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Original Article

Assessment of Reasons for Referral and Activities of Hospital Palliative Care Teams Using a Standard Format: A Multicenter 1000 Case Description

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Abstract

Context. The many benefits of hospital palliative care teams (PCTs) are well known. However, their specific activities have not been fully clarified, and no standardized methods for reporting PCT activities are available.

Objectives. The aim of this study was to investigate, through the use of a standard format, the activities performed by hospital PCTs in Japan.

Methods. This was a prospective observational study. A total of 21 hospital PCTs were included in this study, and each recruited approximately 50 consecutively referred patients. Participating PCTs filled in a standard form for reporting activities.

Results. We obtained data from 1055 patients who were referred to PCTs. Of the 1055 patients, 1005 patients (95%) had cancer. The median number of reasons for referral and problems identified by PCTs was two (0–22) and four (0–18), respectively. The two major reasons for referral were pain (63%) and anxiety/depression/grief/emotional burden (22%). The major recommendations were pharmacological treatment (74%), care for the patient's physical symptoms (49%), and support for patient's decision making (38%). The major activities performed by the PCTs were comprehensive assessment (90%), care for the patient's physical symptoms (77%), and pharmacological treatment (74%).

Conclusion. The components of hospital PCT activities were successfully measured using the Standard Format for Reporting Hospital PCT Activity. The results of this study and the format for reporting hospital PCT activity could be effective in improving hospital PCT practice and for the education of new hospital PCT members. J Pain Symptom Manage 2013;■:■–■.

Key Words

Palliative care, hospital palliative care team, consultation, activity, multicenter study

Introduction

Since the Cancer Control Act was introduced in 2006 to improve the quality of life of patients with cancer in Japan, palliative care has been accredited as an essential part of cancer services, and access to hospital palliative care teams (PCTs) has been required in all designated cancer hospitals. The number of designated cancer hospitals is now 388. Hospital PCT services are one of the most common specialized palliative care services worldwide,[1,2] which provide palliative care in the early course of disease and increase patient quality of life.

Many benefits of hospital PCTs have been reported and include symptom improvement,[3–6] improved insight of patients into their disease,[7] patient and staff satisfaction, and cost reduction.[8,9] Intervention by hospital PCTs is complex, but their specific activities are not well described. Therefore, it is also unclear what components of interventions are the most beneficial.

Complex interventions need to be described fully,[10] and by doing so, the intervention can be reproduced and compared between sites or countries. Kuin et al.[11] prospectively investigated 2040 consultations from 19 community PCTs and examined the components of those consultations. The results showed that the most frequently discussed topics during consultation were pain, choice of pharmacological treatment, and constipation. Jacobsen et al.[12] examined 67 patients with lung cancer in palliative care outpatient consultations and determined that the greatest amount of time in the initial consultation was spent addressing symptom management, patient and family coping, and understanding of the illness. These findings provide valuable insights to understanding the activities of hospital PCTs, but the components of the intervention and the respective proportions would vary between inpatient palliative care consultations and the outpatients/community because patient conditions are different. Furthermore, hospital PCTs work more closely with referring staff, which means that hospital PCTs may have a different role than PCTs performing consultations with outpatients and patients at home.

The aim of this study was to investigate the activities performed by hospital PCTs in Japan through the use of a standard format. This would enable PCTs to review their practices and compare PCT activities between sites or countries, leading to improved quality of care.

Methods

Design and Participants

This was a prospective observational study. The inclusion criteria for participating PCTs were: 1) a hospital-based PCT, 2) performing palliative care consultations, and 3) able to register at least 50 consecutive inpatients referred to the PCT. We recruited PCTs through a mailing list of approximately 350 voluntarily registered palliative care multiprofessionals; a total of 21 PCTs that met the inclusion criteria agreed to participate.

Development of a Standard Format for Reporting Hospital PCT Activities

Based on a systematic literature review of published articles about PCT activities[13–19] and on unpublished data that investigated activities for 200 referred patients by one hospital PCT, two palliative care physicians, three palliative care nurses, and a researcher in the palliative care field discussed and developed the format for reporting PCT activities (Standard Format for Reporting Hospital PCT Activities: SF-PCTA). Before using this format, we conducted a pilot study with 100 patients from 10 PCTs from April 2009 to January 2010, and confirmed the face validity and feasibility of the format through a questionnaire survey and a group interview with PCT members. Based on the pilot study, several items of the format were modified. No psychometric analysis was performed. The format included the following three sections:

1. Cover sheet

This included: day of referral, patient age, sex, diagnosis, treatment status, Eastern Cooperative Oncology Group performance status, referring person, the last date of observation, and the reason the observation ended.

2. Reasons for referral/problems identified by hospital PCT

This section comprised ten categories: physical/pharmacological issues, emotional/spiritual issues, diagnosis/treatment issues, social issues, family issues, place of care, ethical issues, bereaved family issues, discussion of referral options, and other. Details of the items in each category are shown in Appendix. In this study, "reason for referral" means the situation described in the referral form for which the referring staff wanted consultation. At the time of referral, the PCT members (principally a physician or nurse) extracted all referral reasons from the referral form and identified the problems of the referred patient. The relevance of the identified problems was discussed at a PCT meeting once a week.

