

Figure 1. Participating areas of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study are shown with the resident population number.

Table 2. Interventions of the Outreach Palliative Care Trial of Integrated Regional Model Study

Target Area	Intervention	Main Contents
Lack of standardized clinical tools	To standardize and improve the knowledge, skills, and continuity of palliative care in the community	Dissemination of standardized clinical tools via printed and Web materials Interactive workshop and on-demand Web lectures Contents Assessment tools Treatment algorithm Education materials for patients and family members Patient-held records Discharge planning program
Lack of knowledge about palliative care by the general public, patients and their family	To provide appropriate information about palliative care	Distribution of materials via hospitals, Web, visits, patient library, symposia, and local mass-media Materials Leaflets and posters DVDs Books
Lack of whole-region organization to coordinate community palliative care	To establish regional palliative care centers to coordinate community palliative care	Coordination and information service about palliative care services for community residents Regional conference to create local networks and identify local problems Community palliative care team Educational outreach
Specialized palliative care services less available in community	To increase availability of specialized palliative care services for community patients	

Abbreviation: DVD, digital video disc.

the Support Team Assessment Schedule), (2) 3-step ladder-based symptom control algorithm for 9 leading symptoms, (3) educational materials for patients and families, (4) patient-held records, and (5) discharge planning program with a discharge conference as an essential part.

Outcome Measures

Primary end points are quality of palliative care as reported both by patients and the bereaved family, the number of patients who received specialized palliative care services, and place of death. The quality of palliative care is measured by the Care Evaluation Scale, a validated tool to quantify user-perceived quality of care.²⁸

Secondary outcome measures include knowledge, competency, and difficulties of regional physicians and nurses, and quality indicators of regional palliative care, including opioid consumption and the number of nursing agencies providing around-the clock services.

Conclusion

Palliative care in Japan is rapidly progressing through multiple nationwide actions with support from the Cancer Control Act. Palliative care specialists will overcome the challenges and grasp this unique opportunity in cooperation with other specialties to disseminate quality palliative care throughout Japan. The OPTIM study has received much attention and will contribute to improving patient quality of life by proposing a regional palliative care model suitable for Japan. The OPTIM study will be completed in March 2011, and initial results are expected in mid-2012.

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

Mitsunori Miyashita, RN, PhD, Tatsuya Morita, MD, Satoru Tsuneto, MD, PhD, Kazuki Sato, RN, MHLthSci, and Yasuo Shima, MD

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

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

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

In Japan, the Ministry of Health, Labor, and Welfare has strongly supported the dissemination of specialized palliative care services, with coverage of palliative care units (PCUs) by National Medical Insurance since 1990. The number of PCUs has dramatically increased from 5 in 1990 to 175 in 2007. In contrast, the growth of home hospice has been slow; inpatient palliative care teams were not

covered by National Medical Insurance until 2002. Therefore, the most common type of specialized palliative care service in Japan is the PCU.¹⁻³

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

From the Department of Adult Nursing/Palliative Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, University of Tokyo, Tokyo (MM, KS), Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, Shizuoka (TM), Department of Palliative Medicine, Osaka University Graduate School of Medicine, Osaka (ST), and Department of Palliative Medicine, Tsukuba Medical Center Hospital, Ibaraki (YS), Japan.

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Address correspondence to: Dr Mitsunori Miyashita, RN, PhD, 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; e-mail: miyasita-ky@umin.net.

