



The needs of patients with noncancer diseases and their families from hospital-based specialized palliative care teams in Japan

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Background: Hospital-based specialized palliative care teams (HSPC) are important for symptom management and ethics support, especially during complex decision-making, but the needs of patients with noncancer diseases and their families from the HSPC are unclear. This study aimed to (I) compare the prevalence of symptom between patients with and without cancer and explore changes in symptom intensity after HSPC consultation in patients with noncancer; (II) determine factors related to ethics support; and (III) compare the percentage of request contents from patients and their families when a certified nurse specialist in gerontological nursing (geriatric care nurse below) is present in the HSPC to that when a certified nurse specialist in palliative care (palliative care nurse below) is present in the HSPC.

Methods: We utilized a retrospective cohort study to analyze 761 patients (360 with noncancer and 401 with cancer) referred to our HSPC at the National Center for Geriatrics and Gerontology using 10-year data (since 2011) available in an electronic medical record database. (I) Symptom scores of the Support Team Assessment Schedule were compared between noncancer and cancer groups and between initial and 1-week assessments for noncancer patients. (II) Ethics support was compared between noncancer (including dementia) and cancer. The presence or absence of ethics support requests, which was set as the objective variable, was examined using logistic regression analysis. (III) The percentage of request contents selected from nine items defaulted on the electronic medical record when a geriatric care nurse was present in our HSPC were compared to those when a palliative care nurse was present in our HSPC.

Results: Compared to those with cancer, patients with noncancer suffered more from dyspnea and sputum accumulation. More than 10% of patients with noncancer had suffered from pain, dyspnea, sputum accumulation, and anorexia that required treatment, with symptom scores showing improvement after 1 week of HSPC involvement, except for the sputum accumulation. Moreover, for anorexia, symptom scores improved, but >10% of these patients continued to suffer. Patients with noncancer diseases, including dementia, received ethics support than those with cancer without dementia. More requests for ethics support were received when a geriatric care nurse was in the HSPC than when a palliative care nurse was in the HSPC. Logistic regression analysis revealed that requests for ethics support were more frequent from patients or families

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with impaired decision-making capacity or when the patient lacked an advocate.

Conclusions: The needs of patients with noncancer diseases and families from the HSPC in Japan included (I) symptom management for intractable conditions, such as sputum accumulation; (II) ethics support for patients with noncancer diseases, including dementia, with impaired decision-making capacity, and without advocates; and (III) advice on ethics issues from a geriatric care nurse.

Keywords: Chronic illness; ethics; geriatric nursing; palliative care; symptom management

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Introduction

Background

Hospital-based specialized palliative care teams (HSPC) were developed for patients with palliative care needs

and their families with a focus on relieving suffering and improving the quality of life (QoL) (1). Despite the decline in hospital deaths throughout Japan after 2019, when coronavirus disease 2019 (COVID-19) expanded, it is important to consider the needs for adequate HSPC given the high rates of hospital deaths among those aged 65 years and older, which can reach as high as 67.8% (2). Global estimates show that the most rapid increases in palliative care needs will occur among low-income countries, among people over age 70 years, and among people with dementia (3). Moreover, HSPC has been shown to provide modest gains in patient outcomes (4), such as symptom burden (5), health-related QoL (HRQoL) (6), satisfaction with care (7), and death at the patient's preferred location (8), compared with usual care. Decision support and advance care planning are also noted among the needs from HSPC (1,9).

Rationale and knowledge gap

Globally, few studies have focused on the impact of HSPC for patients with advanced noncancer illnesses cared for within general hospital wards and the intensive care unit (10-13). Despite palliative care being noted as relevant and important for patients with dementia and chronic advanced respiratory illnesses, involvement of HSPC remains low (14-16). Although nearly 70% of deaths in Japan and South Korea occur in hospitals, only <30% of deaths in the Netherlands and Norway transpire in hospitals, suggesting large differences between countries (17). Despite the decline in hospital deaths throughout Japan after 2019, the rate of hospital deaths among those aged 65 years and older has remained quite high at 67.8% (2). Very few studies on optimal HSPC have been conducted in this different health care settings, including differences in accessibility

Highlight box

Key findings

- Three needs of patients with noncancer diseases and families from hospital-based specialized palliative care teams (HSPC) in Japan.
- Symptom management that are more frequent than cancer and difficult-to-improve such as sputum accumulation.
- Ethics support for patients with noncancer diseases, including dementia with impaired decision-making capacity without an advocate.
- Advice on ethics issues from a certified nurse specialist in gerontological nursing (geriatric care nurse below).

What is known and what is new?

- Previous studies revealed symptoms that were easy to ameliorate. Our study revealed symptoms that were difficult to ameliorate.
- Previous studies revealed the importance of ethics support. Our study revealed a high need target for ethics support.
- Previous studies revealed the role of HSPC affiliated palliative care nurses. Our study revealed the role of HSPC affiliated geriatric care nurses in ethics support.

What is the implication, and what should change now?

- Findings from the study on needs of patients with noncancer diseases from the HSPC imply that we need to rethink of the new role of such teams and composition of their members. The HSPC should focus on symptom management for difficult-to-improve conditions, provide ethics support (especially in cases requiring complex decision making), and include geriatric care nurses as new members or work closely with them to provide ethics support. A new service model that adds these three roles to the existing HSPC should be developed.

to palliative care and differences in mortality rates between countries.