3. Activity

We used the word "activity" instead of "intervention" in the study because we intended to describe the broader practice of PCTs including team management. This section comprised 13 major components, namely comprehensive assessment, care for patients' physical symptoms, care for patients' psychiatric symptoms/emotional support for patients, support for patient's decision making, support for decision making about place of care, support for patient at home, family support, support for ethical issues, referral to specialists, medical procedures/investigations, staff support, coordination within the PCT, and pharmacological treatment. Details of each component can be found in Appendix. The PCT members checked each item that they recommended to the referring team and/or actually performed themselves, no matter how many times they recommended or performed the items during the observation period. We defined "recommendation" as what the PCT suggested to the referring team and "performance" as what the PCT implemented directly with or without recommendation. One of the PCT members (principally a physician or nurse) was requested to fill out the standard form on the day they recommended or performed the items. To avoid duplication and omission, what they recommended or performed was confirmed at a PCT meeting once a week.

Procedures

We asked each PCT to recruit 50 consecutively referred patients within six months, and to fill out a form for reporting PCT activities for each patient. We developed a manual for completing the form and held an orientation meeting for participating PCTs to explain how to use it before conducting the study. The observation period for each patient was set at four weeks from the time of referral. This study was conducted from August 2010 to October 2011. We decided not to obtain informed consent from each patient because this was an observational study that described the routine clinical practice of PCTs. The forms filled out by PCTs were sent to one of the researchers (To.S.) anonymously. The protocol was approved by the institutional review board of each participating institution.

Statistical Analysis

Descriptive statistics were performed. We determined the percentages of each item for all patients included in the study. To simplify the results of recommendations and performance of activities by PCTs, we also show the percentages of each major component for all patients. To calculate the percentages for each major component, we recorded one check for major categories when at least one detailed item was checked. The form was not constructed to distinguish between recommendations and the performance of activities for pharmacological treatments, and we treated the check for pharmacological treatments as both recommendation and performance. The statistical package SPSS v. 15.0J for Windows (SPSS, Inc., Chicago, IL) was used for all statistical analyses.

Results

Hospital and Patient Backgrounds

Among the 21 hospitals participating in the study, the median number of beds was 621 (range 327–1182) and 16 hospitals were registered as designated cancer hospitals. The median number of PCT members was five (range 2–25). The median numbers of professions were: three physicians (range 1–7), two nurses (range 1–5), and one pharmacist (range 1–3). The median number of referrals the previous year was 182 (63–2000), and 12 PCTs (57%) had been in operation for more than three years.

Table 1 summarizes the characteristics of the 1055 patients who were referred to PCTs during the study. The median number of patients included in the study per PCT was 50 (range 35–58). Of the 1055 patients, 1005 were patients with cancer (95%). More than half of the referred patients had completed anticancer treatment, and more than half of the referred patients had a performance status higher than three (54% and 59%, respectively). The mean

Table 1
Characteristics of Referred Patients

Characteristics	*N* = 1055, *n* (%)
Age (y)	
Mean ± SD	65.9 ± 14.3
Sex	
Male	576 (55)
Female	471 (45)
Diagnosis	
Cancer	1005 (95)
Noncancer	41 (4)
Cancer site	
Lung	189 (18)
Colon	124 (12)
Stomach	99 (9)
Pancreas	84 (8)
Breast	80 (8)
Unknown	80 (8)
Uterus/ovary	70 (7)
Head and neck	65 (6)
Kidney/urinary tract/bladder	58 (5)
Other	238 (23)
Treatment status	
No further anticancer treatment	573 (54)
Under anticancer treatment	335 (32)
Before anticancer treatment	78 (7)
ECOG performance status	
0	32 (3)
1	139 (13)
2	248 (24)
3	334 (32)
4	288 (27)
Median	3
Referring person	
Physician	967 (92)
Nurse	80 (8)
Outcome 4 wk after referral	
Discharge/transfer to other institution	385 (36)
End of the observation period	347 (33)
Died	262 (25)
Problem resolved	30 (3)

ECOG = Eastern Cooperative Oncology Group.
Percentages do not equal 100% in some cases owing to rounding or missing value.

actual observation period was 17.5 days (SD = 9.6).

Reasons for Referral/Problems Identified by PCTs at the Time of Referral

Table 2 summarizes the reasons for referral and the problems identified by PCTs. The median numbers of reasons for referral and of problems identified by PCTs were two (range 0–22) and four (range 0–18), respectively. The major reasons for referral were pain, 669 (63%); anxiety/depression/grief/emotional distress, 227 (22%); place of care, 171 (16%); appetite loss/difficulty in oral intake, 168 (16%); and dyspnea/cough/sputum, 167 (16%).

The major problems identified by PCTs were pain, 651 (62%); anxiety/depression/grief/emotional distress, 394 (37%); and appetite loss/difficulty in oral intake, 306 (29%).

Recommendations and Activities Performed by Hospital PCTs

Fig. 1 shows the percentages by major components of recommendations made and activities performed for all patients by hospital PCTs. Of the 1055 referred patients, the major components of recommendations were: pharmacological treatment, 778 (74%); care for patients' physical symptoms, 514 (49%); and support for patient's decision making, 403 (38%). The major components of activities performed were: comprehensive assessment, 954 (90%); care for patients' physical symptoms, 809 (77%); and pharmacological treatment 778 (74%).

