

interventions, and explore the predictors of successful and unsuccessful intervention. A significantly higher frequency of neural blocks occurred when the leading physician's specialty was anesthesiology. Pain intensity and opioid consumption were significantly lower in the neural block group within one week of the procedures. No improvement was seen in the Communication Capacity Scale, occurrence of delirium or performance status. Epidural nerve block, neurolytic sympathetic nerve block and intrathecal nerve block with phenol were the three most common procedures (12). Active participation of anesthesiologists in palliative care and relatively limited availability of types of opioid agonists may have contributed to the relatively high frequency of neural blocks and use of adjuvant analgesics. An example of the latter is the use of ketamine for difficult pain syndromes – such as neuropathic pain, incident pain or rapidly developing opioid tolerance – that fail to respond to available opioid agonists.

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Cancer pain – progress and ongoing issues in New Zealand

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The health care system of New Zealand is predominantly a National Health Care system, funded by the government, with some elements of private health care. Total health care spending is 9.3% of the gross domestic product, of which the state funds 78%. The average life expectancy is 79.9 years (Organisation for Economic Co-operation and Development statistical data). Despite being a small country, it has significant diversity in the health care environment, with a geographical mix of metropolitan and rural areas, and is multiethnic, particularly in the metropolitan areas. New Zealand has a national Palliative Care Strategy, first released in 2001, that has clear goals of providing services for all people who are dying and could benefit from palliative care. It has nine strategies that it will implement over a five- to 10-year period to achieve this (1). These include education of health care professionals, as well as raising community awareness of palliative care services. New Zealand also has a Cancer Control Strategy, which has a Palliative Care Working Party subgroup.

In New Zealand, cancer pain in advanced cancer is mainly managed by palliative care services in hospitals and hospices. Hospital palliative care teams are dependent on general practice and hospices to continue care and review pain and symptoms at home. Hospices are community organizations, mainly based on the St Christopher's Hospice model (London, United Kingdom). St Christopher's Hospice was founded by Dame Cicely Saunders, who first described the concept of total pain, which is comprised of physical, psychological, social and spiritual dimensions (2). Despite the clear direction from the Crown, through both the Maori Health Strategy and the Palliative Care Strategy (1,3), the challenge remains to deliver a service that reflects the demography and actual needs of local communities. In Auckland, this is reflected in the variable uptake of hospice services by different ethnic groups.

TABLE 1
Referrals to Mercy Hospice Auckland and ethnic mix of Auckland District Health Board (DHB) and New Zealand populations

	Hospice referral, %	Auckland DHB, %	New Zealand, %
European	74	66	80
Maori	4	8	15
Pacific peoples	9	13	7
Asian peoples	8	19	7
Other nations	3	2	0.5

Hospice services (and therefore specialist pain services) are not adequately reaching three major population groups, namely the Maori, Pacific and Asian peoples. Of these, the former two have attitudes and cultural expectations aligned to the traditional hospice model (holistic care, family focus, spiritual practice and desire to be cared for at home) whereas the Asian people have expectations of increasing intensity of care, often in an institutional setting. Attitudes toward use of opioids as analgesics vary among ethnic and cultural groups. Opioids tend to be less acceptable in traditional cultures, with

Original Article

Development of a Standard for Hospital-Based Palliative Care Consultation Teams Using a Modified Delphi Method

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Abstract

Although palliative care consultation teams are rapidly being disseminated throughout Japan as a result of government policy, the role of these teams has not been standardized. The aim of this study was to develop a hospital-based palliative care consultation team standard. We adopted a modified Delphi method to develop a standard. Twenty-seven multiprofessional panelists were selected according to two criteria: adequate experience as part of a palliative care consultation team and representative of 16 palliative care-related organizations. Panelists rated the appropriateness of 33 statements in a provisional standard, which was generated by the authors, using a nine-point Likert-type scale in a first-round survey. We set two criteria for agreement: the median value was 8 or more, and the difference between the minimum and maximum was 4 or less. There were 15 disagreements in the first-round survey. Based on discussions through e-mails and a panel meeting, these 15 statements were dealt with as follows: one was rejected, one was combined with another statement, three were unmodified, and 10 underwent minor revisions. Moreover, two statements that generated agreement were divided into two statements each. Consequently, the number of statements was 37. In a second-round survey, three statements engendered disagreement and were modified. At the end of the process, there were 37 statements in four areas: "philosophy and policy," "structure for care provision," "contents of activities," and "quality assurance and care improvements." This standard may be useful as a clinical

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Key Words

Palliative care, palliative care consultation team, standard, modified Delphi method, cancer

Introduction

There is increasing awareness of the suffering of patients with pain, other physical symptoms, and psychosocial distress.^{1,2} As a result, specialized palliative care services have proliferated worldwide.^{3–6} In Japan, the Ministry of Health, Labour, and Welfare has strongly supported the dissemination of specialized palliative care as a part of the National Cancer Program. Since National Medical Insurance started to cover inpatient palliative care units (PCUs) for terminal cancer patients in 1990, PCUs have been a dominant palliative care service. However, more than 90% of cancer deaths occur in general wards,⁷ and it has been reported that the care of cancer patients is inadequate.^{8–10} With the consideration of this situation, palliative care consultation services have been covered by National Medical Insurance since 2002, and it became mandatory for Regional Cancer Centers to establish palliative care consultation teams. The number of Regional Cancer Centers is now 351.¹¹

In this way, palliative care consultation teams are being rapidly disseminated as a result of government policy. However, the role of such teams has not been standardized. The government released only six statements regarding the entity of the palliative care consultation team:¹² 1) a palliative care consultation team should include a palliative care physician and nurse and provide specialized palliative care for cancer patients; 2) specialized palliative care can be provided at outpatient clinics; 3) the palliative care consultation team holds care meetings to discuss patient symptom management at least once a week; 4) sufficient information is provided to cancer patients; 5) the attending physician, nurses, and the palliative care consultation team provide patients with information and education regarding palliative care before discharge, collaborating with their home care doctor; and 6) a palliative

care network with other hospitals and home care agencies in the same region is established. Although a standard for palliative care developed by Hospice Palliative Care Japan exists,¹³ it originally targeted the activity of PCUs and it is not detailed enough for new palliative care consultation teams to understand what they should do.