An indicator for assessing the activities of HSPC for patients with noncancer diseases is the Support Team Assessment Schedule (STAS) (18-21), a previous version of the Integrated Palliative Care Outcome Scale (IPOS) (22,23). Most palliative care studies conducted using the STAS as an indicator have been conducted on patients with cancer, and only a few reports have been conducted on patients with noncancer diseases (24). Both the STAS and IPOS can be used to assess symptom management, the patient's and family's decision-making capacity, and the presence of a patient advocate. Although the STAS is a tool used by others to conduct an assessment, the IPOS is a tool for self-assessment but can also be used by others, such as when patients lack decision-making capacity.

Integrating palliative care into the health care system is an ethical imperative (3). In fact, the palliative care model has been reported to reduce the selection of aggressive treatment within 30 days prior to death among patients with renal failure, suggesting that such a model possesses an ethics support function (25). Japanese policymakers have hoped to create a model for ethics consultation that can aid in medical decision-making for hospitalized patients without relatives (26). However, medical professionals in the field have faced several problems, such as how to make a request and what kind of content to include in an ethics consultation (27). Studies in other countries have revealed that some hospital palliative care teams provide ethics support for treatment selection and discontinuation (28,29). The Japanese Ministry of Health, Labor and Welfare and the Japan Geriatrics Society have stated the importance of ethics support in decision support, especially in cases requiring complex decision-making (30,31). There are no Japanese papers on the ethics support implemented by HSPC for patients with noncancer diseases.

There is an ongoing debate as to which area of professionally educated nurses should be included in the HSPC (1). For instance, in the paper by Bajwah *et al.*, studies that include certified experts in palliative care and those that are unclear about training of health care providers in palliative care are discussed separately (1). Moreover, evidence shows that better palliative care is provided to elderly heart failure patients with high palliative care needs when certified nurse specialists in both gerontology and chronic heart failure are involved (32). Estimates through 2060 indicate that low-income countries, the elderly, and patients with dementia will have the fastest

growing burden of health-related suffering and the greatest need for integrating palliative care into their health care systems (3). Considering the association between palliative care utilization and cognitive dysfunction (33), the role of nurses in assessing the palliative care needs of persons with dementia has been discussed (34), with studies also looking into the integration of palliative and geriatric care (7). These discussions emphasize the importance of discussing the expertise of multiple professions in HSPC, especially that of nurses.

In Japan, although HSPC are active, they still focus mainly on patients with cancer. The percentage of noncancer diseases in the HSPC registry of the Japanese Society of Palliative Medicine was 5.3% (n=104,331) (35). Compared to the rest of the world, Japan has developed a model of palliative care that is hospital- and cancer patient-centered. In recent years, the setting of palliative care has expanded from hospitals to homes and elderly care facilities, and the target diseases of palliative care have expanded from cancer to heart failure. However, the role and membership of the HSPC as an optimal model of care has still been the subject of debate.

We were motivated by the lack of evidence on the needs of HSPC regarding, first, symptom management in patients with noncancer diseases; second, ethics support as a branch of decision support; and third, the expertise of nurses as key team members.

Objective

We hypothesized that in Japan, patients with noncancer diseases would have the following different needs compared to those with cancer from HSPC: needs related to (I) symptom management; (II) ethics support, especially for cases requiring complex decision-making; and (III) advice from a certified nurse specialist in gerontological nursing.

The objectives of this study are: (I) to compare the prevalence of symptom between patients with and without cancer and to explore changes in symptom intensity after HSPC consultation in patients with noncancer disease; (II) to determine factors related to ethics support, especially in cases requiring complex decision-making; and (III) to compare the percentage of request contents made to HSPC from patients and their families through their attending physicians and ward nurses when a certified nurse specialist in gerontological nursing was present in HSPC and when a certified nurse in palliative care was present in HSPC. We aimed to achieve these three objectives to identify the

needs of patients with noncancer diseases and families from HSPC in Japan. We present this article in accordance with the STROBE reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-24-42/rc>).

Methods

Definition of HSPC, ethics support, and request

We operationally defined “HSPC” as a multidisciplinary team that consults with and advises health care providers on palliative care for hospitalized patients and their families (1). In this study, we did not include outpatient services or outreach services among the services performed by the HSPC.

“Ethics support” was operationally defined as helping patients and their families make complex decisions, whereas “request” was operationally defined as an order placed by patients and their families to the HSPC through their attending physicians or ward nurses in the electronic medical record.

The following nine “requests” were set by defaulted in the electronic medical records: (I) physical pain; (II) psychological pain; (III) family care; (IV) social pain; (V) ethics support; (VI) spiritual pain; (VII) nutritional support; (VIII) medications; and (IX) rehabilitation. Patients and their families could select any of them through their attending physicians or ward nurses.

Study design

The study design was an analytical retrospective cohort study that was performed using an electronic medical record database.

Survey procedure

This study was approved by the Institutional Review Board of the National Center for Geriatrics and Gerontology (No. 1655) and conformed to the provisions of the Declaration of Helsinki (as revised in 2013). Individual consent for this retrospective analysis was waived.

Information about the performance of the research was disclosed on the website of the National Center for Geriatrics and Gerontology, and, if a research subject or his/her family refused to allow the use of his/her medical information for the analysis, the information was removed from the study. In some cases, such as when research results had already been published in academic conferences or

papers, we could not delete the analytical results; thus, we also disclosed information to that effect.

Participants

The subjects were inpatients whose attending physician or ward nurse consults the HSPC at the National Center for Geriatrics and Gerontology using the order system on the electronic medical record, to resolve problems related to palliative care for inpatients during the 10-year period from 2011 to 2020.