Table 2

Reasons for Referral and Problems Identified by hospital Palliative Care Teams (PCTs) at the Time of Referral

		N = 1055	
Categories	Items	Reasons for Referral, *n* (%)	Problems Identified by Hospital PCTs, *n* (%)
Physical/pharmacological issues	Pain	669 (63)	651 (62)
	Appetite loss/difficulty in oral intake	168 (16)	306 (29)
	Dyspnea/cough/sputum	167 (16)	228 (22)
	Fatigue	140 (13)	272 (26)
	Nausea/vomiting	110 (10)	163 (15)
	Present symptom palliation review	104 (10)	155 (15)
	Abdominal swelling/ascites	101 (10)	164 (16)
	Choice of drugs/change in the drug dosage or the route of administration	87 (8)	151 (14)
	Constipation	47 (4)	170 (16)
	Edema/lymphedema	44 (4)	114 (11)
	Drowsiness	32 (3)	145 (14)
	Oral problem	12 (1)	87 (8)
	Others	35 (3)	64 (6)
Psychiatric/emotional/spiritual issues	Anxiety/depression/grief/emotional burden	227 (22)	394 (37)
	Insomnia	91 (9)	243 (23)
	Delirium	78 (7)	158 (15)
	Spiritual issues	22 (2)	72 (7)
	Others	61 (6)	142 (13)
Diagnosis/treatment issues	Illness understanding/choice of treatment	30 (3)	125 (12)
	Anxiety about side effects of anticancer treatment	16 (2)	57 (7)
	Communication difficulties with clinical staff	14 (1)	71 (5)
Social issues	Economic/work problem	19 (2)	63 (6)
	Absence of caregiver	24 (2)	75 (7)
Family issues	Anxiety/depression/grief/emotional burden	50 (5)	160 (15)
	Illness understanding/choice of treatment	20 (2)	79 (5)
	Shortage of practical knowledge/skills	12 (1)	55 (7)
Place of care		171 (16)	298 (28)
Ethical issues		8 (1)	28 (3)
Bereaved family issues		2 (0)	3 (0)
Discussion of referral options		69 (7)	95 (9)
Others		12 (1)	16 (2)

Items are ordered by prevalence of reason for referral in each category.

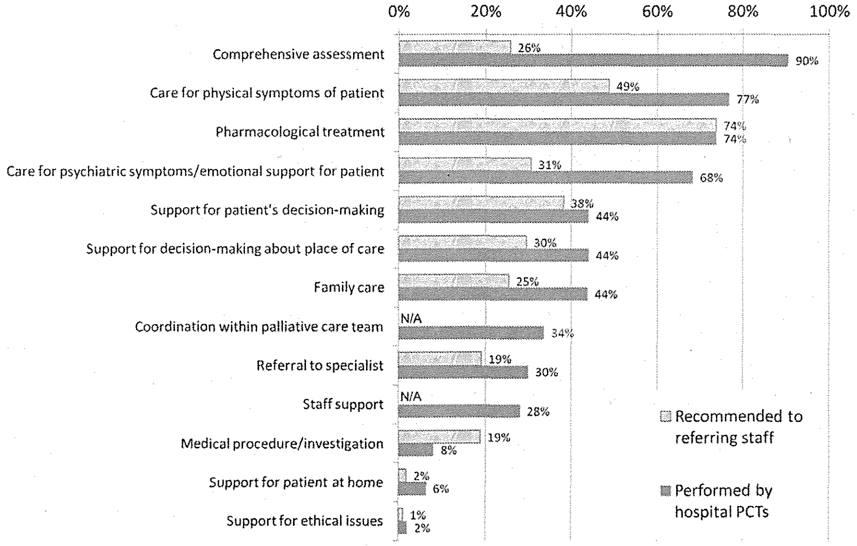

Fig. 1. Percentages by components of hospital PCTs activities in all referred patients ($N = 1055$). Components are ordered by prevalence of performance by inpatient PCTs. PCT = palliative care team; N/A = not applicable.

Table 3 shows the major activities of hospital PCTs for all referred patients. The major recommendations were: care for pain, 291 (28%); assess patient's physical symptoms, 214 (20%); and confirm family's preference and coordinate, 200 (19%). The major activities performed were: assess patient's physical symptoms, 910 (86%); identify what patient worries about the most, 844 (80%); and assess patient's psychological status, 762 (72%).

Table 4 shows the percentages of recommendations made and/or activities performed by PCTs regarding pharmacological treatment. The most common recommendation and/or activity was adjustment of regular opioids, 430 (41%); followed by new administration of regular opioids, 262 (25%); and new administration of rescue opioids, 238 (23%).

Discussion

This study prospectively examined to what extent hospital PCTs performed their activities for each referred patient for four weeks after referral using a standard format. The most important finding in this study was that the major components of the hospital PCTs' activities were quantitatively determined. In addition, clarifying the details of hospital PCT activities was also of value.

Major referral reasons to hospital PCTs were pain and other symptoms and place of care. These findings are consistent with previous studies,[4,15,20,21] and confirm that they are the main issues for patients with cancer referred to hospital PCTs. The PCTs received referrals for a wide range of reasons, although the proportions varied. This indicates that PCTs have to meet broad needs, and, therefore, patients referred to hospital PCTs should be managed by a multidisciplinary team.

The median number of problems identified by PCTs at the time of referral was greater than the number of reasons for referral. Additionally, the hospital PCTs performed comprehensive assessments for approximately 90% of referred patients by themselves. These data show that patients are referred to the PCTs with several specific problems, but that the PCTs perform comprehensive assessments attempting to address all existing problems.[12]

The PCTs also provided a certain amount of staff support, such as information sharing, education, and emotional support. Although little is known about the type of staff support hospital PCTs provide, the data that are available show a positive effect.[22] Consequently, staff support as well as patient support is an important role for PCTs. To clarify which staff was actually supported might be an area for further exploration.