In Western countries, where palliative care consultation teams were developed from the early 1990s, palliative care standards comprising a wide range of palliative care services have been proposed.^{14–17} However, it is inappropriate to apply them directly to Japan because of a different social background and health care system. Thus, Japan needs its own standard specific to palliative care consultation teams.

“Consultation” has been practiced in Japan, and the general style is for consultants to play a more direct role in referrals. Palliative care consultation, in contrast, remains the primary responsibility of the referring team, which provides advice and gives recommendations.¹⁸ Moreover, emotional and educational support for the referring team is also an important role of the palliative care consultation team, in addition to the addressing of patients’ problems.^{19,20} Therefore, consultation by a palliative care team crucially differs from conventional consultation. For a new palliative care consultation team to function effectively and smoothly, we need to provide guidance, including the concrete step of consultation. The aim of this study was to develop a hospital-based palliative care consultation team standard.

Methods

We adopted a modified Delphi method²¹ to develop a palliative care consultation team standard.

Development of a Provisional Standard

To develop a provisional standard, we adopted the following procedures: First, the authors discussed the basic assumption of this standard and decided that it should be a fundamental standard, designed to show new palliative care consultation teams what to do at the very least. The subject was cancer patients because palliative care in Japan mostly targets such patients presently, and we have insufficient clinical experience of palliative care for non-cancer patients. The concept of the Donabedian model was applied because this standard was expected to be used for evaluation as well, and the framework of the standard was referred to existing standards and manuals on palliative care.^{13-15,17,22} Second, one author (T. S.) generated statements in line with the framework based on a literature review.^{6,13-15,17,22-29} Third, the authors discussed the appropriateness and coverage of the statements to reach a consensus regarding validity and then the provisional standard was formulated, consisting of four domains and 33 statements.

Expert Panel Selection

As there are no universally accepted criteria for the selection of experts using this method,³⁰ we selected expert panelists to create a multiprofessional panel based on the following criteria: 1) clinicians with adequate experience as part of a palliative care consultation team and 2) representatives of palliative care-related organizations.

Criterion 1. From the palliative care consultation team registration data of the Japanese Society for Palliative Medicine (December 2006) and the 2007 annual conference data of Hospice Palliative Care Japan, palliative care consultation teams that started their activity before April 2005 and received more than 80 referred patients per year were selected. Next, we contacted clinicians whose experience as part of a palliative care consultation team spanned over at least two years, and authors agreed that their activity levels were high within the palliative care consultation teams. One group of panelists comprised five physicians, two psychiatrists, and five nurses, showing diversity regarding hospital types

(cancer center, university hospital, and general hospital).

Criterion 2. We contacted 16 palliative care-related organizations (Table 1) by mail and asked them to participate in this study and recommend a panelist. As a condition to be a panelist, we proposed an extensive knowledge of palliative care and work experience within/with palliative care consultation teams. The total number of panelists was 27 experts (one panelist was recommended by two organizations).

Data Collection and Analysis

First, each panelist was asked to review 28 related reports.^{6,19,24,26-29,31-51} The reason why we asked the panelists to review these was to standardize their knowledge regarding the roles and activities of palliative care consultation teams, as such teams are relatively new in Japan, before study commencement.

Second, two months later, we implemented a first-round survey, mailing a questionnaire with the outline of a provisional standard to each panelist. Each member was asked to rate the appropriateness of each statement using a nine-point Likert-type scale (inappropriate 1-3, intermediate 4-6, and appropriate 7-9). In cases where panelists were unfamiliar with items due to their specialty, "incapable of rating" was also prepared. Panelists who rated a statement as less than 6 were asked to give the reason. We set two criteria for agreement:

Table 1
List of Palliative Care-Related Organizations Participating in This Study

Japanese Society for Palliative Medicine
Japan Psycho-Oncology Society
Japan Society of Clinical Oncology
Japanese Society of Medical Oncology
Japan Society of Pain Clinicians
Japanese Society for Therapeutic Radiology and Oncology
Japanese Society of Cancer Nursing
Japanese Nursing Association
Hospice Palliative Care Japan
Japanese Society for Pharmaceutical Palliative Care and Sciences
Japanese Society of Pharmaceutical Health Care and Sciences
Japanese Association of Social Workers in Health Services
The Japanese Psychological Association
The Association of Japanese Clinical Psychology
The Japanese Physical Therapy Association
Japanese Association of Occupational Therapists

the median value was 8 or more, and the difference between the minimum and maximum was 4 or less. A summary of the first-round survey was sent to each panelist and author, and disagreements were discussed by e-mail for two weeks. We asked the panelists, especially those who would not be able to attend a panel meeting, to give their opinions.

Third, after discussion by e-mail, an expert panel meeting was convened on January 19, 2008, in Tokyo to discuss statements causing disagreement face-to-face. At the meeting, a summary of the first-round survey and discussion through e-mail was distributed. After the panel meeting, a summary of the meeting and a revised version of the standard were sent to all panelists to confirm corrections or determine whether there were additional opinions.

Fourth, we implemented a second-round survey using the same method as in the first-round survey, and a revised version of the standard based on the expert panel meeting. For statements considered inappropriate, the relevant panelists were contacted by e-mail individually and we tried to reach a compromise.

This study was conducted from April 2007 to March 2008. The protocol was approved by the Institutional Review Board of the Graduate School of Comprehensive Human Sciences, University of Tsukuba. All statistical analyses were carried out using the statistical package SAS version 9.1 (SAS Institute, Inc., Cary, NC).

Results

The backgrounds of the panelists are summarized in Table 2. Of the 27 panelists, 25 had experience working as a member of a palliative care consultation team and the mean working period was 5.3 years.