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

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

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

Methods

Participating Institutions

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

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

Study Design

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

Questionnaires

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

Common Questionnaires

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

Place of death

Questionnaires

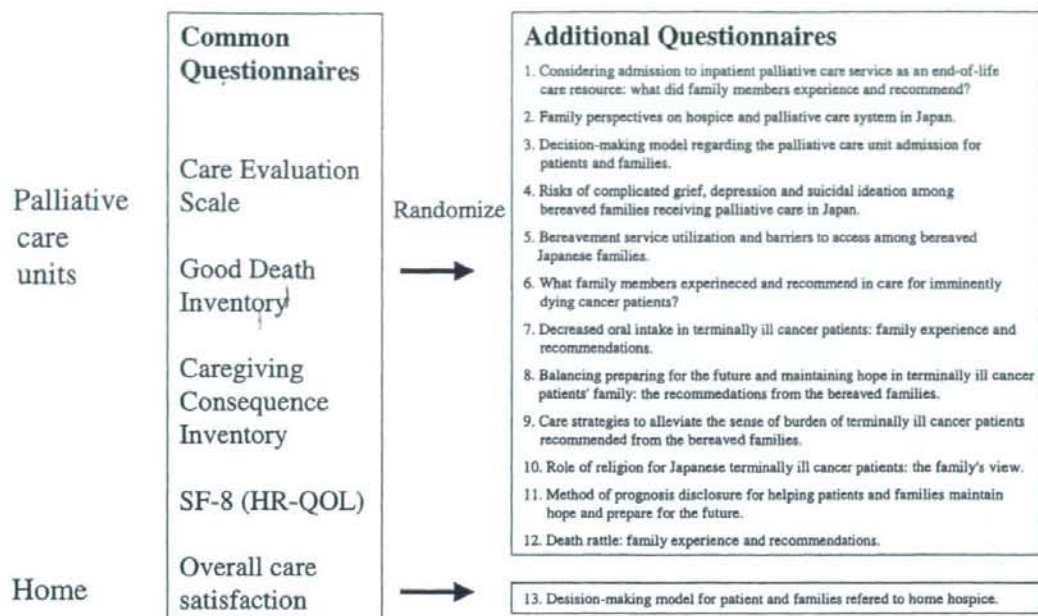


Figure 1. Contents of questionnaire of J-HOPE study.

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

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

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

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

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

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

Subject Characteristics

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

Additional Questionnaires

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

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

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

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

Ethical Consideration

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

Results

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

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

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

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

(continued)

Table 1. (continued)

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

Note: PCU; palliative care unit.

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

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

Discussion

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

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

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

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

Note: PCU; palliative care unit.

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

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

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

Table 4. Bereavement Care for the Family Members

	PCU		Home Hospice	
	n	%	n	%
Regular meetings for the bereaved				
For all bereaved	65	65	5	36
For a portion of bereaved	13	13	3	21
None	22	22	6	43
Communication after death by mail				
For all bereaved	78	78	4	29
For a portion of bereaved	15	15	7	50
None	7	7	3	21
Communication after death by phone				
For all bereaved	9	9	3	21
For a portion of bereaved	59	59	8	57
None	32	32	3	21
Participation in funerals				
For all bereaved	2	2	9	64
For a portion of bereaved	61	61	5	36
None	37	37	0	0
Other				
For all bereaved	91	91	10	71
For a portion of bereaved	9	9	4	29
None	0	0	0	0

Note: PCU; palliative care unit.

variables, such as number of physicians and nurses, comedicals, percentage of private rooms, percentage of charge-free private room, number of admitted patients per year, number of deaths per year, and average hospitalized days, there were different features in the Japanese PCUs.

The information obtained from this study comprises initial data on home hospice care in Japan. Of note, the number of cancer deaths at home varied from 4 to 193 among institutions. We know that there are several large-scale home hospices in Japan. One of them participated in this study. We also know that they have different features compared with PCUs. In addition, 93% of them provided around-the-clock care by physicians and/or nurses. Around-the-clock care is necessary for cancer patients and is one of the barriers to dissemination of home hospice in Japan.²¹ Moreover, the home death rate is 6% for cancer patients in Japan. Therefore, cooperation with general inpatient wards and inpatient PCUs is important for relieving the family caregiver's burden.

We obtained information on available treatments in the PCUs and home hospices. Some variability exists among the PCUs. However, other treatments, such as oral chemotherapy, radiation

therapy, and nerve block, also varied among hospices. Although availability of treatments might depend on the institution's equipment, it is important to understand the Japanese health insurance system. In 1990, PCUs were institutionalized by the medical system. However, the payment system for PCUs was the Prospective Payment System (PPS). In 2005, the medical service fee for 1 patient per day was 37 800 Yen (\$315) regardless of actual medical treatment. Therefore, in some PCUs, cost of treatment was higher than on the general wards. In addition, the philosophy of PCUs might have affected the available treatment. In some PCUs, cure-oriented treatment may have been withheld. Detailed descriptions of medical treatment in the PCUs, including analgesia, surgical procedures, and alternative therapies, have been described in another article.²²

The majority of home hospices provided intravenous hydration (93%), intravenous hyperalimentation (79%), oral chemotherapy (71%), and pleurocentesis and paracentesis (64%). In addition, surgery (78%), intravenous chemotherapy (85%), radiation therapy (79%), nerve block (99%), and physiotherapy (71%) were available in hospice or the patients were referred to hospitals. In other words, these treatments were considered necessary components of home hospice.

