferences for place of terminal care and of death among cancer patients and their families in Korea. *Support Care Cancer* 2005;13:565-572.
- Lee A, Pang WS: Preferred place of death—A local study of cancer patients and their relatives. *Singapore Med J* 1998;39:447-450.
- Brazil K, Howell D, Bedard M, Krueger P, Heidebrecht C: Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliat Med* 2005; 19:492-499.

8. Sanjo M, Miyashita M, Morita T, Hirai K, Kawa M, Akechi T, Uchitomi Y: Preferences regarding end-of-life cancer care and associations with good-death concepts: A population-based survey in Japan. *Ann Oncol* 2007;18:1539-1547.
9. Ida E, Miyachi M, Uemura M, Osakama M, Tajitsu T: Current status of hospice cancer deaths both in-unit and at home (1995-2000), and prospects of home care services in Japan. *Palliat Med* 2002;16:179-184.
10. Fukui S, Fukui N, Kawagoe H: Predictors of place of death for Japanese patients with advanced-stage malignant disease in home care settings: A nationwide survey. *Cancer* 2004;101:421-429.
11. Pugh EM: An investigation of general practitioner referrals to palliative care services. *Palliat Med* 1996;10:251-257.
12. Weggel JM: Barriers to the physician decision to offer hospice as an option for terminal care. *WMJ* 1999;98:49-53.
13. Friedman BT, Harwood MK, Shields M: Barriers and enablers to hospice referrals: An expert overview. *J Palliat Med* 2002;5:73-84.
14. Ogle KS, Mavis B, Wyatt GK: Physicians and hospice care: Attitudes, knowledge, and referrals. *J Palliat Med* 2002;5:85-92.
15. Sanders BS, Burkett TL, Dickinson GE, Tournier RE: Hospice referral decisions: the role of physicians. *Am J Hosp Palliat Care* 2004;21:196-202.
16. Brickner L, Scannell K, Marquet S, Ackerson L: Barriers to hospice care and referrals: Survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization. *J Palliat Med* 2004;7:411-418.
17. Miyashita M, Hirai K, Morita T, Sanjo M, Uchitomi Y: Barriers to referral to inpatient palliative care units in Japan: A qualitative survey with content analysis. *Support Care Cancer* 2008;16:217-222.
18. Hu W-Y, Chiu T-Y, Cheng Y-R, Chuang R-B, Chen C-Y: Why Taiwanese hospice patients want to stay in hospital: Healthcare professionals' beliefs and solutions. *Support Care Cancer* 2004;12:285-292.
19. Sepulveda C, Marlin A, Yoshida T, Ulrich A: Palliative Care: the World Health Organization's global perspective. *J Pain Symptom Manage* 2002;24:91-96.
20. Morita T, Akechi T, Ikenaga M, Kizawa Y, Kohara H, Mukaiyama T, Nakaho T, Nakashima N, Shima Y, Matsubara T, Uchitomi Y: Late referrals to specialized palliative care service in Japan. *J Clin Oncol* 2005;23:2637-2644.
21. Sanjo M, Miyashita M, Morita T, Hirai K, Kawa M, Uchitomi Y: Perception of specialized inpatient palliative care: A population-based survey in Japan. *J Pain Symptom Manage* 2008;35:275-282.
22. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA: Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA* 2000;284:2476-2482.
23. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V: Family perspectives on end-of-life care at the last place of care. *JAMA* 2004;291:88-93.
24. Hirai K, Morita T, Kashiwagi T: Professionally perceived effectiveness of psychosocial interventions for existential suffering of terminally ill cancer patients. *Palliat Med* 2003;17:688-694.

Address reprint requests to:

Mitsunori Miyashita, R.N.

Department of Adult Nursing/Palliative Care Nursing

School of Health Sciences and Nursing

Graduate School of Medicine

The University of Tokyo

7-3-1, Hongo

Bunkyo-ku 113-0033

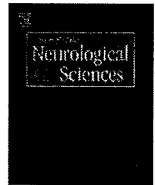
Japan

E-mail: miyashita-ty@umin.net



Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: [www.elsevier.com/locate/jns](http://www.elsevier.com/locate/jns)

## Care burden and depression in caregivers caring for patients with intractable neurological diseases at home in Japan<sup>☆</sup>

Mitsunori Miyashita<sup>a,\*</sup>, Yugo Narita<sup>b</sup>, Aki Sakamoto<sup>c</sup>, Norikazu Kawada<sup>d</sup>, Miki Akiyama<sup>c</sup>, Mami Kayama<sup>e</sup>, Yoshimi Suzukamo<sup>f</sup>, Shunichi Fukuhara<sup>g</sup>

<sup>a</sup> Department of Adult Nursing/Palliative Care Nursing, School of Health Science and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

<sup>b</sup> Medical Care Networking Centre, Mie University Hospital, Mie University, Mie, Japan