All panelists responded to the first-round survey, and 17 (63%) participated in the panel meeting. In the first-round survey, 15 of 33 statements led to disagreements. We analyzed the reasons for the 15 disagreements and found that the minimum goal of a palliative care consultation team differs among the members, and the range of palliative care consultation team activities is not clear, whether for hospital inpatients or for the community. During the discussions by e-mail and in the panel meeting, the following were agreed: 1)

Table 2
Background of Panelists (n = 27)

Sex	
Male	15
Female	12
Specialty	
Physician	11
Psychiatrist	3
Nurse	7
Psychologist	2
Pharmacologist	1
Medical social worker	1
Occupational therapist	1
Physical therapist	1
Years of clinical experience (mean \pm SD)	18.9 \pm 6.1
Experience in PCT activity, yes	25
Years of PCT activity, n = 25 (mean \pm SD)	5.3 \pm 3.1

SD = standard deviation; PCT = palliative care team.

the standard should be achieved within five years, taking into account the wide-ranging skills of teams, not the minimal or lowest acceptable practices; 2) this standard should be applied to cancer patients first and then expanded to other diseases in the future; and 3) this standard should focus on consultation activities within a hospital.

According to the results of the first-round survey and discussion at the panel meeting, the 15 statements that produced disagreement were dealt with as follows: one was rejected, one was combined with another statement, three were unmodified on clarifying the basic assumption, and 10 underwent minor revision. Moreover, two other statements were divided into two statements each for explicitness. Consequently, the statements numbered 37.

In the second-round survey, all panelists responded. As a result, three of 37 statements produced disagreements. As disagreement was expressed by only one panelist for each statement and seems to have occurred from a misunderstanding of the statements, we contacted the panelists and gave more precise explanations. Subsequently, agreements were obtained from the panelists. For satisfactory statements that included some minor comments such as expressions, we revised them based on a discussion among authors. The final version of the standard is shown in the Appendix.

Discussion

We developed a palliative care consultation team standard using a modified Delphi

method and using a multiprofessional expert panel. The standard comprised 37 statements encompassing four areas: "philosophy and policy," "structure for care provision," "contents of activities," and "quality assurance and care improvements." It is important in terms of developing a standard to use a clear methodology. Furthermore, this standard would be of help to both new and existing palliative care consultation teams as a guideline. In addition, the activities of palliative care consultation teams could be evaluated based on this standard, which contributes to improvement in the quality of care.

In the first-round survey, 15 of 33 statements led to disagreement. This is a poor result compared with other studies using the Delphi method.^{52,53} The outcome suggests that what is viewed as the minimum of palliative care consultation team activities differs from person to person, as mentioned previously, and it might be difficult to achieve a common understanding of the role of palliative care consultation teams, not only for palliative care consultation team users^{54,55} but also for palliative care consultation team members themselves. The role of palliative care consultation teams became clearer using this standard. As a next step, we need to investigate to what extent the palliative care consultation team actually fulfills its role and how effective it is.

Given the lack of a clearly defined role, this standard was rather general. Common elements of palliative care, such as spiritual and bereavement care, were not included. Although spiritual and bereavement care have been acknowledged as essential elements in palliative care in Japan as well,¹⁸ it is difficult to actually provide these types of care as a part of daily practice in the acute setting^{20,56} and panelists might have believed that it would be difficult to achieve the goal within five years. Another possible reason would be that we tried to include the consultation steps in the standard, and thus, it made the standard a more general one that can be applied to any type of medical care.

Our study had several limitations. First, some statements were not precise enough because we intended the standard to be applied by both new and established palliative care consultation teams. Too precise a description would make it difficult for panelists to

reach an agreement. Second, panelists in this study consisted of diverse professionals, but the number of physicians was large. Thus, this standard might be biased to reflect physicians' opinions. Third, palliative care consultation teams cannot be directly evaluated with this standard. For actual evaluation, assessment criteria are needed. Fourth, the clinical effectiveness of this standard remains unclear, although it was developed by clinical experts.

In conclusion, we developed a palliative care consultation team standard consisting of 37 statements in four areas. Although this standard might not be precise, we believe that it is worthwhile in terms of developing a standard using a clear methodology. This standard is helpful both as a clinical activity guideline and as a method to evaluate palliative care consultation teams. As the next step, palliative care consultation team activities should be advanced with this standard, along with the development of criteria based on the standard, and the implementation of further evaluation.

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Appendix

Hospital-Based Palliative Care Consultation Team Standard

This standard was developed to define the goal of hospital-based palliative care consultation teams working in hospitals.

Palliative care is administered for all patients with life-threatening diseases. This standard has been devised mainly for palliative care consultation teams for cancer patients, as most patients receiving palliative care in Japan suffer from cancer. However, it can also be applied by palliative care consultation teams to non-cancer patients.

This standard only refers to the activities of the palliative care consultation team in a hospital and does not mention activities in the local community, for the following two reasons: 1) palliative care consultation in the local community is not common in Japan, and there are few authorities on this, although it is expected to become more common in the future, and 2) the activities of palliative care consultation teams in hospitals and local communities are markedly different; thus, it would be difficult to devise a standard covering both activities.

Definition of the Terms Used in This Standard

Palliative Care. An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (the World Health Organization definition).

Palliative Care Consultation. Support to enable health care professionals to efficiently deal with difficult issues regarding palliative care.

Direct Care. Medical intervention and care provided by a palliative care consultation team directly to patients and family.

Structure

I. Philosophy and Policy

1. Philosophy. Palliative care consultation teams educate and support health care professionals and provide direct care for patients and their families by providing clinical knowledge and skills to improve the quality of life of both parties.

2. Policy. The palliative care consultation team should:

- a. Consult with health care professionals working in hospitals.
- b. Provide direct care for patients and their families when necessary, after consensus with the referring health care professionals.
- c. Work according to the needs of the referring health care professionals as well as patients and their families.
- d. Have discussions with the referring health care professionals and decide on the care plan for patients and their families.

II. Structure for Care Provision

1. Occupational Structure. It is desirable for palliative care consultation teams to include the human resources mentioned below or for the teams to have access to such professionals whenever needed:

- a. Physician who is skilled in the palliation of physical symptoms.
- b. Physician who is skilled in the palliation of psychiatric symptoms.