Matsushima surveyed bereavement services provided by 50 PCUs in 1999.²³ Matsushima reported that 84% of PCUs sent memorial cards, 59% conducted memorial services, 35% held social group meetings, and 32% contacted the bereaved by telephone.²³ In our study, 93% communicated by mail with the bereaved after discharge and 78% held regular meetings. During 6 years, bereavement care services have progressed in Japan. As for home hospice, our survey was the first study in this field. It is interesting to note that 64% of them participated in funerals for all deceased patients, and the remaining 36% participated for some of the deceased patients. In addition, more hospices communicated after death by phone; 78% of the PCUs communicated by mail. These results suggest that home hospice builds closer relationships with family members than do PCUs.

The major outcomes and additional results will be presented in subsequent articles. In addition, we now plan further research on bereaved family members from Japanese nationwide regional cancer centers. We would like to compare the quality of end-of-life care among PCUs, home hospices, and regional cancer centers in the near future.

Conclusions

We described the design of the J-HOPE study for bereaved family members of Japanese PCU and home hospice patients. One hundred PCUs and 14 home hospices participated in this survey; 7955 questionnaires were sent to bereaved family members of PCU patients and 447 families of home hospices patients. In addition, we acquired valuable information on the participant institutions' characteristics regarding structure of care, available treatments, and bereavement care for family members. The information obtained by this study is the first data of its kind on home hospices in Japan.

Appendix A Short Version of the Care Evaluation Scale

1. Doctors dealt promptly with discomforting symptoms of the patient.
2. Nurses had adequate knowledge and skills.
3. The staff tried to bolster the patient's hope.
4. The doctors gave sufficient explanation to the patient about the expected outcome.
5. The doctors gave sufficient explanation to the family about the expected outcome.
6. The patient's room/home environment was convenient and comfortable.
7. Consideration was given to the health of the family.
8. The total cost was reasonable.
9. Admission (use) was possible when necessary without waiting.
10. There was good cooperation among staff members, such as doctors and nurses.

Appendix B Short Version of the Good Death Inventory

1. Patient was free from physical distress.
2. Patient was able to stay at his or her favorite place.
3. Patient had some pleasure in daily life.
4. Patient trusted the physician.
5. Patient was not being a burden to others.
6. Patient spent enough time with his or her family.
7. Patient was independent in daily activities.
8. Patient lived in calm circumstances.
9. Patient was valued as a person.
10. Patient felt that his or her life was completed.
11. Patient received enough treatment.
12. Patient died a natural death.

(continued)

Appendix B (continued)

13. Patient was able to say what he or she wanted to dear people.
14. Patient knew what to expect about his or her condition in the future.
15. Patient lived as usual without thinking about death.
16. Patient felt burden of exposing his or her physical and mental weakness to family.
17. Patient felt that his or her life is worth living.
18. Patient was supported by religion.

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CASE REPORT

A case of respiratory akathisia in a cancer patient: A case report

YU SUNAKAWA, M.D.,¹ MAKOTO WADA, M.D.,² TOMOMI NISHIDA, M.D.,² MEI WADA, C.P.,²
KAZUHIRO ARAKI, M.D.,¹ HISASHI ENDO, M.D.,¹ FUMIO NAGASHIMA, M.D.,¹
WATARU ICHIKAWA, M.D.,¹ TOSHIMICHI MIYA, M.D.,¹ HIDEKI ONISHI, M.D. PH.D.,²
MASARU NARABAYASHI, M.D. PH.D.,^{1,3} AND YASUTSUNA SASAKI, M.D. PH.D.¹

¹Department of Clinical-Oncology, Comprehensive Cancer Center, Saitama Medical University International Medical Center, Saitama, Japan

²Department of Psycho-Oncology, Comprehensive Cancer Center, Saitama Medical University International Medical Center, Saitama, Japan

³Department of Palliative Medicine, Comprehensive Cancer Center, Saitama Medical University International Medical Center, Saitama, Japan

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ABSTRACT

Objective: It has been reported that akathisia is a neurological side effect induced by antiemetic drugs and/or antipsychotics. Akathisia can occur in any area of the body, but respiratory akathisia is an unusual type of akathisia. Cases of respiratory akathisia in cancer patients taking antiemetic drugs have not previously been reported.