HSPC at the National Center for Geriatrics and Gerontology is a unique example of a long-term active HSPC in Japan, where noncancer diseases account for about 40–50% of the target patients. The National Center for Geriatrics and Gerontology encompasses a clinical research mission and 25 clinical departments, including geriatrics, neurology, psychiatry, respiratory medicine, cardiology, gastroenterology, hematology, gastroenterology surgery, neurosurgery, and orthopedics, as well as an attached Center for Comprehensive Care and Research on Memory Disorders, and Center for Frailty and Locomotive Syndrome. Hence, the HSPC being considered in this study is a team operating in the unique environment of the National Center for Geriatrics and Gerontology. The center’s HSPC primarily comprises the following five occupations: (I) physicians skilled in alleviating physical symptoms; (II) nurses with expertise and certification in the field of palliative care and geriatric care; (III) pharmacists skilled in palliative care; (IV) medical social workers; and (V) registered dietitians. However, the standard palliative care team in Japan does not include nurses with expertise and certification in the field of geriatric care (36). Within 10 years, since 2011, a certified nurse in palliative care was affiliated with HSPC for the first 3.5 years and was replaced with a certified nurse specialist in gerontological nursing for the second 6.5 years because of retirement. The certified nurse specialist in gerontological nursing and the certified nurse in palliative care completed a master’s degree program and 600 h of training, respectively, before being certified by the Japanese Nursing Association.

Data, including STAS scores, were extracted in the form of comma separated values (CSV) files from the electronic medical record database in 2022. The cohort included 761 patients, 360 patients with noncancer diseases and 401 with cancer. STAS scores were measured at the first time and at the second time, about 1 week after the first time (7 ± 3 days after the first measurement). The first measurements were taken

on the day the HSPC first visited the patient and discussed care with the attending physician and ward nurses. The timing of the second measurement seemed appropriate at 7 days after the first measurement based on previous studies (37,38). However, in actual clinical practice, accurately measuring 7-day intervals was difficult due to the patient's general condition and examination schedule. Therefore, measurement results at intervals of 7 ± 3 days were extracted as CSV files.

Overall, 761 patients were included in the study based on the following criteria: (I) patients who requested HSPC in the 10 years since 2011, when it was initiated; (II) continuous sampling using an electronic medical record database; (III) patients with STAS scores entered twice, at the first time and then after 7 ± 3 days. The 10-year data extraction period was determined for the following reasons: (I) this study was initiated 10 years after the HSPC began its activities; (II) Japanese people tend to consider 10 years as the milestone of a project; (III) the nurses affiliated with HSPC were replaced in 2014 from a certified nurse in palliative care to a certified nurse specialist in gerontological nursing. We were motivated, at the start of this study, to identify the impact of differences in nurses' expertise.

Measurements

The STAS was developed by Higginson *et al.* (18) and its reliability and validity were confirmed by Carson *et al.* (19) whereas Miyashita *et al.* confirmed its reliability and validity in the Japanese population (20,21). The STAS Basic version includes four domains: physical symptoms, psychological symptoms, patient/family perception of illness, and communication among stakeholders (20). A patient STAS score of 9 denotes an incapacity for decision-making. A family STAS score of 9 denotes an incapacity for decision-making. A family STAS score of 8 denotes the lack of a family member that can advocate for the patient's wishes.

The STAS symptom version includes 22 symptoms. Twenty-two symptoms are rated on a 5-point scale, from 0 to 4, in the STAS symptom version (21). A STAS score of ≥ 2 denotes symptoms that require immediate treatment, whereas a STAS score of < 2 denotes symptoms that do not necessarily require immediate treatment.

Patient demographics, disease title, client's job title, the nature of the request, decision-making capacity, STAS score, request and implementation of ethics support, and HSPC nurse expertise, including a certified nurse specialist in gerontological nursing and a certified nurse in palliative

care, were extracted from the electronic medical record database.

Main group analysis

We used these extracted data for the following analyses.

For univariate analyses, we investigated the following differences: (I) differences in the prevalence of symptom between patients with noncancer diseases and those with cancer at the evaluation 1 week after the initial visit, and differences in symptom intensity between the initial and 1-week follow-up evaluation in patients with noncancer diseases; (II) differences in the frequency of implementing ethics support between the noncancer (including dementia) and cancer groups and between the dementia and nondementia groups, excluding patients with cognitive impairments related to delirium and or advanced disease (brain cancer, etc.) in the diagnosis of dementia; (III) differences in the percentage of request contents from patients and their families made to HSPC through their attending physicians and ward nurses when a certified nurse specialist in gerontological nursing was present in HSPC and when a certified nurse in palliative care was present in HSPC. Certified nurse specialists in gerontological nursing and palliative care were certified by the Japanese Nursing Association.

Differences between the initial and 1-week follow-up evaluation in patients with cancer were not analyzed in detail given our focus on noncancer diseases. Request contents were selected from the nine items set by default and extracted as a CSV file from the electronic medical records available in the database.

For the multivariate analysis, we conducted a logistic regression analysis, with the presence or absence of requests for ethics support as the objective variable. Based on the literature by Chen *et al.* (39), we focused on the presence or absence of the following explanatory variables for ethics support: dementia, decision-making capacity, and an advocate.

Subgroup analysis

Comparisons were made for main groups such as noncancer *vs.* cancer, but not for subgroups such as chronic lung disease, cerebrovascular disorders, lung cancer, colon cancer, and blood tumor, except for dementia.

Analysis to reduce bias

Continuous sampling was used to address selection bias, the timing of extraction of cancer–noncancer diagnostic data was fixed at the time of request to address information bias, and logistic regression analysis was used to address

confounding bias.