- c. Nurse who is qualified as a certified nurse specialist/certified expert nurse in palliative care.
- d. Pharmacologist who is skilled in palliative care.
- e. A medical social worker.
- f. A psychotherapist.
- g. Health care professionals involved in rehabilitation (physical, occupational, speech therapists, etc.)
- h. A registered dietitian.
- i. Other professionals who contribute to improve patients' and their families' quality of life.

2. Structure of Activity. The palliative care consultation team should:

- a. Be clearly positioned within the organization of the hospital.
- b. Specify its philosophy and policy to the hospital.
- c. Inform health care professionals in the hospital, patients, and their families about the team framework (position in the hospital, members, working hours, and contents of activities).
- d. Inform health care professionals in the hospital of who has access to the team (staff who can request referral and the process involved).
- e. Establish a referral system that facilitates prompt action.

Process

III. Contents of Activities

1. Clinical Activities. The palliative care consultation team should:

- a. Provide patients with symptom management, emotional support, support for decision making, a place of care, and support for terminal problems, as well as support for the families and health care professionals.
- b. Carry out a comprehensive assessment of patients and their families based on information from referring staff, physical examinations of patients, discussions with the family, medical charts, and the results of other examinations and provide recommendations and direct care.
- c. Make an assessment using a standardized tool whenever possible.
- d. Provide recommendations and direct care based on existing clinical practice guidelines if possible, taking the individual situations/conditions of patients into consideration.
- e. Record the contents of assessments/recommendations and direct care on medical charts.
- f. Review and follow up the results of recommendations and direct care.
- g. Inform patients and their families about the contents of direct care and obtain consent.
- h. Hold conferences with the referring health care professionals if needed.
- i. Facilitate communication within the palliative care consultation team through regular meetings, etc.

2. Organizing Resources. The palliative care consultation team should:

- a. Allocate a palliative care link nurse to a ward or outpatient division as needed.
- b. Facilitate a guideline for palliative care in the hospital.
- c. Promote a cooperative relationship with facilities related to palliative care (e.g., palliative care units, clinics, home-visiting nursing stations, and pharmacies) in the local community.

3. Educational Activities. The palliative care consultation team should:

- a. Educate health care professionals in hospitals through their daily activities.
- b. Give regular lectures on palliative care to health care professionals.
- c. Provide regular study sessions and lectures to educate inpatients/outpatients and their families.

IV. Quality Assurance and Care Improvements

The palliative care consultation team should:

- a. Evaluate and improve activities by holding regular case reviews and conferences.
- b. Evaluate activities by collecting and analyzing information on the referred patients and activities of the team (e.g., diagnosis, the reason for referral, and number of referrals).
- c. Make maximum efforts to obtain up-to-date information on palliative care.

Administrators' perspectives on end-of-life care for cancer patients in Japanese long-term care facilities

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Abstract

Purpose The purpose of this study was to clarify administrators' perspectives on availability of recommended strategies for end-of-life (EOL) care for cancer patients at long-term care (LTC) facilities in Japan.

Methods A cross-sectional survey was conducted with administrators at Japanese LTC facilities. Participants were surveyed about their facilities, reasons for hospitalization of cancer patients, and their perspectives on availability of and strategies for EOL care.

Results The 97 responses were divided into medical facility ($n=24$) and non-medical facility ($n=73$) groups according to physician availability. The most frequent reasons for

hospitalization were a sudden change in patient's condition (49.4%), lack of around-the-clock care (43.0%), and inability to palliate symptoms (41.0%). About 50% of administrators believed their facilities could provide EOL care if supported by palliative care experts. There was no significant difference between facility types ($P=0.635$). Most administrators (81.2%) regarded unstable cancer patients as difficult to care for. However, many (68.4%) regarded opioids given orally as easy to administer, but regarded continuous subcutaneous infusion/central venous nutrition as difficult. Almost all administrators believed the most useful strategy was transferring patients to hospitals at the request of patients or family members (96.9%),

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followed by consultation with palliative care experts (88.5%).

Conclusion Although LTC facilities in Japan currently do not provide adequate EOL care for cancer patients, improvement might be possible with support by palliative care teams. Appropriate models are necessary for achieving a good death for cancer patients. Interventions based on these models are necessary for EOL care for cancer patients in LTC facilities.

Keywords Palliative care · Administrators · Long-term care facilities · Cancer care

Introduction

With a rapidly aging society, long-term care facilities and residential homes for older people are becoming more common in Japan as well as in western countries [20, 21]. In the USA, over 1.75 million people reside in nursing homes, and 43% of individuals who reach age 65 will spend time living in a nursing home [5, 6]. In Japan, 1.4% of those over 65 years old live in nursing homes [20] and approximately 0.8 million people used institutional services financed through the long-term care insurance system in 2006 [23]. Some researchers predicted that the number of residents would increase because implementation of long-term care insurance promoted willingness to use institutional care for older adults [10, 11, 23]. Many Japanese elders are likely to enter long-term care facilities in the near future.

Some residents and their family members might prefer nursing homes as a place for dying, though only about 2% of Japanese people died in nursing homes in 2003 [20]. In western countries, patients tend to prefer nursing homes and assisted living facilities to acute care hospitals as a site of death [10, 14, 16, 18]. To promote end-of-life (EOL) nursing home care, in 2006, the Japanese government amended the insurance law so that nursing homes could receive additional reimbursement for providing EOL care. The number of deaths in the facilities or residential homes is expected to increase in the near future in Japan.

Currently, more than 80% of patients with cancer die in general hospital wards in Japan [13]. However, more patients with cancer may die in long-term care settings in coming years because there are few hospices or palliative care units. In the near future, long-term care facilities in Japan are likely to have to care for more terminal cancer patients than at present.

EOL care for cancer patients, however, might be especially difficult for facilities in Japan due to lack of trained staff, including doctors, nurses, and nursing assistants, inappropriate pain/symptom management, and negative attitudes toward EOL care [19, 22, 24, 25]. Earlier research indicated that the quality of EOL care might also be low in long-term care facilities in western countries [2,

3, 12]. For example, pain and other symptoms may be managed inappropriately [14, 19]. Hanson et al. have reported that surviving family members expressed greater dissatisfaction with nursing homes than with any other component of terminal care [4, 7].