Methods: We report on a case of a cancer patient taking prochlorperazine as an antiemetic drug who experienced dyspnea accompanied by severe restlessness associated with respiration. By administration of biperiden, his restlessness in respiration and dyspnea promptly disappeared.

Results: This finding led us to conclude that this cancer patient was experiencing respiratory akathisia.

Significance of results: Respiratory akathisia is uncommon. It is important for cancer patients that dyspnea induced by disease progression be ruled out as a cause of the respiratory restlessness. It is necessary to consider the possibility of akathisia in patients that complain of vague anxiety, chest discomfort, or dyspnea following antipsychotic medication.

KEYWORDS: Respiratory akathisia, Cancer, Antiemetic drug

INTRODUCTION

Akathisia is a neurological side effect produced by antipsychotic or antiemetic drug therapy (Blaisdell, 1994). The clinical picture of akathisia is a feeling of inner restlessness in the limbs, especially in the legs (Gibb & Lee, 1986). However, reports have indicated that akathisia can occur in any area of the body,

such as the arms or abdomen (Raskin, 1972; Ratey & Salzman, 1984; Walters et al., 1989). A rare manifestation of akathisia reported by patients receiving antipsychotic treatment is an inner restlessness in respiration as dyspnea.

Prochlorperazine is an antiemetic agent frequently used by cancer patients taking opioids (e.g., morphine, oxycodone) for cancer pain. In oncological settings, prochlorperazine is used as an antiemetic drug for nausea, a side effect of opioid. It is a phenothiazine antiemetic that has central dopamine antagonist properties and that has been reported to cause acute extrapyramidal side effects,

Address correspondence and reprint requests to: Yu Sunakawa, Department of Clinical-Oncology, Comprehensive Cancer Center, Saitama Medical University International Medical Center, 1397-1 Yamane, Hidaka, Saitama, 350-1298, Japan. E-mail: yu_s@saitama-med.ac.jp

parkinsonism, dystonia, and akathisia (Bateman et al., 1989). It is well known that neuroleptic-induced akathisia may be difficult to recognize and can occur in the absence of other extrapyramidal signs. Furthermore, cases of akathisia due to antiemetic drugs used by cancer patients have been little reported.

CASE REPORT

The patient was an 66-year-old man with squamous cell carcinoma of the esophagus, stage II(T2N0M0). Due to his renal impairment and the presence of emphysema, surgical resection was not performed; furthermore, chemotherapy was not indicated. Therefore, he attempted radiation therapy and received a total dose of 70.2 Gy. He used opioid, 20 mg/day of morphine hydrochloride, for pain of esophagitis by irradiation, with taking prochlorperazine as an antiemetic drug. He complained of chest discomfort after receiving 5 mg/day of prochlorperazine p.o. for 3 weeks and was admitted to the hospital. When he arrived in the hospital, he acknowledged dyspnea with vague anxiety and a subjective restlessness in respiration, with a temperature of 36.8°C, blood pressure of 118/72 mm Hg, pulse 79 beats/min, respiratory rate 18 breaths/min. Resting room-air oxygen saturation was 98%. First, radiation pneumonitis was suspected, but chest X-ray was normal. He felt that he could not respire leisurely nor stop breathing at any time because of this restlessness in respiration. He denied restlessness in the limbs or other body areas except for the chest. He showed no signs or symptoms of parkinsonism. He was administered 5 mg of biperiden d.i.v.; his restlessness in respiration and dyspnea simultaneously disappeared approximately 1 h later (Hirose & Ashby, 2000). Subsequently, 6 mg of oral biperiden was added to the treatment regimen. The next day, the dyspnea with vague anxiety and other restless movements completely ceased. No signs or symptoms of akathisia have appeared in this patient since that time.