One of the interesting findings in this study was that the percentage of major activities performed by PCTs themselves was higher than

Table 3
Major Activities of Hospital Palliative Care Teams (PCTs) for all Referred Patients

			N= 1055	
Components	Categories	Detailed Items/Actions	Recommended to Referring Staff, *n* (%)	Performed by Hospital PCTs, *n* (%)
1. Comprehensive assessment				
		Assess patient's physical symptoms	214 (20)	910 (86)
		Identify what the patient worries about the most	171 (16)	844 (80)
		Assess patient's psychological status	168 (16)	762 (72)
		Assess patient's illness understanding	118 (11)	488 (46)
2. Care for physical symptoms of patient				
	Care for pain[a]		291 (28)	646 (61)
3. Care for psychiatric symptoms/emotional support for patient				
	General psychiatric support	Establish relationship with patient	80 (8)	576 (55)
		Help patient accept disease understanding	79 (7)	326 (31)
		Help patient accept their own feelings	79 (7)	313 (30)
5. Support for decision making about place of care				
	Confirmation of preference and coordination	Confirm patient's preference and coordinate	187 (18)	330 (31)
		Confirm family's preference and coordinate	200 (19)	236 (22)
7. Family support				
	Comprehensive assessment	Identify what the family worries about the most	137 (13)	364 (35)
11. Staff support				
	Comprehensive assessment	Identify what referring staff feels is the difficulty	—	616 (58)
		Clarify underlying problems	—	434 (41)
	Sharing information among staff in an institution	Confirm whether information is shared	—	540 (51)
		Coordinate individually to encourage sharing information	—	379 (36)
	Education for staff	Explain to staff what patient's distress is, the extent of the patient's distress, and the cause of the patient's distress	—	473 (45)
		Explain to staff how we can palliate patient's distress	—	430 (41)
	Emotional support for staff	Give positive feedback about treatment/care that staff provided	—	376 (36)
		Accept staff feelings	—	330 (31)
12. Coordination within palliative care team				
		Organize in preparation for when PCT members are unavailable	—	319 (30)

Only detailed items with more than 30% in activity performed by hospital PCTs are shown.
Component's number is corresponding to the ones in *Appendix*.

[a] Any of: comprehensive assessment, setting a treatment goal, identifying exacerbating or ameliorating factors, introducing a method of symptom palliation matching patient's and family's needs, and educating how to address worsening symptoms/educating how to prevent symptom exacerbation.

Table 4
Percentages of Detailed Activities in Pharmacological Treatment Made by Hospital Palliative Care Teams in All Referred Patients

		$N = 1055$	
		Actions	
Major Categories	Minor Categories	New Administration, *n* (%)	Adjustment, *n* (%)[a]
Analgesics	Opioids (regular)	262 (25)	430 (41)
	Opioids (rescue)	238 (23)	223 (21)
	Nonopioid analgesics	152 (14)	108 (10)
	Adjuvant analgesics	131 (12)	59 (6)
Antiemetics	Antidopaminergics, antihistaminergics	112 (11)	45 (4)
	Prokinetic agents	28 (3)	20 (2)
Psychoactive drugs	Anxiolytics	157 (15)	71 (7)
	Antipsychotics	139 (13)	43 (4)
	Antidepressants	60 (6)	19 (2)
Corticosteroids		143 (14)	56 (5)
Gastrointestinal agents	Laxatives	60 (6)	48 (5)
	Gastric secretion inhibitors	32 (3)	5 (0)
Anticholinergics	Scopolamines	11 (1)	1 (0)
Others		90 (9)	36 (3)

Minor categories are ordered by prevalence of new administration in each major category.
[a] Adjustment means either increase, decrease/withdrawal, change, addition, or route change.

the percentage of major recommendations made for most components of hospital PCT activities. This is a surprising result because it is a general belief that hospital PCTs' main role is to make recommendations on palliative care issues to referring staff.[23] One possible interpretation is that the PCTs surveyed in this study worked in a complementary way with staff rather than merely giving advice.

A final version of our format is shown in Appendix. Minor modifications were made based on the results of this study. This format is detailed, and we suggest that the category level of the format can be used to record daily PCT activity, and that detailed items be used to periodically gather national data (eg, every five years). If each hospital PCT collects data using this format, they can compare their activities to the national data, leading to a review of their own practice. We also can expect an educational benefit for new PCT staff because they can grasp the required tasks by seeing the activities described in this format and their average percentages.

Our study had several limitations. First, the PCTs in the study appeared to be weighted to mature teams whose activities were well established in their hospitals because the median number of referrals to PCTs in the previous year was large. The percentages of activities performed in newly established PCTs might be different from those of well-established PCTs. Second, the validity of this format was not formally evaluated, and this format might be limited in relevance and comprehensiveness. Third, most PCTs were composed of more than one member, so data on all of the PCT's activities may not have been completely collected. Fourth, we did not collect data on all of the problems that referring staff identified. Thus, the referring staff might have already assessed some of the problems with referred patients that the PCT also identified at the time of referral. Fifth, because the role of hospital PCTs and other styles of PCT differ, this format would not be as easily used in outpatient or community palliative care consultations.

In conclusion, we examined the activities performed by hospital PCTs through the use of a standard format for each referred patient for four weeks after referral. Hospital PCTs received referrals for a wide range of reasons and also identified new problems at the time of referral. The major components of the hospital PCTs' activities were comprehensive assessment, pharmacological treatment, and care for the patient's physical symptoms. The results of this study and the format for reporting hospital PCT activity could be effective for improving hospital PCT practice and for the education of new hospital PCT members.

Disclosures and Acknowledgments

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The authors declare no conflicts of interest.