To improve palliative care for cancer patients in the community, including long-term care facilities, the Ministry of Health, Labor, and Welfare in Japan launched a nationwide intervention research project, the Outreach Palliative Care Trial of Integrated Regional Model Study (OPTIM-Study), which is a 5-year project from 2006 to 2011 with a yearly budget of 2.5 million US dollars. The details of the OPTIM-Study design are published elsewhere [26]. The present survey was conducted as a part of the OPTIM-Study.

As decision makers in medical facilities, administrators influence the quality of care that is provided by those facilities [7, 17]. Little is known, however, about administrators' perspectives on EOL care for cancer patients in long-term care facilities and residential homes in Japan. The purpose of the present study is to clarify administrators' perspectives on the current availability of and recommended future strategy for EOL care for cancer patients at long-term care facilities in Japan in preparation for the OPTIM-Study. This study provides necessary information for considering and creating future effective interventions and systems of EOL care for cancer patients in the community, including long-term care facilities, in Japan.

Methods

Design

This cross-sectional study was conducted in Chiba, Shizuoka, Nagasaki, and Yamagata Prefectures in Japan. These areas were openly recruited for the OPTIM-Study and selected because of the specific features of EOL care resources in each community. Specifically, Chiba Prefecture has a national cancer center that plays a central role in the EOL care system, Shizuoka Prefecture has a general hospital that is renowned for palliative care and plays a central role in EOL care, and Nagasaki Prefecture has an efficient support system managed by an association of regional primary care physicians. In contrast, Yamagata Prefecture was selected because it did not have any noteworthy resources at the time.

Participants and procedures

We mailed a structured survey to 275 administrators in all of the long-term care facilities in four areas. Researchers had developed the survey questionnaire from earlier research and their own clinical experience. Administrators received the questionnaire and were informed of the survey

protocol. The 103 administrators who consented to participate in the study replied anonymously. We excluded six responses because of missing data regarding facility type. The responses with missing data on other items were included in the study in order to maximize the sample size for analysis. During statistical analysis, items with missing responses were excluded.

Questionnaire

Characteristics of facilities

The questionnaire included items on types of targeted facilities. For analysis, we divided the study sample into two groups according to the availability of physicians: medical facility and non-medical facility. We chose this simple classification due to the small sample size, though there is considerable variety among long-term care facilities in Japan [9]. The survey also asked about other characteristics of the facilities. Size (number of beds) was divided into three groups. The number of nurses working at night was summarized dichotomously. We also included questions on the number of cancer patients in the previous year who had died, either in the facility or acute-care hospitals after transfer, and the number of cancer patients who had died in the facility without being transferred in the previous year.

Reasons for transfer to acute-care hospitals

Respondents rated the frequency of ten reasons for transfer of cancer patients to acute-care hospitals. The reasons included items such as “unexpected change in patient’s condition.” Each reason was rated on a five-point Likert-type scale (1 = none, 2 = rarely, 3 = sometimes, 4 = often, and 5 = always) and responses were divided dichotomously.

Administrators’ perspectives on availability of EOL care

We asked the administrators about their opinion on the feasibility of EOL care in their facilities under a variety of situations. First, we inquired whether it was possible to provide cancer patients with EOL care if palliative care experts supported them. Second, we asked whether they could accept respite stay and admissions of four types of cancer patients into their facilities if palliative care experts supported them. The types of patients illustrated included ones such as “respite stay of stable cancer patient without intravenous line.”

Administrators’ perspectives on availability of palliative therapies

Administrators were asked about the availability of six types of therapy if palliative care experts were available to patients,

such as opioids given orally and continuous subcutaneous infusion of morphine. Participants rated the questions using three categories (1 = impossible, 2 = possible with expert support, and 3 = possible) and responses were divided dichotomously.

Administrators’ perspectives on strategies to provide EOL care

Finally, participants answered questions about the usefulness of coordinating interdisciplinary teams for six coordinated actions, which included items such as “regular visits by palliative care experts,” “contact with practitioners in specialized home care support clinics whenever needed,” and “transfer to hospitals whenever patients or family desire admission.” Specialized home care support clinics were uniquely defined in 2006 in Japan as facilities that provide home care for a wide range of patients in the community and include long-term care facilities [26]. Administrators rated the responses using a five-point Likert-type scale (1 = useless, 2 = somewhat useful, 3 = useful, 4 = very useful, and 5 = indispensable) and responses were divided dichotomously.

Analyses

Descriptive comparisons between facility types were conducted utilizing cross-tabular breakdowns with Fisher’s exact test for dichotomous variables and Kruskal–Wallis test for ordinal variables. Significance was defined as $P < 0.05$. All analyses were conducted using SAS 9.1. The study method was reviewed and approved by the review board of the OPTIM-Study organized by the Ministry of Health, Labor, and Welfare.

Results

Characteristics of study sample

Of the 97 administrators whose data were included in the analysis, 24 were from medical facilities (MF) and 73 were from non-medical facilities (NMF). MF included ten geriatric hospitals and 14 geriatric health service facilities; NMF included 36 nursing homes, 21 public facilities similar to assisted living facilities in the USA, and 16 private for-profit nursing homes.

Table 1 shows the characteristics of the participants. About half of the facilities had 41 to 80 beds. Sixty percent of them did not have night-shift nurses. This was especially true of most of the NMF. There were no cancer patient deaths in 30% of the facilities, including death after being transferred to acute-care hospitals. Also, 60% of the facilities had no cancer patients.

