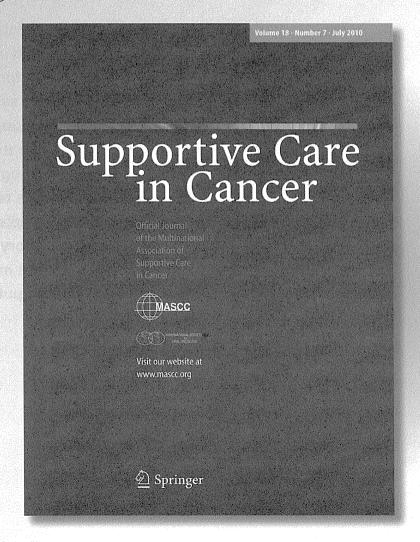
Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan

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#### ORIGINAL ARTICLE

# Knowledge, beliefs, and concerns about opioids, palliative care, and homecare of advanced cancer patients: a nationwide survey in Japan

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#### Abstract

Purpose Patients' knowledge, beliefs, or concerns about opioids, palliative care, and homecare can be potential barriers to providing quality palliative care. The primary aim of this study was to clarify knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients.

Methods An anonymous questionnaire was sent to 1,619 outpatients with advanced cancer at 25 hospitals in four different regions of Japan. The respondents were asked to report their knowledge about opioids, beliefs about palliative care, and concerns about homecare, in addition to the levels of their sense of security regarding receiving cancer care in the region.

Results A total of 925 responses were received. In total, 28% believed that opioids are addictive and/or shorten life; 52% believed that palliative care is only for terminally ill patients; 75% agreed that being taken care of at home puts a

heavy burden on the family; and 61% agreed that homevisit services cannot respond to sudden changes in a patient's condition. Levels of patients' sense of security were significantly higher in those who agreed that "opioids can relieve most pain caused by cancer" "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "pain can be alleviated as effectively through home-visit services as it can at the hospital", and those who disagreed with the statements that "home-visit services cannot respond to sudden changes in a patient's condition" and "being taken care of at home puts a burden on the family". Conclusions Advanced cancer patients frequently had incorrect knowledge about opioids, a belief that palliative care is only for terminally ill patients, and concerns about homecare, especially the family burden and responses to sudden changes. Providing appropriate information about the safety of opioids, the availability of palliative care

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during the entire course of the disease, and realistic information about homecare is of marked importance to promote patients' sense of security.

**Keywords** Cancer · Palliative care · Homecare · Knowledge · Opioids

#### Introduction

The numerous barriers to quality end-of-life care are related to patients, families, medical professionals, and the health care system itself [1]. Among them, multiple empirical studies have identified knowledge, beliefs, or concerns about opioids, palliative care, and homecare in the general population and cancer patients as potential barriers for quality palliative care [2–19]. Many surveys have shown that incorrect knowledge about cancer pain and opioids could interfere with optimal pain management, especially an unrealistic fear of addiction and life-shortening [2-7]. Negative beliefs about palliative care were also one of the significant determinants of the potential underuse of specialized palliative care services [8-12]. Moreover, many patients have concerns and difficulties about homecare, such as the burden on the family, concerns about sudden changes in physical conditions, and the unavailability of physicians visiting their home, and these could influence patients' decisions regarding whether or not to receive homecare [13-19].

These findings indicate that providing appropriate information is of marked importance to achieve optimal palliative care, but, to our best knowledge, no large systematic large survey has been performed to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in a representative sample of advanced cancer patients.

In addition, a sense of security is being acknowledged as a very important concept for cancer patients and their families

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[20–23]. The sense of security is evaluated from the perspective of patients living in a region, and these perspectives reflect the quality of the regional system for providing healthcare services and awareness among the population of the services provided by the system. Funk and colleagues indicated that a feeling of security consisted of trust in competent professionals; timely access to necessary care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals [20]. Despite the increasingly perceived importance of the concept of a sense of security, to date, no empirical studies have measured sense of security levels in advanced cancer patients, and explored the potential association between the levels and patients' knowledge, beliefs, and concerns.