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Appendix

Standard Format for Reporting Hospital Palliative Care Team Activities (SF-PCTA)

I. Cover Sheet

Date of referral (dd/mm/yy)	/ /		
Age	( ) years old		
Sex	☐Male	☐Female	
Diagnosis	☐Cancer	☐Noncancer	
Cancer site	☐Lung	☐Esophagus	☐Stomach
	☐Colon/rectum	☐Liver	☐Pancreas
	☐Biliary tract	☐Breast	☐Uterus/ovary
	☐Kidney/bladder	☐Prostate	☐Head and neck
	☐Central nervous system	☐Lymph node/hematology	☐Unknown
	☐Under investigation	☐Other	
Status of anticancer treatment	☐No further anticancer treatment		
	☐Under anticancer treatment		
	☐Before anticancer treatment		
ECOG Performance Status	☐0 ☐1 ☐2 ☐3 ☐4		
Referring person	☐Doctor ☐Nurse ☐Other		
Patient outcome when observation ends	Discharge or transfer to		
	☐Home		
	☐Inpatient hospice/palliative care unit (PCU)		
	☐Other		
	☐Observation period ended		
	☐Died		
	☐Problem resolved		

ECOG = Eastern Cooperative Oncology Group.

II. Reason for Referral and Initial Assessment

Category	Item	Reason for Referral	Problem Identified by Palliative Care Team (PCT)
Physical/pharmacological issues	Pain		
	Appetite loss/difficulty in oral intake		
	Dyspnea/cough/sputum		
	Fatigue		
	Nausea/vomiting		
	Abdominal swelling/ascites		
	Constipation		
	Edema/lymphedema		
	Drowsiness		
	Oral problem		
	Present symptom palliation review		
	Choice of drugs/change in the drug dosage or the route of administration		
	Other		
Psychiatric/emotional/spiritual issues	Anxiety/depression/grief/emotional distress		
	Insomnia		
	Delirium		
	Spiritual issues		
	Other		
Diagnosis/anticancer treatment issues	Illness understanding/choice of treatment		
	Anxiety about side effects of anticancer treatment		
	Communication difficulties with clinical staff		
Social issues	Economic/work problem		
	Absence of caregiver		
Family issues	Anxiety/depression/grief/emotional burden		
	Illness understanding/choice of treatment		
	Shortage of practical knowledge/skills		
Place of care			
Ethical issues			
Bereaved family issues			
Discussion of referral options	Establishing rapport between patient and PCT in preparation for future deterioration		
Other			

III. Activity

Component	Category	Detailed Item	Recommended	Performed
1. Comprehensive assessment				
		Identify what the patient worries about the most		
		Assess patient's physical symptoms		
		Assess patient's psychological status		
		Assess patient's illness understanding		
2. Care for patient's physical symptoms				
	Patient education about opioids	Educate how to use opioids effectively		
		Address anxiety about using opioids		
	Help to prevent physical distress	Any of: increasing or decreasing number of body position changes, using or changing devices for comfort, devising a way of transfer, changing or designing diet, encouraging or designing oral care		
	Care for pain	Any of: comprehensive assessment, setting a treatment goal, identifying exacerbating or ameliorating factors, introducing a method of symptom palliation matching patient's and family's needs, educating how to address worsening symptoms/educating how to prevent symptom exacerbation		
	Care for dyspnea			
	Care for nausea/vomiting/appetite loss			
	Care for abdominal swelling/ascites			
	Care for dry mouth			
	Care for fatigue			
	Care for edema/lymph edema			
	Care for drowsiness			
3. Care for psychiatric symptoms/emotional support for patients				
	Care for delirium			
	Care for insomnia			
	General psychiatric support	Establish relationship with patient		
		Help patient accept reality of their condition		
		Help patient accept their own feelings		
		Enhance social support		
		Provide relaxing environment		
	Individual care	Enhance relationships with family		
		Enhance patient's sense of physical control		
		Enhance patient's sense of control of the future		
		Help patient maintain their identity		
		Help maintain patient's hope		
		Relieve the sense of burden to others		
		Help to complete unfinished business		
		Relieve anxiety about death		

4. Support for patient's decision making		
		Assess for insight and preference of disclosure
		Provide additional information to support decision making
		Coordinate additional information for patients
		Bridge thoughts between all involved persons
5. Support for decision making about place of care		
	Confirmation of preference and coordination	Confirm patient's preference and coordinate
		Confirm family's preference and coordinate
	Support when discharged	Any of: assessing environment at home, changing or coordinating medical procedures to those that are easily used at home, referring to community health services, addressing when patient has distress at home, confirming contact person or section after discharge
	Support when transferred to PCU	Judge whether the timing of transfer to PCU is appropriate or not/co-ordinate
		Refer to PCU
6. Support for patient at home		
		Any of: monitoring or addressing patient at home, reporting the results of monitoring to physicians in outpatient services, providing advice for community health care professionals
7. Family support		
	Comprehensive assessment	Identify what the family worries about the most
	Emotional support	Assess family's psychological status
		Accept the feelings of the family
		Give advice on how to treat patient
		Explain the dying process
	Support for decision making	Any of: assessing for preference of disclosure, providing additional explanation to support decision making, coordinating for patients to have additional explanation, bridging thoughts between all involved persons
	Care for family's burden	Assess family's burden
		Coordinate care services for the patient
8. Support for ethical issues		
9. Referral to specialist		
		Specialist in psychological field
		Radiotherapist, medical oncologist, surgeon, orthopedist
		Pain clinician/anesthesiologist
		Discharge section/medical social worker
		Rehabilitation
		Other (nutrition support team, wound, ostomy and continence nurse, dental hygienist)

(*Continued*)