Statistical analysis

Data from patients who did not refuse to participate in this study were analyzed. There were no missing data on age, gender, disease name, or consultation details in the electronic medical record database. No missing data were also observed on the request and implementation of ethics support, as this is positioned as a quality indicator for our hospitals and should be submitted monthly. However, <10% of the STAS scores were missing due to omissions. Missing STAS score data were processed using a listwise method. Moreover, the STAS score included an evaluation of “not determinable”. Therefore, we used only the determinable STAS scores with no missing data in our analysis.

Continuous variables are presented as the mean and standard deviation, and categorical variables are presented as frequencies and percentages. P values, 95% confidence intervals, and effect sizes are presented. Significance was set at $P < 0.05$. Effect sizes were determined by referring to Cohen (40). When examining differences in means, the d value was used as the effect size, with 0.2 as small, 0.5 as medium, and 0.8 as large. When examining differences in proportions, ϕ values were used as effect sizes, with 0.1 as small, 0.3 as medium, and 0.5 as large.

Comparisons of STAS symptom scores were tested for sensitivity analysis using categorical and continuous variables. Logistic regression analysis was performed for sensitivity analysis using the stepwise and round-robin methods, in which all explanatory variables were entered.

Microsoft® Excel® 2016 MSO (version 2022) produced by Microsoft Corporation, USA and EZR (41) version 1.55 were used for statistical analyses.

Results

The characteristics of the patients who were attended by the HSPC are listed in *Table 1*. There were 360 (47.3%) patients with noncancer diseases and 401 (52.7%) patients with cancer. The former were older and more often female compared with the latter. The top-three noncancer diseases were dementia, chronic lung disease, and cerebrovascular disorders, which accounted for 67.0% of the total conditions. The top-three cancers were lung cancer, colon cancer, and blood tumors, which accounted for 58.8% of the total conditions. In addition, there were 126 (16.6%) and 635 (83.4%) patients with and without dementia, respectively.

Differences in symptom intensity between patients with noncancer diseases and those with cancer at the evaluation 1 week after the first visit are shown in *Table 2*. At the evaluation 1 week after the first visit, patients with noncancer diseases had more dyspnea and sputum with STAS scores of ≥ 2 than those with cancer. Conversely, patients with cancer had more pain, numbness, fatigue, nausea, vomiting, constipation, and anxiety with STAS scores of ≥ 2 than those with noncancer diseases.

Differences in symptom intensity between the initial and 1-week follow-up evaluation in patients with noncancer diseases are presented in *Table 3*. More than 10% of patients with noncancer diseases were in suffering with STAS scores of ≥ 2 in pain, dyspnea, sputum, and anorexia at the time of the first evaluation. The ratio of STAS scores of ≥ 2 for the sputum at the time of the first evaluation did not show a statistically significant decrease after 1 week. The ratio of STAS scores of ≥ 2 for pain, dyspnea, and anorexia during the first evaluation showed a statistically significant decrease after 1 week. However, the ratio of STAS scores of ≥ 2 for anorexia was still >10% after 1 week.

Differences in the frequency of the implementation of ethics support between the noncancer and cancer groups or the dementia and nondementia are noted in *Table 4*. A higher percentage of ethics support was implemented to patients with noncancer diseases and dementia than those with cancer and without dementia with a large and moderate effect size, respectively.

The differences in the content of the consultations according to the expertise of the HSPC's nurses are noted in *Table 5*. When a certified nurse specialist in gerontological nursing were in the HSPC, consultations about ethics support were more common; moreover, when a certified nurse in palliative care were in the HSPC, consultations about physical pain, psychological pain, social pain, and spiritual pain were more common.

Logistic regression analysis with the presence or absence of ethics support requests as the objective variable is noted in *Table 6*. The following six explanatory variables were selected: (I) age; (II) gender; (III) whether the patient had a noncancer or cancer disease; (IV) whether the patient's STAS score for perceived medical condition was 9; (V) whether the family's STAS score for perceived medical condition was 8 or 9; and (VI) whether the nurse on the HSPC is a certified nurse in palliative care or a certified nurse specialist in gerontological nursing. Six explanatory variables were selected by referring to Chen *et al.*'s work (39). We also referred to the results of univariate analysis in this

Table 1 Characteristics of the patients referred to the palliative care team

Variables	Cancer group (N=401)	Noncancer group (N=360)	P value
Sex, n (%)			0.002*
Male	243 (60.6)	178 (49.4)	
Female	158 (39.4)	182 (50.6)	
Age (years), mean \pm SD	75.7 \pm 9.97	82.2 \pm 9.51	<0.001*
Underlying noncancer disease, n (%)			–
Dementia	–	126 (35.0)	
Chronic lung disease	–	68 (18.9)	
Cerebrovascular disorders	–	47 (13.1)	
Central nervous system disorders	–	40 (11.1)	
Heart failure	–	30 (8.3)	
Frailty	–	19 (5.3)	
Renal failure	–	10 (2.8)	
Liver cirrhosis	–	3 (0.8)	
Arteriosclerosis obliterans	–	3 (0.8)	
Sepsis	–	2 (0.6)	
Other diseases [†]	–	12 (3.3)	
Underlying cancer, n (%)			–
Lung cancer	154 (38.4)	–	
Colon cancer	49 (12.2)	–	
Blood tumor	33 (8.2)	–	
Prostate cancer	32 (8.0)	–	
Stomach cancer	29 (7.2)	–	
Carcinoma of unknown origin	14 (3.5)	–	
Pancreatic cancer	14 (3.5)	–	
Breast cancer	13 (3.2)	–	
Kidney cancer	11 (2.7)	–	
Esophageal cancer	8 (2.0)	–	
Bladder cancer	8 (2.0)	–	
Brain tumor	7 (1.7)	–	
Liver cancer	6 (1.5)	–	
Ureteral cancer	6 (1.5)	–	
Ovarian cancer	4 (1.0)	–	
Bone cancer	3 (0.7)	–	
Gallbladder cancer	3 (0.7)	–	
Other diseases [‡]	7 (1.7)	–	