DISCUSSION

We reported respiratory akathisia in cancer patients taking prochlorperazine as antiemetics. This is the first report of respiratory akathisia recognized in cancer patients.

It was necessary that other medical problems known to produce dyspnea, such as panic attacks and dyskinesia and dystonia or pulmonary diseases, could be ruled out as a cause of the respiratory restlessness (Hirose, 2000). In this case, the patient did not have anxiety about dying or a history of panic disorder before. Respiratory dyskinesia presents

as involuntary movements of respiratory muscles, but not as a restless feeling in respiration, and is not improved on treatment with biperiden (Kruk et al., 1995; Esmail et al., 1999; Heard et al., 1999). Furthermore, in this case, dystonia was ruled out by the absence of tonic contractions of respiratory muscles (Dressler & Benecke, 2005).

Respiratory akathisia is uncommon, so one needs to ask specific questions about restlessness in breathing to recognize this type of akathisia. Therefore, if physicians is not aware of inner restlessness in respiration, it is possible that dyspnea in akathisia may be overlooked or misdiagnosed as a symptom of anxiety disorders, agitation, or respiratory symptoms of cancer itself (Hirose, 2000).

Antiemetics possessing a central antidopaminergic effect are suspected to have caused the akathisia (Seeman, 2002; Matsui-Sakata et al., 2005). Antiemetic-induced akathisia has been reported in cancer patients receiving metoclopramide or prochlorperazine to help control chemotherapy-related nausea and vomiting (Fleishman et al., 1994; Tsuji et al., 2006). In this case, prochlorperazine was used as an antiemetic drug for nausea and vomiting, a side effect of opioid.

Prochlorperazine is a phenothiazine antiemetic that has central dopamine antagonistic properties. It has been reported that the presumed community standard of prescribing prochlorperazine, dexamethasone, or a 5HT₃ receptor antagonist after moderately high to highly emetogenic chemotherapy results in equivalent outcomes in terms of control of vomiting and measures of satisfaction and quality of life (Burriss et al., 1996; Crucitt et al., 1996).

In Japan, many cancer patients taking opioids for cancer pain clinically use prochlorperazine as an antiemetic drug. Therefore, it should be noted that akathisia is considered a possible side effect during the management of cancer pain.

The clinicians' attitude toward akathisia is important to recognize. It is also important to consider the possibility of akathisia in patients that complain of vague anxiety, chest discomfort, or dyspnea following antipsychotic medication.

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CASE REPORT

Activation syndrome caused by paroxetine in a cancer patient

TOMOMI NISHIDA, M.D.,¹ MAKOTO WADA, M.D.,¹ MEI WADA, C.P.,¹ HIROSHI ITO, M.D.,²
MASARU NARABAYASHI, M.D., PH.D.,² AND HIDEKI ONISHI, M.D., PH.D.¹

¹Department of Psycho-oncology, Saitama Medical University International Medical Center, Saitama, Japan

²Department of Palliative Medicine, Saitama Medical University International Medical Center, Saitama, Japan

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ABSTRACT

Individuals with cancer have two to four times an increased risk of depressive disorders compared to the general population. Depressive symptoms are related to impaired daily life functioning and a rise in health care utilization. Pharmacological treatments for depression are usually effective to reduce depressive symptoms, but sometimes lead to serious adverse reactions. We describe a cancer patient who developed sudden psychological and behavioral abnormalities after administration of the antidepressant paroxetine. Impulsive and aggressive symptoms are a so-called activation syndrome that can cause violent or suicidal tendencies. Palliative care staff should pay close attention to these potentially lethal reactions and make an immediate and correct diagnosis.

KEYWORDS: Activation syndrome, Selective serotonin reuptake inhibitors (SSRIs), Paroxetine, Cancer, Akathisia

INTRODUCTION

Recent reports have confirmed that selective serotonin reuptake inhibitors (SSRIs) cause adverse mental and behavioral reactions, so-called activation syndrome (Teicher et al., 1990; Breggin, 2003/2004). We describe a cancer patient who developed activation syndrome soon after receiving an SSRI, paroxetine.