III. Continued

Component	Category	Detailed Item	Recommended	Performed
10. Medical procedure/investigation				
	Drainage	Pleural effusion, ascites		
	Artificial hydration	Reducing the amount, withdrawing, changing the types of hydration		
	Nerve block	Nerve block, TENS, acupuncture		
	Investigations	Blood tests, X-ray, CT, MRI, bone scintigraphy, PET		
	Other	Initiating blood transfusion or oxygen, using prosthetics, initiating or withdrawing inhalation, initiating or withdrawing suction		
11. Staff support				
	Comprehensive assessment	Identify what referring staff feels is the difficulty		
		Clarify underlying problems		
	Sharing information among staff in an institution	Confirm whether information is shared		
		Coordinate individually to encourage sharing information		
		Hold a conference for sharing information		
	Sharing information among staff in a community	Any of: confirming whether information is shared, coordinating individually to encourage sharing information, or holding a conference for sharing information		
	Education of staff	Explain to staff what patient's distress is, the extent of the patient's distress, and the cause of the patient's distress		
		Explain to staff how we can palliate patient's distress		
	Emotional support for staff	Give positive feedback about treatment/care that staff provided		
		Accept staff feelings		
	Assessment for institution, sections, staff	Assessment for characteristics, competency, function in institution, sections, and staff		
12. Coordination within PCT				
		Organize in preparation for when PCT members are unavailable		
		Assess and coordinate work balance of team members of PCT		
13. Pharmacological treatment				
Analgesics	Non-analgesics	New administration		
		Adjustment		
	Opioids (regular)	New administration		
		Adjustment		
	Opioids (rescue)	New administration		
		Adjustment		
	Adjuvant analgesics	New administration		
		Adjustment		

Antiemetics	Prokinetic agents	New administration
		Adjustment
	Antidopaminergics, antihistaminergics	New administration
		Adjustment
Psychoactive drug	Anxiolytics	New administration
		Adjustment
	Antipsychotics	New administration
		Adjustment
	Antidepressants	New administration
		Adjustment
Corticosteroids		New administration
		Adjustment
Gastrointestinal agents	Laxatives	New administration
		Adjustment
	Gastric secretion inhibitors	New administration
Anticholinergics	Scopolamines	New administration
Others		New administration
		Adjustment

TENS = transcutaneous electrical nerve stimulation; MRI = magnetic resonance imaging; PET = positron emission tomography.

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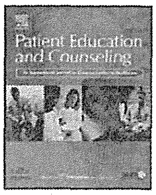

Short Communication

Characteristics associated with empathic behavior in Japanese oncologists

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ABSTRACT

Objective: Oncologists must have empathy when breaking bad news to patients who have incurable advanced cancer, and the level of empathy often depends on various individual characteristics. This study aimed to clarify the relationship between these characteristics and empathic behavior in Japanese oncologists.

Methods: We videotaped consultations in which oncologists conveyed news of incurable advanced cancer to simulated patients. Oncologists' empathetic behaviors were coded, and regression analysis was performed to determine the existence of any relationships with factors such as age, sex, and specialism.

Results: Sixty oncologists participated. In a multivariate model, only age was related to the empathy score ($r = 0.406$, $p = 0.033$); younger oncologists scored higher than did older oncologists.

Conclusions: We found that empathic behaviors were more frequent in younger oncologists.

Practice implications: This information could be useful in determining the best approach for implementing future empathy and communication training programs for experienced oncologists in Japanese medical institutions.

1. Introduction

Patients with incurable advanced cancer suffer intense emotional anguish, particularly when first receiving the bad news of their disease. However, physicians' empathy—defined in medical settings as "a predominantly cognitive attribute that involves an understanding of experiences, concerns and perspectives of the patient" [1]—is reportedly related to relatively high patient satisfaction and relatively low distress, especially when bad news is being delivered [2–4].

Oncologists' characteristics—such as age, sex, and specialism—may be associated with their empathic behavior. Previous studies analyzed empathy using self-reported questionnaires or audio-recorded conversations, with researchers investigating oncologists' reactions to patients' verbal distress cues. However, self-report questionnaires lack objectivity; furthermore, empathy has non-verbal aspects. Indeed, cancer patients' behavior is richly varied, making it difficult to identify empathy through oncologists' reactions to verbal expressions. Therefore, video-recorded conversations between oncologists and simulated patients (SPs) reacting to oncologists' behavior in a standardized way would allow us to make comparisons between consultations, leading to more useful information.

To examine how oncologists' characteristics influence their empathic behavior when breaking bad news, we analyzed video-recorded conversations between oncologists and SPs.

2. Methods

This study was approved by the Ethics Committee of the National Cancer Center of Japan.

2.1. Participants

2.1.1. Oncologists

Sixty oncologists from the National Cancer Center Hospital in Tokyo and the National Cancer Center Hospital East participated.

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Table 1
Empathy score of oncologists during bad news consultations ($N = 60$).

	Range	Median	*SD*	Correlation to the total
9 items total[a]	6–35	20.5	7.8	–
Empathy score item[b]				
Encouraging patients to ask questions	0–4	4	1.6	0.657
Asking about your worries and concerns	0–4	0	1.4	**0.748**
Saying words to prepare you mentally	0–4	3	1.9	0.634
Remaining silent to consider your feelings	0–4	1	1.7	0.689
Accepting your expression of emotion	0–4	3	1.7	**0.702**
Saying words that soothed your feelings	0–4	3	1.7	**0.755**
Telling the news in a hopeful way	0–4	4	1.0	0.265
Telling what you can hope for	0–4	4	1.1	0.373
Assuming responsibility for your care until the end	0–4	2	1.6	0.536

[a] Sum of 9 items of empathy score (range; 0–36).
[b] Responses were based on a 5-point scale (0 = not at all, 4 = extremely).
Correlations greater than 0.7 are in bold.