Table 1 Characteristics of facilities

	Total <i>n</i> (%)	Medical facility <i>n</i> (%)	Non-medical facility <i>n</i> (%)	<i>P</i> value
Number of beds (<i>n</i> =97) ^a				
1–40	13 (13.4)	3 (12.5)	10 (13.7)	0.002
41–80	55 (56.7)	6 (25.0)	49 (67.1)	
81–436	29 (29.9)	15 (62.5)	14 (19.2)	
Nurses working at night (<i>n</i> =95) ^a				
Yes	36 (37.9)	23 (100.0)	13 (81.9)	<0.001
No	59 (62.1)	0 (0.0)	59 (18.1)	
Death of cancer patients in hospital or facility after a transfer (<i>n</i> =93) ^a				
0	30 (32.3)	4 (19.0)	26 (36.1)	0.012
1–5	57 (61.3)	12 (57.1)	45 (62.5)	
6–10	6 (6.5)	5 (23.8)	1 (1.4)	
Death of cancer patients in the facility without being transferred (<i>n</i> =93) ^a				
0	56 (60.2)	12 (54.5)	44 (62.0)	0.368
1–5	35 (37.6)	8 (36.4)	27 (38.0)	
6–10	2 (2.2)	2 (9.1)	0 (0.0)	

^a Sample size for items varied because of missing values

Reasons for transfer to acute-care hospital

Table 2 shows possible reasons for hospitalization of cancer patients. The most frequent reasons were unexpected change in patient's condition (49.4%), followed by lack of around-the-clock care during nights and weekends (43.0%), and the inability to palliate pain and other symptoms (41.0%). Of the ten reasons, significant differences between facility types were observed for the lack of doctor ($P=0.025$) and caregiving burden felt by family members ($P=0.018$).

Administrators' perspectives on availability of EOL care

The first line in Table 3 presents administrators' perspective on the ability of their facilities to care for cancer patients with support from palliative care experts. Overall, slightly more than 50% of administrators speculated that they could provide EOL care for cancer patients. Fisher's exact test did not show a difference between facility types ($P=0.635$).

Administrators believed that they could accept respite stay and admission of stable cancer patients with palliative care expert support. However, if a patient was unstable and used

Table 2 Reasons for transfer to acute-care hospital

Reasons for hospitalization	<i>n</i> ^a	Total (%) ^b	Medical facility (%) ^b	Non-medical facility (%) ^b	<i>P</i> value
Unexpected change in patient's condition	83	49.4	50.0	49.2	1.000
Lack of around-the-clock care during nights and weekends	79	43.0	37.5	45.5	0.623
Inability to palliate pain or other symptoms	83	41.0	33.3	44.1	0.463
Lack of nurses	79	34.2	30.4	35.7	0.796
Lack of careworkers	80	27.5	16.7	32.1	0.183
Anxiety of patient or family member	55	27.3	25.0	28.2	1.000
Lack of doctor	80	26.3	8.3	33.9	0.025
Inability to palliate delirium	79	19.7	29.2	15.4	0.216
Caregiving burden felt by family member	70	18.6	36.4	10.4	0.018
Lack of collaboration between doctors and nurses/family members	76	13.2	4.3	17.0	0.266

^a Sample size for items varied because of missing values

^b Percentage for responses of often/always among five options including none, rarely, sometimes, often, and always

Table 3 Administrators' perspectives on availability of end-of-life care

Questions	Total (<i>n</i> =96)	Medical facility (<i>n</i> =24)	Non-medical facility (<i>n</i> =72)	<i>P</i> value
Is it possible to provide cancer patients with end-of-life care to the end if palliative care experts support them? (%) ^a	56.3	62.5	54.2	0.635
Is it possible to accept respite stay of stable cancer patients without intravenous lines if palliative care experts support them? (%) ^b	69.8	83.3	65.3	0.126
Is it possible to accept respite stay of stable cancer patients without intravenous lines but taking opioids orally if palliative care experts support them? (%) ^b	60.4	70.8	56.9	0.335
Is it possible to accept admissions for end-of-life care for stable cancer patients expected to live for some time with a chronic illness like post-stroke if palliative care experts support them? (%) ^b	48.4	66.7	42.3	0.058
Is it possible to accept admissions for end-of-life care for unstable patients using continuous subcutaneous infusion of morphine to control symptoms if palliative care experts support them? (%) ^b	18.8	37.5	12.5	0.013

^a Percentage for response of possible between two options including possible and impossible

^b Percentage for response of possible among three options including impossible, difficult, and possible

continuous subcutaneous infusion of morphine, admission was regarded as difficult. Administrators of NMF considered it more difficult than administrators of MF ($P=0.013$).

Administrators' perspectives on availability of palliative therapies

Table 4 presents the availability of six palliative therapies with support from palliative care experts. Administrators believed that using opioids given orally was easiest, and continuous subcutaneous infusion and central venous nutrition were the most difficult routes of administration. MF had greater availability than NMF for all therapies, especially central venous nutrition ($P=0.002$).

Administrators' perspectives on strategies to provide EOL care

Table 5 shows administrators' perspectives on coordination to care for cancer patients. Administrators thought that the most useful coordination was transport to hospitals when-

ever patients or families desired admission (96.9%), followed by consultation with palliative care experts (88.5%), and contact with physicians in specialized home care support clinics (85.3%). Rental of medical devices was regarded as the least useful (60.4%). Differences between facilities were shown only for contact with physicians in specialized home care support clinics ($P=0.004$).

Discussion

This article has described reasons for hospitalization of cancer patients who have been admitted to Japanese long-term care facilities and administrators' opinions on the feasibility of EOL care, availability of palliative therapies, and effective therapeutic coordination strategy for EOL care for cancer patients. The results also indicated some differences in administrators' opinions according to the type of long-term care facility (medical vs. non-medical).