<sup>c</sup> Department of Psychiatric Nursing, School of Health Science and Nursing, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan

<sup>d</sup> Department of Neurology, Matsusaka Chuo General Hospital, Mie, Japan

<sup>e</sup> Department Psychiatric Nursing, St. Luke's College of Nursing, Tokyo, Japan

<sup>f</sup> Department of Physical Medicine and Rehabilitation, Tohoku University Graduate School of Medicine, Miyagi, Japan

<sup>g</sup> Department of Epidemiology and Healthcare Research, School of Public Health, Kyoto University, Kyoto, Japan

### ARTICLE INFO

#### Article history:

Received 1 April 2008

Received in revised form 12 September 2008

Accepted 16 September 2008

Available online 26 October 2008

#### Keywords:

Neurological disease

Care burden

Depression

Parkinson disease

Spinocerebellar degeneration

Multiple system atrophy

Amyotrophic lateral sclerosis

### 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.

© 2008 Elsevier B.V. All rights reserved.

### 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

<sup>☆</sup> *Disclosure:* This study was supported by a grant from the Ministry of Health, Labor, and Welfare of Japan for the study of “Outcomes Research of Specific Diseases.” We have no conflict of interest regarding this research.

\* Corresponding author. Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, 7-3-1 Hongo, Bunkyo-ku, Tokyo 113-0033, Japan. Tel.: +81 3 5841 3507; fax: +81 3 5841 3502. E-mail address: [miyasita-tky@umin.net](mailto:miyasita-tky@umin.net) (M. Miyashita).



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 <sup>a</sup>	
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

<sup>a</sup> 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

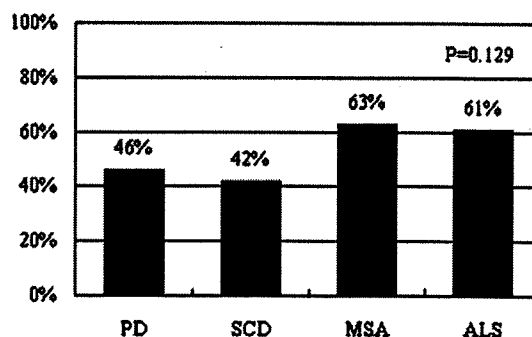
Before implementing this study, the ethical and scientific validity was approved by ethics committees at Mie University Hospital in

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

	Regression coefficient	Standard error	P value
<b>Time-dependent burden (<math>R^2=0.442</math>)</b>			
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
<b>Emotional burden (<math>R^2=0.133</math>)</b>			
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
<b>Existential burden (<math>R^2=0.171</math>)</b>			
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
<b>Physical burden (<math>R^2=0.425</math>)</b>			
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
<b>Service-related burden (<math>R^2=0.056</math>)</b>			
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
<b>Total care burden (<math>R^2=0.379</math>)</b>			
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
<b>BIC total (<math>R^2=0.399</math>)</b>			
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.

## Acknowledgments

This study was supported by a grant from the Ministry of Health, Labor, and Welfare in Japan for the study "Outcomes Research of

Specific Diseases" (PI: S. Fukuhara). We express our appreciation to Sayumi Tanide, Department of Health and Welfare, Mie Prefectural Government, for survey planning.