Investigators (*M.F. & Y.Y.*) met with each interested oncologist and fully described the study to them. Oncologists who volunteered to participate signed a consent form and gave information on 4 characteristics: age, sex, specialism, and years in practice.

2.1.2. Simulated patients (SPs)

Trained adult SPs participated in the study. Two male and four female adult SPs, all of whom had received at least 3 years of training as simulated cancer patients, participated in this study. The scenario was of middle-aged or elderly patients with advanced cancer, who had undergone numerous diagnostic procedures such as biopsy, having a consultation with their oncologists when being informed of their diagnosis. We videotaped each consultation. None of the SPs had encountered the oncologists previously.

2.2. Survey measures

Empathy score: To score empathy, we used the behavior rating scale, which was based on our previous survey on Japanese cancer patients' communication style preferences when receiving bad news [5–7]. The behavior rating scale included 32 items in 4 subscales, with each item rated on a 5-point scale (0 = not at all to 4 = extremely). The scale assesses the quality and quantity of each empathic behavior, encompassing verbal and non-verbal communication (*e.g.*, atmosphere, tone of voice, expressions, and glances throughout the interview). All items were chosen through discussion with research experts in the field and experienced oncologists and psycho-oncologists. Of the subscales, we chose to use "Reassurance and Emotional support," which consists of 9 items, with a total empathy score ranging from 0 to 36 (Table 1). This subscale correlates with the Interpersonal Reactivity Index, a self-reported questionnaire used for assessing empathy ($r = 0.676$, $p < 0.05$). Two independent coders received over 3 months of training in using the scale manual and videotaped 17 interviews as a preparatory experiment, which accounted for approximately 30% of the analyzed data. Inter-rater and intra-rater reliability for these preliminary interviews were high for the behavior rating scale ($\kappa = 0.826$ and 0.800, respectively).

2.3. Statistical analyses

Univariate analysis between empathy scores and characteristics was performed using Spearman's rank correlation coefficients and the Mann–Whitney *U* test, where appropriate; all characteristics (age, sex, specialism, and years in practice; $p < 0.05$) were retained. The correlation between age and years of practice was strong ($r = 0.924$, $p < 0.001$); thus, we only included age as an independent variable in the multiple regression model to control for multicollinearity. Multiple regression analysis was then performed with empathy score as the dependent variable and the characteristics as independent variables. All *p* values are two-tailed. Analyses were conducted using SPSS version 15.0J (PASW Collaboration and Deployment Services).

3. Results

3.1. Participant characteristics

Sixty Japanese oncologists (50 men; mean age = 36 years) participated in this study (Table 2). Most were surgeons (57%), whereas others specialisms included internal medicine (42%) and radiology (3%).

3.2. Empathy score

Across all consultations, the median empathy score was 20 (Table 1).

Table 2
Characteristics of oncologists ($N = 60$).

		N	%
Age (years)			
Range	28–65		
Mean	36		
SD	6.7		
<35		29	48.0%
36–45		22	37.0%
46<		9	15.0%
Sex			
Male		50	83.0%
Female		10	17.0%
Specialism			
Surgery		34	56.7%
Gastroenterology		18	30.0%
Otorynolaryngology		6	10.0%
Urology		3	5.0%
Gynecology		3	5.0%
Breast oncology		3	5.0%
Respiratory		1	1.7%
Internal medicine		25	41.7%
Gastroenterology		12	20.0%
Respiratory		6	10.0%
Breast oncology		5	8.3%
Hematology		1	1.7%
Radiation oncology		1	1.7%
Radiology		1	1.7%
Physicians' experience (years)			
Range	4–31		
Mean	10		
SD	6.4		
<10		30	50.0%
11–20		21	35.0%
21–30		8	13.3%
>31		1	1.7%

Table 3
Multiple regression analysis of factors associated with empathy score ($N = 60$).

Factor	Coefficient β	Standardized β	t	p value
Age[a]	−0.335	−0.289	−0.289	0.033
Sex; male/female	2.325	0.112	0.862	0.392
Specialism; internal medicine/the other	−2.159	−0.138	−0.995	0.324

Multiple $R = 0.461$, multiple $R^2 = 0.165$, adjusted multiple $R^2 = 0.120$.
[a] Continuous variable.

3.3. Relationships between characteristics and empathy

In the multivariate model, only age was related to the empathy score: younger oncologists scored higher than older oncologists (Table 3).

4. Discussion and conclusion

4.1. Discussion

This is the first reported study on the relationship between oncologists' characteristics and the verbal and non-verbal empathic behavior of oncologists, performed by videotaping oncologists delivering bad news to a SP.

In Western countries, characteristics such as age, sex, and specialism have been found to be associated with oncologists' empathic behavior [8]. In a multivariate model in this study, age was the only factor related to the empathy score: younger oncologists scored higher than older ones. This was in agreement with a previous study and could be because younger oncologists are less likely to have experienced emotional burnout from cancer care [9].

Additionally, younger oncologists may score higher because of changes in educational methods and content. In Japanese medical settings, "empathy" is often confused with "sympathy"—feelings of pity or sorrow for patients' suffering [10]—and senior Japanese physicians are more likely to have been discouraged from empathizing by mentors, because intense emotional involvement with patients could lead to difficulties in making clinical judgments [11] or cause physician burnout [12]. Physician-patient communication skills were commonly taught in medical schools and residencies in the early 1990s in Western countries: however, such practices did not begin in Japan until the early 2000s.