CASE REPORT

A 60-year-old man was admitted to our cancer center for treatment of abdominal pain. The patient had been diagnosed with pancreas cancer 18 months previously and had received three courses of chemotherapy without success. The primal lesion in the pancreas had invaded the para-aortic lymph nodes,

causing severe abdominal pain. He had been taking acetaminophen, morphine sulfate, and H2-blocker before and after admission without any adverse side effects. His hepatic and renal functions were well preserved. There was no clinical evidence of brain metastasis or neurological abnormality. He had never experienced a psychotic episode, although he had previously been quite sensitive and anxious about his physical condition. Other symptoms included hopelessness and passive suicidal thoughts due to unbearable pain without any suicidal attempts. The next day after admission, these complaints abated as he realized that his pain could be well controlled with intravenous administration of morphine chloride. His pain was finally well controlled with oral morphine sulfate on day 18 after admission. Nevertheless, he complained of several other symptoms, including depressive mood, anhedonia (he had no interest in investments although he used to be an ambitious shareholder), general fatigue, psychomotor retardation and insomnia.

Address correspondence and reprint requests to: Tomomi Nishida, Department of Psycho-oncology, Saitama Medical University International Medical Center, 1397-1 Yamane, Hidaka city, Saitama 350-1298, Japan. E-mail: t-nishida@saitama-med.ac.jp

Based on the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR), he was diagnosed with major depressive disorder by a psycho-oncologist. He was started on paroxetine 10 mg/day. The day after beginning paroxetine treatment (day 19 after admission), he became talkative and laughed frequently in conversation with his family. On day 2 after beginning administration, he appeared more outgoing and hyperactive (he went home, cooked, and did household chores, and came back to the hospital late at night). On day 3, he insisted on going to a hot spring instead of receiving cancer treatment. He had never showed such behavior before. In the morning on day 4, he abruptly complained of inner restlessness and inability to keep his feet still. He screamed incoherent bizarre ideas and expressed a strong urge to harm himself ("I want to stab my limbs or jump out of the window"). He appeared extremely agitated and showed akathisia-like movements of rocking his feet and head.

Paroxetine treatment was discontinued and levomepromazine (LPZ) was administered for 2 days (25 mg on that day and 15 mg the next day). His subjective complaints of mental and physical restlessness improved several hours after LPZ administration, but he still made inappropriate jokes and aggressive statements the next day. On day 3 after stopping paroxetine, he was quite calm but had a short episode of hyperventilation. His objective stimulated mental symptoms were alleviated 4 days after paroxetine was stopped. Over 1 month after the discontinuation of paroxetine, the patient made a full recovery from the stimulated state and was also free from the major depressive disorder.

DISCUSSION

Although abnormal psychomotor and behavioral conditions have been observed with SSRIs, to our knowledge, this is the first report of so-called activation syndrome in a cancer patient. In the issued advisory by the U.S. Food and Drug Administration, "activation" includes the following symptoms: irritability, anxiety, agitation, insomnia, panic attacks, hostility, impulsiveness, akathisia (severe restlessness occasionally leading to suicidal thoughts and attempts), hypomania, and mania. We would like to draw attention to this potentially lethal drug reaction. Depression is quite common during cancer treatment (Rodin et al., 2007) and SSRIs are more likely to be prescribed to cancer patients because of their fewer cardiovascular side effects compared to classic tricyclic antidepressants (MacGillivray et al., 2003).

On the other hand, several adverse reactions related to SSRIs have been reported, ranging from gastrointestinal symptoms, serotonin syndrome, and activation syndrome to suicidal thoughts and violent behavior (Wagstaff et al., 2002). Unfortunately, abnormal psychotic conditions are often under- and misdiagnosed in cancer treatment settings due to the difficulty of arranging psychiatric consultations (Culpepper et al., 2004); however, it is crucial for clinicians to be aware of the clinical features of activation syndrome because of easier opportunities for self-harm in general hospitals compared to psychiatric wards. In fact, our case would have jumped out of the hospital window if his family had not been with him.

It is also important to make a correct diagnosis of activation and to distinguish it from worsening depression, which could lead to an increased dose of the inappropriate medication and worsen the condition. In previous reports, beta-adrenergic blockers and/or benzodiazepines are usually recommended for the management of SSRI-induced akathisia (Leo, 1996). Our patient required a major tranquilizer to control the intense impulse to self-harm. Although the underlying mechanisms of SSRI-induced akathisia remain uncertain, previous studies have suggested their possible pathophysiology (Lipinski et al., 1989). Our case showed immediate alleviation of the inner restlessness and characteristic leg movement after oral LPZ administration, which implies a different pathomechanism of akathisia between neuroleptics and SSRIs.