The primary aim of this study was therefore to clarify the knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients. Secondary aims included: (1) to clarify the levels of a sense of security, (2) to explore factors associated with knowledge, beliefs, and concerns, and (3) to explore the potential associations between the levels of a sense of security and knowledge about opioids, beliefs about palliative care, and concerns about homecare.

#### Subjects and methods

A cross-sectional study was performed by sending questionnaires to consecutive outpatients with metastatic or recurrent cancer in four regions of Japan. This survey was part of the preintervention measurements collected for the regional intervention trial, the Outreach Palliative Care Trial of Integrated Regional Model study, and the study's methodology is reported in detail elsewhere [24]. The ethical and scientific validity of this study was confirmed by the institutional review board of the Japan Cancer Society, as well as by those of all participating hospitals (protocol registration number, UMIN000001274 of the University hospital Medical Information Network Clinical Trials Registry).

### Participating hospitals

Four study regions were chosen for intervention studies to cover a variety of areas with different palliative care systems across Japan: Tsuruoka (population 170,000, Yamagata Prefecture), Kashiwa (population 670,000, Chiba prefecture), Hamamatsu (population 820,000, Shizuoka Prefecture), and Nagasaki (population 450,000, Nagasaki Prefecture). Kashiwa and Hamamatsu, which are relatively large urban cities, have specialized hospital palliative care teams in a cancer center and general hospitals, respectively; Nagasaki has a coordinated palliative care system for home patients in addition to hospital palliative care teams; and

Tsuruoka, which is a typical rural town, had no formal specialized palliative care service at the time of survey.

Due to the lack of an established method to identify all cancer patients living in a specific area in Japan, we identified all hospitals in the study areas with reference to hospital lists from the Japan Hospital Association, the largest authorized organization of hospitals in Japan, and local resource information. Of the 54 hospitals identified, we excluded 20 hospitals primarily treating psychiatric, rehabilitation, and geriatric non-cancer patients. We approached the remaining 34 hospitals (11,033 beds), and a total of 23 hospitals (8,964 beds, 81%) participated in this survey: 3 hospitals (Tsuruoka), 7 hospitals (Kashiwa), 8 hospitals (Hamamatsu), and 5 hospitals (Nagasaki).

#### **Patients**

Inclusion criteria for patients in this study were: (1) adult cancer patients with a primary tumor site in the lung, esophagus, stomach, colon, rectum, pancreas, liver, biliary system, kidney, prostate, bladder, breast, ovary, or uterus; (2) presence of metastatic or recurrent cancer; (3) outpatient visits to the hospital between April and June 2008; and (4) disclosure of malignancy. Exclusion criteria included: (1) incapacity of the patient to complete the questionnaire (dementia, cognitive failure, or psychiatric illness), (2) severe emotional distress of the patient as determined by the principal treating physician, (3) poor physical condition unable to complete the questionnaire, and (4) language difficulty or visual loss. Patients were recruited consecutively, with hospitals either sending each eligible patient a questionnaire by mail or delivering it directly by hand to the patient.

#### Measurements

Data were collected on: (1) knowledge about opioids, beliefs about palliative care, and concerns about homecare; (2) sense of security; (3) pain intensity; and (4) patient-perceived quality of palliative care. The questionnaire (available from the authors) was constructed based on an extensive literature review, expert consensus among the authors, and a previous study [2–23, 25–27].

Knowledge about opioids, beliefs about palliative care, and concerns about homecare

We asked the respondents to rate the extent to which they agreed with the statements about their knowledge of opioids, beliefs about palliative care, and concerns about homecare on a 5-point Likert-type scale (1 strongly disagree, 2 disagree, 3 unsure, 4 agree, 5 strongly agree) [2]. Knowledge about opioids was examined using two items: "opioids can relieve most pain caused by cancer" and

"opioids are addictive and/or shorten life". Beliefs about palliative care were examined using three items: "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "palliative care is only for terminally ill patients". Concerns about homecare were examined based on five items: "pain can be alleviated as effectively through home-visit services as it can at the hospital", "home-visit services cannot respond to sudden changes in a patient's condition", "it is hard to find home-visiting physicians", and "being taken care of at home puts a burden on the family".