None of the oncologists in this study had taken a communication skills course; education *via* these courses might be the key to unlocking more empathetic behavior and improving patient–physician communication. Some researchers believe that empathy is a personality trait that can decline over time with medical education and medical care [13], and Fujimori et al. have reported that oncologists, who participate in communication skills course, behave more empathic than the oncologists who have not participated in [14]. Therefore, further investigation should be conducted to determine the best timing for communication skills courses during the medical career.

In multivariate analysis, sex and specialism were not significantly associated with empathic behavior.

Regarding specialism, Hojat et al. reported that average empathy ratings were significantly higher among physicians in "people-oriented" specialties (primary care, psychiatry, *etc.*) than among those in "technology-oriented" specialties (surgery, surgical subspecialties, *etc.*) [15,16].

Gender differences in empathy have been attributed to intrinsic factors (*e.g.*, evolutionary-biological gender characteristics) and extrinsic factors (*e.g.*, socialization and gender role expectations) [1,8,17]. For example, women are believed to develop more caregiving attitudes toward their offspring than men, according to the evolutionary theory of parental investment. Furthermore, women are more receptive to emotional signals [15]. Other researchers reported that female physicians spend more time with fewer patients and conduct more patient-oriented care [18]. Although we found no significant correlation between sex and the empathy score, this might be due to a small number of women in the sample, resulting in a lack of statistical power to detect any effect of sex. It could be inequality in sex among Japanese doctors, the ratio that women occupy is around 20%, but increases of late years.

This study has several limitations. First, the sample size was small. Second, data from SPs, not real cancer patients, was used; furthermore, the conversation was video-recorded, so oncologists could have modified their behavior to meet the experimental demands. However, all participants had reported that the SPs had seemed like real patients, they did not give thought to being recorded. Finally, all oncologists who participated in this study belonged to the National Cancer Center Hospitals, and this may limit generalization. Many oncologists employed by these hospitals communicate daily with their patients, and thus, most would score well. Nevertheless, this study is a step toward measuring and improving oncologists' empathy in Japan.

4.2. Conclusion

This report investigated the relationship between oncologists' personal characteristics and their empathic behavior. In multivariate analysis, age was the only factor related to the empathy score: younger oncologists scored higher than older ones.

4.3. Practice implications

Our research could have implications for the selection and education of oncologists. The findings indicate that communication skills training in Japan should be provided not only to younger physicians, but perhaps more importantly also to more experienced physicians.

Disclosure

I confirm that all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

Conflict of interest

Dr Shirai, Yamada, and Kondo had received research and salary support through for the Third Term Comprehensive 10-Year Strategy for Cancer Control and Research, Japanese Ministry of Health, Labour and Welfare.

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Impaired mental health among the bereaved spouses of cancer patients

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Abstract

Objective: **Few cancer physicians routinely provide bereavement follow-up in clinical practice. The purpose of this study was to identify the prevalence of impaired mental health among the bereaved spouses over several years and explore the indicators for early detection of high-risk spouses during end-of life (EOL) care.**

Methods: **A cross-sectional mail survey was conducted for the bereaved spouses of patients who had died at the National Cancer Center Hospital of Japan. Bereaved spouses with potential psychiatric disorders were identified by the cut-off score of the 28-item General Health Questionnaire. Associated factors of potential psychiatric disorders were explored by logistic regression analysis.**

Results: **A total of 821 spouses experiencing bereavement from 7 months to 7 years returned the-questionnaires. Overall mean prevalence of potential psychiatric disorders was 44% (360/821). Bereaved spouses 'under 55 years' (71%) or '2 years after bereavement' (59%) revealed a significantly higher prevalence ($p < 0.01$). Associated factors during EOL care were several characteristics such as 'spouses' history of psychiatric disorder (odds ratio (OR) = 3.19), 'patients' with stomach cancer (OR = 1.87), and 'patients' using psychiatric consultation services (OR = 1.52) as well as spouses' dissatisfaction with EOL care such as 'physicians' treatment of physical symptoms' (OR = 3.44) and 'time spent communicating with patients' (OR = 1.55).**

Conclusions: **Nearly half the bereaved spouses showed potential psychiatric disorders even 7 years after bereavement. Patients' psychological distress, spouses' history of psychiatric disorder, and dissatisfaction with EOL care were indicators of high-risk spouses.**

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Introduction

Conjugal bereavement was the strongest risk factor for depression among elderly community subjects in a meta-analysis of 20 studies (odds ratio (OR) = 3.3) [1] and bereaved spouses showed a significant increase in the risk of depression compared with married people in large cohort studies (1.5-fold, 3.6-fold) [2,3]. In oncology settings, spouses experienced the highest levels of distress among family members at the time of patient death [4] and bereavement brought an increased risk of major depressive disorder [5,6]. Cancer is a leading cause of death worldwide and accounted for 7.6 million deaths (around 13% of all deaths) in 2008 [7]; however, few cancer physicians routinely provide bereavement follow-up in clinical practice [8].

Several longitudinal studies have reported that impaired mental health among the bereaved clearly diminishes over time. The prevalence of major depressive disorder among caregivers of cancer patients was identified by clinical interview: 28% at the time of hospice enrollment, 12% at 6 months after death, and 7% at 1 year after death [5,6]. Depression, anxiety, and grief measured by self-administered questionnaire decreased during the first year after bereavement [9–11] and then remained unchanged over the next year [11]. On the other hand, cross-sectional studies reported that negative effects such as anger, sadness, self-blame, and guilt did not decrease among those who had been bereaved for more than 4 years [12,13] and 25% of the bereaved parents had not worked through their grief even 4–9 years after the loss [14]. However,