The results showed that the most frequent reason for hospitalization was the unexpected change in a patient's

Table 4 Administrators' perspectives on availability of palliative therapies

Types of therapies	<i>n</i> ^a	Total (%) ^b	Medical facility (%) ^b	Non-medical facility (%) ^b	<i>P</i> value
Opioids given orally	95	68.4	73.9	66.7	0.612
Intravenous hydration	94	52.1	65.2	47.9	0.160
Subcutaneous hydration	93	41.9	60.9	35.7	0.051
Continuous subcutaneous infusion of sedative	93	36.6	52.2	31.4	0.085
Continuous subcutaneous infusion of morphine	93	35.5	52.2	30.0	0.078
Central venous nutrition	93	33.3	60.9	24.3	0.002

^a Sample size for items varied because of missing values

^b Percentage for response of possible/possible with expert support among three options including possible, possible with expert support, and impossible

Table 5 Administrators' perspectives on strategies to provide end-of-life care

Items for coordination	<i>n</i> ^a	Total (%) ^b	Medical facility (%) ^b	Non-medical facility (%) ^b	<i>P</i> value
Transfer to hospital whenever patients or family desire admission	97	96.9	95.8	97.3	1.000
Consultation with palliative care experts about palliation whenever needed	96	88.5	79.2	91.7	0.136
Contact with physicians in specialized home care support clinic whenever needed	95	85.3	65.2	91.7	0.004
Regular visit of palliative care experts	95	80.0	69.6	83.3	0.229
Contact with visiting nurses whenever needed	92	72.8	60.9	76.8	0.177
Rental of rarely used medical devices from regional hospitals	91	60.4	54.5	62.3	0.618

^a Sample size for items varied because of missing values

^b Percentage for response of useful, very useful, and indispensable among five options including useless, somewhat useless, useful, very useful, and indispensable

condition. This result differs from Buchanan's research, which indicated that non-clinical factors such as patient preferences were more important in the decision to hospitalize a resident. Lack of an advance directive system in Japan might also contribute to this difference. To prevent the unexpected deterioration of a patient's condition or symptoms, educational outreach by palliative care specialists, which is included in the OPTIM-Study [26], might be effective. Additionally, this approach would also be useful in improving the ability to palliate pain and other symptoms, a reason that was cited for hospitalization. Lack of around-the-clock care, which was noted as another reason, might arise partly because NMF were not required to employ a night-shift physician or nurses. Previous research also indicated that inadequate staffing was an obstacle for the provision of EOL care [1, 8]. Coordination with physicians in specialized home care support clinics is likely to be effective for supporting such institutions in providing EOL care. Addressing these causes of hospitalization may help to reduce unnecessary hospitalization of cancer patients. This, in turn, may improve patients' quality of life and decrease medical costs.

It should be noted that half of the administrators believed that their facilities could provide EOL care with proper support by palliative care experts. Moreover, there was no significant difference according to type of facility. These results were similar to Sloane's work, which suggested that EOL care in assisted living facilities appeared to be similar in process and outcomes to that provided in nursing homes [18]. Our results suggest that Japanese long-term care facilities might be able to provide EOL care for cancer patients with proper support, despite gaps between facility types. Palliative care team consultation, such as what occurs in hospices in American nursing homes [12, 15], might facilitate EOL care in Japanese long-term care facilities and improve the quality of care. Therefore, regional palliative care centers included in the OPTIM-

Study, which provide coordination and information services, may be effective. The administrators also believed that their facilities could accept respite stay or admission of stable cancer patients, though they would not admit unstable cancer patients. As a whole, although patients with unstable symptoms or pain should be cared for in hospice or hospitals with a palliative care team, EOL care for cancer patients in long-term care facilities might be feasible with a proper intervention system in Japan.

As for specific palliative therapies, central venous nutrition and continuous subcutaneous infusion for morphine and sedative agents were regarded as difficult to provide in these facilities. These difficulties may be due to the paucity of physicians and nurses in long-term care facilities. However, the administration of opioids given orally and intravenous hydration could be feasible with proper support and existing staff. Zimmerman et al. reported that staff of long-term care facilities emphasized the need for more education in EOL care [27]. Education for less invasive palliative procedures might be effective in promoting palliative care in such institutions. Standardized tools and guidelines derived from the OPTIM-Study will be useful for this type of education [26].

Administrators said that the need for coordination of services was greatest in the transport of patients to other hospitals when patients or family desired admission elsewhere. This request is noteworthy for EOL care for cancer patients in institutions in Japan, as people generally do not regard a long-term care facility as a site for dying. Therefore, patients and family members might prefer hospitalization when cancer is detected or causes symptoms. Moreover, resources such as hospice or outreach programs for EOL care in Japanese long-term care facilities do not exist at this time. Accordingly, administrators are not confident that their facilities can care for cancer patients until death. Administrators' concerns about hospital support are reasonable because the preferences of patients and

family members should be valued at the EOL. Coordination between hospitals and facilities providing EOL care is indispensable.

Consultations and regular visits by palliative care experts were also highly desired. These results suggest that interventions of the OPTIM-Study, establishing community palliative care teams and educational outreach programs, would be needed for long-term care facilities. Although contact with practitioners in specialized home care support clinics was also required, administrators of MF regarded this as less important because MF had at least one full-time physician. In addition, MF administrators may also have assumed that clinic physicians do not have specialized knowledge in EOL cancer care and that physicians who have EOL care competency might be required. In NMF, physicians in specialized home care support clinics are important because many of their facilities have no regular doctor.

The results of this study should be interpreted in light of its limitations. This study has limited applicability because of the small sample size and low response rate. However, this study is noteworthy for being the first published article on Japanese EOL care for cancer patients in institutions for elderly people.

In spite of the study limitations, the results of this study have implications for health care policy and future research. Although EOL care for cancer patients in Japanese institutions is currently insufficient, improvement might be possible with appropriate interventions, such as staff education or support by efficient interdisciplinary expert teams. Future research should create appropriate models for coordination that lead to a good death for cancer patients in Japanese institutions. Previous research conducted abroad has indicated that intervention studies were effective in improving the quality of care [3, 6]. The results of studies in various countries indicate that interventions using OPTIM-Study processes could open new frontiers for EOL care for cancer patients in long-term care facilities in Japan.

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The Long-Term Effect of a Population-Based Educational Intervention Focusing on End-of-Life Home Care, Life-Prolongation Treatment, and Knowledge about Palliative Care

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Abstract / Misconceptions and a lack of knowledge are barriers to providing palliative care. This study examined the long-term effect of an educational intervention with the general public focusing on end-of-life home care, life-prolongation treatment, and knowledge about palliative care. We offered a one-hour educational lecture for community residents in 11 districts in Fukushima, Japan. Lecture attendees were asked to complete pre- and post-questionnaires and a six-month postal follow-up questionnaire. A total of 424 respondents completed and returned the follow-up questionnaire. Beliefs about the feasibility of home death did not significantly change. In addition, many of the other significant changes that occurred immediately after the intervention reverted to initial opinions six months later. This population-based educational intervention was not effective for the long term, except that it had a partial influence on certain misconceptions about palliative care. Therefore, other approaches are needed to achieve substantial long-term effects.