Sense of security about cancer care in the region

The sense of security was measured using the five-item scale to assess feelings of support and security about cancer care in a region [23]. The statements were: (1) "I would feel secure in receiving cancer treatment", (2) "my pain would be wellrelieved", (3) "medical staffs will adequately respond to my concerns and pain", (4) "I would feel secure as a variety of medical care services are available", (5) "I would feel secure in receiving care at home". We asked participants to rate their level of agreement with the statements on a 7-point Likert scale (1 strongly disagree, 2 disagree, 3 slightly disagree, 4 not sure, 5 slightly agree, 6 agree, 7 strongly agree). The total score of five items, ranging from 5 to 35, quantifies the levels of the sense of security; a higher score indicates higher sense of security levels. Factor validity was established based on the emergence of one factor by explanatory factor analysis, and a high Cronbach's alpha coefficient (0.91) demonstrated sufficient internal consistency. Criterion-related validity established a significant difference among the total scores of general populations from several areas with various health care services in Japan.

#### Pain intensity

Pain intensity was measured using the Japanese adaptation of the Brief Pain Inventory, with a score given for the pain at its worst (0-10), at its least (0-10), and a score for the average pain felt (0-10) in the previous 24 h [25]. Its reliability and validity in Japanese populations has been established [25]. For this study, average pain was used for analyses.

### Patient-perceived quality of palliative care

Patient-perceived quality of palliative care was measured using the Care Evaluation Scale [26, 27]. The Care Evaluation Scale is a well-validated and commonly used measurement tool in Japan to quantify the level of patient or family-perceived need for improvements in palliative care. The full version of the Care Evaluation Scale consists of eight subscales (three items for seven domains and two



items for one domain) with a 6-point Likert-type scale from "1 improvement is not necessary at all" to "6 highly necessary": physical care provided by physicians, physical care provided by nurses, psycho-existential care, help with decision making, coordination/consistency of care, environment, availability, and cost. For this study purpose, we used the first five subscales (15 items), because the study aim focused on interpersonal areas, not social areas (i.e., environment, availability, and cost). Each subscale score was calculated as an average of the items belonging to the subscale, and the total score was calculated as an average of subscale scores. All scores were proportionally adjusted to range from 0 to 100 following the original studies, and, thus, higher values indicate a lower perceived necessity for improvement.

In addition, information about the subjects' demographic characteristics (age, sex, and family), performance status, and medical status was collected through self-administered questionnaires. The performance status was measured using the European Organization for Research and Treatment of Cancer performance status: 0 (no symptoms, able to carry out all activities without restrictions), 1 (mild symptoms but ambulatory and able to carry out work of a light or sedentary nature), 2 (ambulatory and capable of self-care for more than 50% of their waking hours), 3 (laying in bed or sitting in a chair for more than 50% of their waking hours), and 4 (laying in bed or sitting in a chair for the entire day).

#### Statistical analysis

The 5-point scale to measure patients' knowledge, beliefs, and concerns was simplified into two categories ("strongly agree" and "agree" vs. others). As the age, sex, and regions of the subjects were considered to affect the knowledge, beliefs, and concerns, they were selected a priori as explanatory variables. The chi-square test was used to examine the rate of "agree" responses in relation to the age, sex, and region. The total sense of security scores were examined employing Student's t test and analysis of variance. To elucidate the influence of the age, sex, pain level, and patient-reported quality of palliative care on patients' knowledge, beliefs, and concerns, multiple logistic regression analyses were performed to determine odds ratios. With sense of security scores, multiple linear regression analyses were used. All models included the following covariates selected a priori: age in years ( $\leq$ 59, 60-74,  $\geq 75$ ); sex; region; number of family members living with the participant; performance status; current medical status; pain level; and the patient-reported quality of care measured by the Care Evaluation Score ( $\leq 49, 50-79, \geq 80$ ). Trend analysis was conducted, and the Care Evaluation Score was included as an ordinal variable. Comparisons were performed with analysis of covariance, adjusting for age and sex, because these two factors were significant

covariates for confidence levels. As the results were essentially the same across the four regions (data not shown), we report only the overall results. All analyses were carried out using STATA ver. 9.1 (College Station, TX, USA).