In summary, we experienced a cancer patient with paroxetine-induced activation syndrome. Not only oncologists but also staff who participate in palliative care medicine should be attentive to possible adverse mental and behavioral reactions during antidepressant treatment. These symptoms sometimes persist after discontinuation of SSRI and need additional treatment. The effects of neuroleptics on SSRI-induced akathisia may have some implications for their pathophysiological assessment.

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Psychosocial factors and survival after diagnosis of inoperable non-small cell lung cancer

Tatsuo Akechi^{1,2}, Hitoshi Okamura^{2,3}, Toru Okuyama^{1,2}, Toshiaki A. Furukawa¹, Yutaka Nishiwaki⁴ and Yosuke Uchitomi^{2*}

¹Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, Nagoya, Japan

²Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, Kashiwa, Japan

³Graduate School of Health Sciences, Hiroshima University, Hiroshima, Japan

⁴Thoracic Oncology Division, National Cancer Center Hospital East, Kashiwa, Japan

*Correspondence to: Psycho-Oncology Division, Research Center for Innovative Oncology, National Cancer Center Hospital East, 6-5-1 Kashiwanoha, Kashiwa 277-8577, Japan. E-mail: yuchitomi@east.ncc.go.jp

Abstract

Objective: Although several previous studies have investigated the association between psychosocial factors and the survival of lung cancer patients, most previous studies were flawed by severe methodological limitations. The purpose of the present study was to use a rigorous study design to investigate the association between relevant psychosocial factors and survival after a diagnosis of inoperable non-small cell lung cancer (NSCLC).

Methods: The subjects were 122 consecutive newly diagnosed patients with inoperable NSCLC. Patients coping with cancer, psychological distress, clinical depression, and social support were evaluated after diagnosis but before treatment and 2 months later. After a 2-year follow-up period, 108 patients had died. The survival data were censored for the remaining 14 patients. The influence of psychosocial factors after diagnosis but before treatment on survival time was analyzed using a Cox regression, with adjustments for well-established (definite and/or possible) prognostic factors. The stability of the investigated psychosocial factors was also examined.

Results: None of the examined psychosocial factors significantly predicted survival time among the patients with inoperable NSCLC. Among the biomedical factors that were examined, advanced clinical stage, a high serum lactate dehydrogenase level, and not receiving chemotherapy were independently associated with shorter survival periods. Most of the psychosocial factors exhibited a moderate to high stability.

Conclusions: We found little convincing evidence that psychosocial factors after cancer diagnosis had a clinically relevant effect on the survival of inoperable patients with NSCLC. Copyright © 2008 John Wiley & Sons, Ltd.

Keywords: coping; social support; survival; cancer; oncology

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Introduction

There is much interest in the association between the mind and body, and this is not exceptional in oncology settings, possibly because cancer is a potentially life-threatening disease and is often accompanied by major psychological distress. Actually, many professionals and the lay public believe that psychosocial factors play a major role in cancer onset and its progression [1,2]. On the other hand, although several previous studies have investigated the effects of psychosocial characteristics (including personality, coping, general psychological distress, depression, and social support) on survival, the influence of psychosocial factors on the survival of cancer patients remains controversial [1,3–5].

Lung cancer is the most common type of cancer and the most common cause of cancer-related death in the world [6,7]. In Japan, lung cancer is the

leading cause of death from cancer among men, and the incidence of lung cancer has been increasing in recent years [8]. In a study examining psychological distress and its relation to the site of cancer, primary lung cancer was strongly associated with psychological distress in cancer patients [9]. In addition, several previous studies have demonstrated that the highest prevalence of psychological distress was observed among patients with lung cancer [10,11]. Our previous study indicated that 19% of advanced lung cancer patients experienced diagnosable anxiety/depression between the time of diagnosis and initial treatment and that 35% of them continued to experience the same disorder for at least 6 months after diagnosis [12]. Thus, in general, psychological distress is highly prevalent among lung cancer patients; consequently, these psychosocial issues should not be neglected.