[†], other diseases included in the noncancer category are the following 12 diseases: acute respiratory distress syndrome, disseminated intravascular coagulation, gangrene, interstitial cystitis, rheumatoid arthritis, traffic trauma, postoperative pain, spinal cord injury, spinal canal stenosis, diabetes mellitus, abscess, and complicated urinary tract infection. Each of these cases accounted for one case; [‡], other diseases included in the cancer category are the following seven diseases: eyelid cancer, splenic intravascular sarcoma, adrenal cancer, thyroid cancer, mediastinal tumors, duodenal cancer, and maxillary cancer. Each of these cases accounted for one case. Females had more noncancer diseases and were older than males. *, P<0.01. SD, standard deviation.

Table 2 Differences in the prevalence of symptom in patients with cancer and noncancer diseases at the time of evaluation 1 week after the first time

Symptoms	STAS score [†]				Cancer vs. noncancer		
	Cancer		Noncancer		P value	ES	95% CI
	Total, N	≥2 [‡] , n (%)	Total, N	≥2 [‡] , n (%)			
Pain	401	59 (14.7)	356	17 (4.8)	<0.001**	0.17	-0.141 to -0.058
Anxiety	392	51 (13.0)	286	16 (5.6)	0.001**	0.12	-0.117 to -0.032
Anorexia	386	46 (11.9)	292	34 (11.6)	0.91	0.00	-0.052 to 0.046
Fatigue	398	46 (11.6)	343	13 (3.8)	<0.001**	0.14	-0.115 to -0.040
Edema	401	34 (8.5)	360	22 (6.1)	0.21	0.05	-0.06 to 0.013
Constipation	401	29 (7.2)	357	13 (3.6)	0.03*	0.08	-0.068 to -0.004
Nausea	401	22 (5.5)	358	0	<0.001**	0.16	-0.077 to -0.033
Insomnia	400	19 (4.8)	352	11 (3.1)	0.26	0.04	-0.044 to 0.011
Sputum	401	15 (3.7)	360	34 (9.4)	0.001**	0.12	0.022 to 0.092
Numbness	400	13 (3.3)	340	2 (0.6)	0.02*	0.08	-0.046 to -0.007
Fever	401	12 (3.0)	360	6 (1.7)	0.34	0.04	-0.035 to 0.008
Abdominal distension	401	12 (3.0)	358	6 (1.7)	0.34	0.03	-0.034 to 0.008
Dyspnea	401	11 (2.7)	355	26 (7.3)	0.004**	0.11	0.014 to 0.077
Delirium	400	10 (2.5)	352	3 (0.9)	0.15	0.05	-0.035 to 0.002
Dry mouth	400	10 (2.5)	351	4 (1.1)	0.27	0.04	-0.033 to 0.005
Vomiting	401	9 (2.2)	360	0	0.01*	0.09	-0.037 to -0.008
Drowsiness	398	8 (2.0)	346	2 (0.6)	0.17	0.05	-0.030 to 0.002
Incontinence	386	7 (1.8)	331	10 (3.0)	0.42	0.03	-0.011 to 0.035
Depression	396	7 (1.8)	312	4 (1.3)	0.83	0.01	-0.023 to 0.013
Cough	401	7 (1.7)	360	3 (0.8)	0.43	0.03	-0.025 to 0.007
Diarrhea	401	5 (1.2)	360	3 (0.8)	0.84	0.01	-0.018 to 0.010
Urinary retention	381	3 (0.8)	326	2 (0.6)	0.86	0.01	-0.014 to 0.011

Note that in the STAS symptom version, an item called “not evaluable” was added to the scores 0, 1, 2, 3, and 4. Variations in the value of N in each symptom score were attributed to this “not evaluable” item. Patients with noncancer diseases have more dyspnea and sputum with STAS score 2 or higher at the time of evaluation 1 week after the first time compared to patients with cancer disease. [†], STAS scores mean the following: 0 = none; 1 = occasional, intermittent. Patient does not need any further treatment now (satisfied with current treatment, no intervention needed); 2 = moderate. Occasionally has bad days and may interfere with activities of daily living (medications need to be adjusted or some other treatment, but not severe symptoms); 3 = often severe, significantly impairs activities of daily living and concentration (severe, often); 4 = severe symptoms are persistent (severe, persistent); [‡], ≥2 denotes a STAS score of =2 or higher. *, P<0.05; **, P<0.01. STAS, Support Team Assessment Schedule; ES, effect size; CI, confidence interval.

study and strongly inferred that noncancer disease and the presence of decision-making capacity were important explanatory variables. As explanatory variables, the presence or absence of STAS score of 9, denoting reduced decision-making capacity, and STAS score of 8, implying that the patient has no family members to advocate on his/her behalf, was used because, as noted by Chen *et al.*, family

members play a major role in advocating on behalf of the patient's wishes in East-Asian cultures. In logistic regression analysis, P value of 0.001 was considered. We have obtained a good regression equation. The variance inflation factor values for the six explanatory variables of age, sex, noncancer disease, or cancer, STAS scores of 9: patient, STAS score of 8 or 9: family, the expertise for nurses were 1.20, 1.11,