## References

- [1] Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20(6):649–55.
- [2] Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. [see comment]. *JAMA* 1999;282(23):2215–9.
- [3] Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983;38(3):344–8.
- [4] Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist* 1989;29(6):798–803.
- [5] Given CW, Given B, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Res Nurs Health* 1992;15(4):271–83.
- [6] Hooker K, Monahan DJ, Bowman SR, Frazier LD, Shifren K. Personality counts for a lot: predictors of mental and physical health of spouse caregivers in two disease groups. *J Geront, Ser B Psychol Sci Soc Sci* 1998;53(2):P73–85.
- [7] Arai Y, Sugiura M, Miura H, Washio M, Kudo K. Undue concern for others' opinions deters caregivers of impaired elderly from using public services in rural Japan. *Int J Geriatr Psychiatry* 2000;15(10):961–8.
- [8] Sorensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 2002;42(3):356–72.
- [9] Arai Y, Zarit SH, Sugiura M, Washio M. Patterns of outcome of caregiving for the impaired elderly: a longitudinal study in rural Japan. *Aging & Mental Health* 2002;6(1):39–46.
- [10] Chou K-R, Jiann-Chyun L, Chu H. The reliability and validity of the Chinese version of the caregiver burden inventory. *Nurs Res* 2002;51(5):324–31.
- [11] Arai Y. Family caregiver burden in the context of the long-term care insurance system. *J Epidemiol* 2004;14(5):139–42.
- [12] Arai Y, Kumamoto K, Washio M, Ueda T, Miura H, Kudo K. Factors related to feelings of burden among caregivers looking after impaired elderly in Japan under the Long-Term Care insurance system. *Psychiatry Clin Neurosci* 2004;58(4):396–402.
- [13] Caap-Ahlgren M, Dehlin O. Factors of importance to the caregiver burden experienced by family caregivers of Parkinson's disease patients. *Aging—Clinical & Exp Res* 2002;14(5):371–7.
- [14] Thommessen B, Aarsland D, Braekhus A, Oksengaard AR, Engedal K, Laake K. The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease. *Int J Geriatr Psychiatry* 2002;17(1):78–84.
- [15] Pinquart M, Sorensen S. Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta-analysis. *J Geront, Ser B Psychol Sci Soc Sci* 2003;58(2):P112–128.
- [16] Pirraglia PA, Bishop D, Herman DS, Elizabeth T, Lopez RA, Torgersen CS, et al. Caregiver burden and depression among informal caregivers of HIV-infected individuals. *J Gen Intern Med* 2005;20(6):510–4.
- [17] Kim Y, Duberstein PR, Sorensen S, Larson MR. Levels of depressive symptoms in spouses of people with lung cancer: effects of personality, social support, and caregiving burden. *Psychosomatics* 2005;46(2):123–30.
- [18] Grov EK, Fossa SD, Tonnesen A, Dahl AA. The caregiver reaction assessment: psychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. *Psychooncology* 2006;15(6):517–27.
- [19] Rochette A, Desrosiers J, Bravo G, Tribble DS-C, Bourget A. Changes in participation level after spouse's first stroke and relationship to burden and depressive symptoms. *Cerebrovasc Dis* 2007;24(2–3):255–60.
- [20] Rivera P, Elliott TR, Berry JW, Grant JS, Oswald K. Predictors of caregiver depression among community-residing families living with traumatic brain injury. *Neurorehabilitation* 2007;22(1):3–8.
- [21] Ushikubo M, Kawamura S, Inaba Y, Shima C, Nakamura T. [Characteristics of home care patients with intractable neurological diseases (Nanbyo) in Tokyo]. *Nippon Koshu Eisei Zasshi — Jpn J Public Health* 1998;45(7):653–63.
- [22] Ushigome M, Ezawa K, Ogura A, Kawamura S, Hirose K. [Factors in continuation of home health care for patients with intractable neurological diseases]. *Nippon Koshu Eisei Zasshi — Jpn J Public Health* 2000;47(3):204–15.
- [23] Aarsland D, Andersen K, Larsen JP, Lolk A, Nielsen H, Kragh-Sorensen P. Risk of dementia in Parkinson's disease: a community-based, prospective study. *Neurology* 2001;56(6):730–6.
- [24] Edwards NE, Scheetz PS. Predictors of burden for caregivers of patients with Parkinson's disease. *J Neurosci Nurs* 2002;34(4):184–90.
- [25] Gelinus DF, O'Connor P, Miller RG. Quality of life for ventilator-dependent ALS patients and their caregivers. *J Neurol Sci* 1998;160(Suppl 1):S134–136.
- [26] Jenkinson C, Fitzpatrick R, Swash M, Peto V, Group AHS. The ALS Health Profile Study: quality of life of amyotrophic lateral sclerosis patients and carers in Europe. *J Neurol* 2000;247(11):835–40.
- [27] Akiyama MO, Kayama M, Takamura S, Kawano Y, Ohbu S, Fukuhara S. A study of the burden of caring for patients with amyotrophic lateral sclerosis (MND) in Japan. *Br J Neurosci Nurs* 2006;2(1):38–43.
- [28] Rabkin JG, Wagner GJ, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. *Psychosom Med* 2000;62(2):271–9.
- [29] Gauthier A, Vignola A, Calvo A, Cavallo E, Moglia C, Sellitti L, et al. A longitudinal study on quality of life and depression in ALS patient-caregiver couples. *Neurology* 2007;68(12):923–6.
- [30] Smith CO, Lipe HP, Bird TD. Impact of presymptomatic genetic testing for hereditary ataxia and neuromuscular disorders. [see comment]. *Arch Neurol* 2004;61(6):875–80.
- [31] Sjostrom A-C, Holmberg B, Strang P. Parkinson-plus patients—an unknown group with severe symptoms. *J Neurosci Nurs* 2002;34(6):314–9.
- [32] Miyashita M, Yamaguchi A, Kayama M, Narita Y, Kawada N, Akiyama M, et al. Validation of the Burden Index of Caregivers (BIC), a multidimensional short care burden scale from Japan. *Health Qual Life Outcomes* 2006;4:52.
- [33] Radloff L. The CES-D scale: a self report depression scale for research I the general population. *Appl Psychol Meas* 1977;1:385–401.
- [34] Shima S, Shikano T, Kitamura T, Asai M. Reliability and validity of CES-D (Atarashii yokuutsusyukado ni tsuite). *Jpn J Psych (Seishinigaku)* 1985;27:717–23.