Résumé / Les préjugés et le manque de connaissances sur ce que sont les soins palliatifs sont deux des éléments qui nuisent à sa mise en place. Cette étude voulait étudier les effets à long terme d'un programme d'information et d'éducation auprès du grand public et qui parlerait surtout sur les soins de fin de vie à la maison, les traitements de prolongation de vie et sur des notions générales sur les soins palliatifs. Nous avons tenu des conférences éducatives d'une heure auprès des résidents de 11 districts de Fukushima au Japon. Les personnes qui assistaient à la conférence ont complété un questionnaire avant et un questionnaire après le conférence. Six mois plus tard un questionnaire de suivi leur a été envoyé par la poste. Un total de 424 personnes ont complété et retourné le dernier questionnaire postal. Les croyances au sujet de la possibilité de mourir à la maison n'avaient pas

changées de façon significative. De plus, plusieurs autres changements plus significatifs qui s'étaient produits immédiatement après l'intervention retournaient aux positions initiales six mois plus tard. Cette intervention éducative de nature démographique n'a pas été efficace à long terme, mais elle a cependant eu une influence à tout le moins partielle sur certaines idées erronées au sujet des soins palliatifs. Il faudra utiliser d'autres approches pour atteindre des objectifs à long terme.

INTRODUCTION

Misconceptions and a lack of knowledge about palliative care are barriers to providing palliative care for end-of-life cancer patients (1-10). Actually, a significant proportion of the Japanese general public has incorrect beliefs about pain medication and communication with physicians (11). Educational intervention is needed to overcome these barriers (1, 7).

In addition, reports have shown that only 6 percent of cancer patients die at home (12), although 55 percent of the general public in Japan prefer home as the place of death (13). A systematic review revealed that the most important factors linked to dying at home are low functional status, patient preference, use and intensity of home care, living arrangements, and extended family support (14). Based on these findings, the authors proposed that public education was one of the actions that would enable people to die at home.

Several educational intervention studies focusing on cancer pain management have been con-

ducted for patients (15-19); and others focusing on knowledge of delirium (20), advanced directives (21), and coping strategies (22-25) have been conducted for caregivers of terminally ill patients. One study examined the general public's reaction to the topic of palliative care using a video on cardiopulmonary resuscitation (CPR), and it demonstrated effective improvement in knowledge immediately after the intervention (26). However, there is limited evidence of the effectiveness of public education on palliative care and no evidence of its long-term effects.

We had previously conducted a prospective educational intervention for the general public focusing on end-of-life home care, life-prolongation treatment, and knowledge about palliative care, and we reported that there were many significant changes in belief before and after the intervention (27). Specifically, belief in the feasibility of home death increased from 9 percent to 34 percent. Furthermore, preference for life-prolongation treatment and attitudes toward end-of-life care, including symptom management at home, misconceptions about opioids, artificial hydration, and communication issues between patients and medical practitioners, significantly improved.

Within this study, we conducted a six-month prospective follow-up study to determine the actual effect of the intervention over time. The aim of the study was to examine the long-term effects of an educational intervention with the general public on the topic of palliative care.

METHOD

Participants and Procedures

Potential participants were those who attended educational community lectures. The researcher explained the aim of the study and spoke about privacy protection and voluntary participation. Self-administered questionnaires were completed before and after the intervention. Demographic characteristics were covered in the pre-questionnaire. A total of 607 people attended the lectures (17 to 188 per lecture), and 595 people completed the pre- and post-questionnaires.

We mailed follow-up questionnaires to those who completed the pre- and post-questionnaires six months after the intervention. Of the 595 participants, 26 were excluded due to previous participation ($n=8$) or unknown name and address ($n=18$). We re-sent questionnaires to those who did not respond within one month. We received 425 questionnaires, one of which was excluded because of a difference in the respondent's name between the pre- and follow-up questionnaires. Finally, 424 participants were included in the analysis (the response rate was 75 percent).

This study was approved by the institutional review board of the Fukushima Medical University.

Intervention

One-hour educational lectures were held for community residents from April 2006 to March 2007. Simple pamphlets about the lectures were distributed; no special invitations were issued. The lectures were free and offered during periodic regional community meetings in the 11 districts of Fukushima City. Fukushima City is the capital of Fukushima Prefecture; it is located about 250 kilometres north of Tokyo, and it has a population of 288,000.

The topics of the lectures were: the limitations of cancer treatment, life-prolongation treatment for end-of-life cancer patients, opioids, artificial hydration, communication between patients and physicians, the feasibility of home care for end-of-life cancer patients, and district health resources for terminally ill cancer patients. A physician gave all of the lectures.

Measures

To examine the effect of the educational intervention, our main outcome criterion was change of belief about the feasibility of home death. The feasibility of home death was rated as "possible," "impossible," or "unsure." We also investigated beliefs about barriers to end-of-life home care, preferences for life-prolongation treatment, and attitudes toward end-of-life care using pre- and follow-up questionnaires. We did not ask facilitators of home death for their preferred place of end-of-life care because this information did not suit the purpose of our intervention.

Barriers to end-of-life home care included: absence of a visiting physician, absence of a visiting nurse, absence of 24-hour consultation, absence of family caring, care burden on the family, anxiety about worsening physical condition, anxiety about arranging immediate hospital admission when physical condition worsened, inadequate living environment, economic burden, and inability to relieve suffering at home. Participants were asked to agree or disagree that these barriers were relevant to their home care situation.

We investigated the preference for life-prolongation treatment if participants were terminally ill cancer patients. We asked about their preference for artificial hydration, artificial nutrition, vasopressors, mechanical ventilation, and CPR using a 4-point Likert scale: want to receive, probably want to receive, probably do not want to receive, and do not want to receive.