Table 3 Differences in symptoms intensity between the first time and 1 week later in patients with noncancer diseases

Symptoms	STAS score [†]				First time vs. 1 week later		
	First time		1 week later		P value	ES	95% CI
	Total, N	≥2 [‡] , n (%)	Total, N	≥2 [‡] , n (%)			
Anorexia	292	59 (20.2)	292	34 (11.6)	0.005**	0.12	-0.145 to -0.027
Dyspnea	356	50 (14.0)	355	26 (7.3)	0.004**	0.11	-0.112 to -0.022
Sputum	359	48 (13.4)	360	34 (9.4)	0.10	0.06	-0.086 to 0.007
Pain	351	35 (10.0)	356	17 (4.8)	0.008**	0.10	-0.09 to -0.014
Anxiety	285	26 (9.1)	286	16 (5.6)	0.11	0.07	-0.078 to 0.007
Edema	360	30 (8.3)	360	22 (6.1)	0.25	0.04	-0.06 to 0.016
Fatigue	339	25 (7.4)	343	13 (3.8)	0.04*	0.08	-0.07 to -0.001
Insomnia	353	24 (6.8)	352	11 (3.1)	0.02*	0.09	-0.069 to -0.005
Dry mouth	349	17 (4.9)	351	4 (1.1)	0.008**	0.10	-0.062 to -0.012
Constipation	355	16 (4.5)	357	13 (3.6)	0.56	0.02	-0.038 to 0.02
Fever	359	15 (4.2)	360	6 (1.7)	0.04*	0.08	-0.05 to -0.001
Incontinence	328	12 (3.7)	331	10 (3.0)	0.65	0.02	-0.034 to 0.021
Deliria	350	13 (3.7)	352	3 (0.9)	0.02*	0.09	-0.051 to -0.007
Cough	358	11 (3.1)	360	3 (0.8)	0.03*	0.08	-0.043 to -0.002
Drowsiness	348	7 (2.0)	346	2 (0.6)	0.18	0.05	-0.031 to 0.002
Abdominal distension	359	7 (1.9)	358	6 (1.7)	>0.99	0.00	-0.022 to 0.017
Diarrhea	360	5 (1.4)	360	3 (0.8)	0.72	0.01	-0.021 to 0.01
Depression	307	3 (1.0)	312	4 (1.3)	0.98	0.00	-0.014 to 0.020
Nausea	356	2 (0.6)	358	0	0.48	0.03	-0.013 to 0.002
Numbness	337	1 (0.3)	340	2 (0.6)	0.99	0.00	-0.007 to 0.013
Vomiting	360	1 (0.3)	360	0	>0.99	0.00	-0.008 to 0.003
Urinary retention	322	1 (0.3)	326	2 (0.6)	0.99	0.00	-0.007 to 0.013

Note that in the STAS symptom version, in addition to scores 0, 1, 2, 3, and 4, there is an item called “not evaluable”. The variation in the value of N in each symptom score is attributed to this “not evaluable” item. More than 10% of patients with noncancer diseases experienced suffering with a STAS score of ≥2 in pain, dyspnea, sputum, and anorexia during the first evaluation. The ratio of STAS scores of ≥2 for the sputum during the first evaluation did not show a statistically significant decrease after 1 week. The ratio of STAS scores of ≥2 for pain, dyspnea, and anorexia during the first evaluation showed a statistically significant decrease after 1 week. However, the ratio of STAS scores of ≥2 for anorexia was still >10% after 1 week. [†], STAS scores mean the following: 0 = none; 1 = occasional, intermittent. Patient does not need any further treatment now (satisfied with current treatment, no intervention needed); 2 = moderate. Occasionally has bad days and may interfere with activities of daily living (medications need to be adjusted or some other treatment, but not severe symptoms); 3 = often severe, significantly impairs activities of daily living and concentration (severe, often); 4 = severe symptoms are persistent (severe, persistent); [‡], ≥2 denotes a STAS score of =2 or higher. *, P<0.05; **, P<0.01. STAS, Support Team Assessment Schedule; ES, effect size; CI, confidence interval.

1.22, 1.19, 1.06, and 1.04, respectively. No multicollinearity issues occurred. Noncancer diseases with STAS score of 9 for the patient’s perception of the medical condition, STAS score of 8 or 9 for the family’s perception of the medical

condition, and the expertise in gerontological nursing were significant variables for which the client requested ethics support. This was the same result after a stepwise method of variable selection.

Table 4 Differences in the frequency of the implementation of ethics support between the cancer and noncancer or between the nondementia and dementia groups

Implementation of ethics support	Cancer, n					Dementia, n				
	Yes	No	Chi-square value	P value	Effect size	Yes	No	Chi-square value	P value	Effect size
Not implemented	139	30	144.6	<0.001***	0.44, large	6	163	72.00	<0.001***	0.308, medium
Implemented	54	179				77	156			
Data not available	208	151				43	316			

First, we performed a χ^2 test between the three groups on the ethics support implementation. We found statistically significant differences among the three groups. Next, we performed a comparison between the groups using the Ryan method. We found statistically significant differences in all three combinations among the three groups. The above results were similar for both comparisons with and without cancer and with and without dementia. Patients with noncancer had a higher ratio of receiving ethics support implementation compared to patients with cancer. Patients with dementia had a higher ratio of receiving ethics support implementation compared to patients with nondementia. ***, $P < 0.001$.

Table 5 Differences in the content of the consultations according to the expertise of nurses on the HSPC

Contents of the consultation	Certified nurse in palliative care (n=309), n (%)	Certified nurse specialist in gerontological nursing (n=452), n (%)	Chi-square value	P value	ES	95% CI
Physical pain	223 (72.2)	259 (57.3)	17.47	<0.001***	0.15	-0.22 to -0.08
Psychological pain	181 (58.6)	140 (31.0)	57.34	<0.001***	0.27	-0.35 to -0.21
Family care	116 (37.5)	166 (36.7)	0.05	0.82	0.01	-0.08 to 0.06
Social pain	50 (16.2)	41 (9.1)	8.81	0.003**	0.11	-0.12 to -0.02
Ethics support	48 (15.5)	179 (39.6)	50.79	<0.001***	0.26	0.18 to 0.30
Spiritual pain	39 (12.6)	37 (8.2)	4.02	0.04*	0.07	-0.09 to 0.00
Nutritional support	38 (12.3)	72 (15.9)	1.96	0.16	0.05	-0.01 to 0.09
Medications	13 (4.2)	17 (3.8)	0.10	0.76	0.01	-0.03 to 0.02
Rehabilitation	6 (1.9)	14 (3.1)	0.56	0.45	0.03	-0.01 to 0.03

When the certified nurse specialist in gerontological nursing was on the HSPC, there were more ethics support consultations than when the certified nurse in palliative care was on the HSPC. *, $P < 0.05$; **, $P < 0.01$; ***, $P < 0.001$. HSPC, hospital-based specialist palliative care team; ES, effect size; CI, confidence interval.

The round-robin method, in which all explanatory variables were entered for sensitivity analysis, performed in the logistic regression analysis had similar results to the stepwise method.

Discussion

Explanations of key findings

To the best of our knowledge, the present study is the first to clarify the needs of patients and families from HSPC for patients with noncancer diseases in Japan. The needs include

(I) symptoms management that are more frequent, such as dyspnea, sputum accumulation than cancer, and less amenable, such as sputum accumulation and anorexia; (II) ethics support for patients with noncancer diseases, including those with dementia, those with impaired decision-making capacity, and those lacking advocates; and (III) advice on ethics issues from a certified nurse specialist in gerontological nursing.

Comparison with similar research on symptom management

The first crucial finding of this study was that patients with noncancer diseases also experienced suffering. Rojas-

Table 6 Logistic regression analysis when the presence or absence of ethics support requests is the objective variable

Explanatory variable	Analysis with all explanatory variables				Variable selection using stepwise method			
	Odds ratio	95% CI		P value	Odds ratio	95% CI		P value
		Lower limit	Upper limit			Lower limit	Upper limit	
Intercept	0.011	0.002	0.053	<0.001***	0.010	0.002	0.048	<0.001***
Age	1.020	0.998	1.040	0.07	1.020	1.000	1.040	0.04
Sex	1.200	0.818	1.750	0.35	–	–	–	–
Noncancer	4.690	3.090	7.130	<0.001***	4.670	3.080	7.090	<0.001***
STAS score 9: patient	2.280	1.540	3.390	<0.001***	2.340	1.580	3.460	<0.001***
STAS score 8 or 9: family	6.340	2.300	17.500	<0.001***	6.180	2.240	17.000	<0.001***
Expertise in gerontological nursing	3.170	2.120	4.760	<0.001***	3.140	2.100	4.710	<0.001***

Age was a continuous variable. Sex was set as 0 for males and 1 for females. Cancer or noncancer was set as 0 for cancer and 1 for noncancer. STAS score of 9: patient was set as 0 if the STAS score was not 9 and 1 if it was 9. STAS score of 8 or 9: family was set as 0 if the STAS score was neither 8 nor 9 and 1 if the STAS score was 8 or 9. Expertise of nurses was set as 0 if the nurse's expertise was palliative care and 1 if geriatric care. A patient STAS score of 9 denotes that the patient does not have decision-making capacity. A family STAS score of 9 denotes that the family does not have decision-making capacity. A family STAS score of 8 denotes that no family member can advocate for the patient's wishes. In logistic regression analysis, P value was <0.0001. We have obtained a good regression equation. The variance inflation factor values for six explanatory variables: age, sex, cancer or noncancer, STAS score of 9: patient, STAS score of 8 or 9: family, qualifications for nurses were 1.20, 1.11, 1.22, 1.19, 1.06, and 1.04, respectively. No multicollinearity issues were observed. Noncancer disease, STAS score of 9 for the patient's perception of the medical condition, STAS score of 8 or 9 for the family's perception of the medical condition, and the nurse's expertise in geriatric care were significant variables for which the client requested ethics support. This was the same result after a stepwise method of the variable selection. ***, P<0.001. CI, confidence interval; STAS, Support Team Assessment Schedule.

Concha *et al.* also showed that the prevalence of reported symptoms did not significantly differ between noncancer patients receiving specialized palliative care and cancer patients (42). Although all similar reports indicate that the distressing symptoms experienced by noncancer patients are substantial (43,44), the types of distressing symptoms vary from one study to another (45). In addition, very few studies have used the STAS for assessment, and the only reports in Japan with large enough sample sizes have been on patients with cancer (46). Conversely, our study noted that patients with noncancer diseases suffer from pain, dyspnea, sputum accumulation, and anorexia, which occur in >10% of the cases. These results were consistent with those reported by Bandedali *et al.* (47). Despite this discussion of palliative care needs for patients with noncancer diseases, the use of specialized palliative care remains limited worldwide (33). Considering the low access to palliative care, we propose the development of an international consensus on referral criteria for older adults with noncancer to ensure access to HSPC (4). The problem of low access to HSPC is similarly prevalent in Japan, with estimates showing that noncancer diseases account for only 5.3% (n=104,331) of

the HSPC registry of the Japanese Society of Palliative Medicine (35). This finding highlights the need for an approach that ensures HSPC access among patients with noncancer diseases in Japan. The current study, in which 47.3% of all requests were about patients with noncancer diseases, will certainly have a significant impact on the future activities of the HSPC in Japan.

Comparison with similar research on ethics support

The second crucial finding of this study was the identification of the needs of ethics support in HSPC, particularly for patients with noncancer diseases and dementia. Previous studies have reported that palliative care specialists implement ethics support; however, there are few reports of HSPC that implement ethics support worldwide (28,29), and none in Japan. There has also been talk of the importance of education in ethics support in palliative care specialists (48) or HSPC (49). By including noncancer diseases, including dementia, in the target population of HSPC, we have an opportunity for practical education in ethics support. To date, Japanese papers have continued to

point out the need for ethics support, especially in medical decision-making for people without relatives, and the problem of access to ethics support models; however, no studies have released findings on ethics support provided by HSPC in Japan (26-29). Our study added to the findings that people with noncancer diseases, particularly those with dementia, those with impaired decision-making capacity, and those lacking advocates, had the needs for ethics support according to the results presented in *Table 6*. We believe that HSPC not only has ethics support needs but also its educational needs.

Comparison with similar research on certified nurse specialists in gerontological nursing

The third, particularly interesting, finding of this study was that different expertise of the nurses were related to the content of consultations. Our study added to the findings regarding the expertise of nurses in an HSPC. The nurse, as an intermediary, has the role of facilitating decision support within the team (50). However, although nurses are key members of interdisciplinary geriatric consultation teams, their role is not always clear (51). In addition, nurses are confident in their ability to manage symptoms of patients with noncancer diseases, but not necessarily in their ability to manage the human aspects of these patients, and thereby, they require education (52). Thus, a certified nurse specialist in gerontological nursing as key members of the HSPC might be expected to facilitate decision support within the HSPC, serve as ethics support in one area of decision support, and facilitate practical education on ethics support in palliative care for patients with noncancer diseases.

Certified nurses in palliative care have been considered as the standard for nurses as HSPC members in Japan (36). In recent years, palliative care for heart failure has been recognized in Japan, with additional reimbursement; however, care provided by certified nurses in chronic heart failure nursing differs from that provided by certified nurses in palliative care to patients and their families, and these nurses do not collaborate with each other (53). Certified nurses in chronic heart failure nursing might be more desirable to be included in the HSPC. Currently in Japan, palliative care for dementia is not recognized as a system, with no additional reimbursement. Certified nurse specialists in gerontological nursing might be more suitable to be included in the HSPC, because, as our research has shown, a certified nurse specialist in gerontological nursing

and a certified nurse in palliative care might have different needs for patient and family care. The integration of palliative and geriatric care has been reported to contribute to patient satisfaction, with one such model having been demonstrated one herein (7).

Additionally, it was interesting to note that the logistic regression analysis showed that the patient's STAS score of 9 and the family's STAS score of 8 influenced the request for ethics support. A STAS score of 9 means that patient lacks decision-making capacity. A STAS score of 8 means that no family member advocates on behalf of the patient's wishes. To the best of our knowledge, this finding has not been reported before. Moreover, we added new findings. The Japanese Ministry of Health, Labour, and Welfare's guidelines (31) on the decision-making process in end-of-life care state that, in such cases, the medical care team should support the decision-making process, focusing on the patients' prior wishes, estimated wishes, or best interest.

Strengths and future research

The strength of our study lies in our identification of the needs of patients and families suffering from noncancer diseases, including dementia, from HSPC in Japanese hospitals, where hospital deaths still remain high and the scope of in-hospital palliative care has yet to expand to noncancer diseases. HSPC, including certified nurse specialists in gerontological nurses, should provide ethics support for people with noncancer diseases requiring complex decision-making, including those with dementia, those with reduced decision-making capacity, and those without an advocate while addressing intractable distress, such as sputum accumulation and anorexia. Research on palliative care for dementia remains insufficient in Japan and perhaps worldwide. For instance, no current HSPC intervention studies have been available for people with end-stage dementia, and although a certain impact may be observed, such as reduced selection of certain medical procedures during hospitalization, the effectiveness of HSPC has not necessarily been demonstrated (54,55). Our research may have a certain impact on this status quo.

Future research should include exploratory study into the causes of sputum accumulation using an electronic medical record database, a qualitative study of the real-world ethics support (56) provided in the context of the Japanese culture using the database, intervention study combining advance care planning and ethics support as early palliative care provided by HSPC. This study is ongoing. Our study might

serve as a basis for considering a one-stop HSPC service with symptom management and ethics support in its role of combining palliative care and geriatric care (57,58).

Limitations

There are four limitations of this study. First, our study utilized a retrospective design. Second, in our study, one patient had multiple diagnoses. Third, the STAS is an evaluation by others. The IPOS (22,23), including self-administered evaluation by the patient, is used worldwide as a successor to the STAS. However, when we implemented the STAS in our electronic health record in 2011, the IPOS had not been tested for reliability and validity in Japanese. Fourth, National Center for Geriatrics and Gerontology is a highly specialized center for dementia and geriatric care; thus, our findings are not necessarily generalizable.

Conclusions

The needs of patients with noncancer diseases and their families from HSPC in Japan included (I) symptom management for intractable conditions, such as sputum accumulation; (II) ethics support for patients with noncancer diseases, including those with dementia, those with impaired decision-making capacity, and those without advocates; and (III) advice on ethics issues from certified nurse specialists in gerontological nursing.

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