#### Results

Of 2,087 patients who met the inclusion criteria, 367 patients were excluded due to: (1) mental incapacity of the patient to complete the questionnaire such as dementia, cognitive failure, or psychiatric illness (n=137), (2) patient death, admission, or changing hospitals during the procedure (n=101), (3) severe emotional distress (n=52), 4) responsible physicians unavailable for technical reasons (n=30), (5) poor physical conditions (n=28), (6) language difficulty or visual loss (n=5), as well as other unspecified reasons (n=14). In addition, 101 patients refused to receive the questionnaire. Questionnaires were thus sent to 1,619 patients, and 5 returned due to being sent to the wrong address. Overall, 925 responses (57%) were obtained, and 833 responses were finally analyzed due to missing values for some of the primary endpoints.

#### Participant characteristics

The participant characteristics are summarized in Table 1. The mean age  $\pm$  standard deviation (SD) was  $67\pm11$  years, and 57% were men. The performance status was 0 or 1 in about 70% of the respondents, and 60% were receiving chemotherapy and/or radiation therapy.

# Knowledge about opioids, beliefs about palliative care, and concerns about receiving care at home

As shown in Table 2, nearly 30% of the patients believed that opioids are addictive and/or shorten life, and about half believed that palliative care is only for terminally ill patients. Regarding concerns about receiving care at home, 75% agreed or strongly agreed that being taken care of at home puts a heavy burden on the family, and about 60% agreed that home-visit services cannot respond to sudden changes in a patient's condition.

# Sense of security

The mean score of the sense of security was  $27\pm5.6$  (Table 2). The proportions of respondents who agreed (i.e., scored 5 or greater on the 7-point Likert-type scale) with each statement were: 82% ("I could feel secure on receiving



**Table 1** Participant characteristics (N=833)

	Number	Percent
Age (years)		
< 60	208	25
60–74	405	49
75 or over	220	26
Sex		
Male	473	57
Female	360	43
Region		
Yamagata	135	16
Chiba	137	16
Shizuoka	302	36
Nagasaki	259	31
Family living with participant <sup>a</sup>		
Yes	771	93
No	61	7
Performance status (EORTC) <sup>b</sup>		
0	234	28
1	367	44
2	174	21
3 or 4	52	6
Current medical status		
Receiving chemotherapy and/or radiation therapy	491	60
Average pain score in previous 24 h		
0–4	721	89
5-10	92	11

 $<sup>^{</sup>a}$   $_{n}$  =832, due to missing values

cancer treatment"), 78% ("pain could be well-relieved"), 78% ("medical staff adequately responded to concerns and pain"), 59% ("I could feel secure as a variety of medical care services are available"), and 75% ("I could feel secure on receiving care at home").

# Factors associated with the patients' knowledge about opioids, beliefs about palliative care, and concerns about homecare

Older respondents and patients who reported lower-level quality of palliative care they received were significantly more likely to have incorrect knowledge about opioids (Table 3). Although male patients were significantly more likely to know that opioids can relieve most pain caused by cancer, they were more likely to have incorrect knowledge that opioids were addictive and/or shorten life (p=0.03). Patients' beliefs about palliative care and concerns about homecare were not significantly influenced by age and

gender, while the patient-reported quality of palliative care was significantly associated that positive beliefs about palliative care ("palliative care relieves pain and distress") and lower levels of concerns about homecare ("pain can be alleviated as effectively through home-visit services as it can at the hospital").

# Associations between the sense of security and knowledge about opioids, beliefs about palliative care, and concerns about homecare

Sense of security levels were significantly higher in patients who agreed that "opioids can relieve most pain caused by cancer", "palliative care relieves pain and distress", "palliative care is provided along with chemotherapy and/or radiation therapy", and "pain can be alleviated as effectively through home-visit services as it can at the hospital", as well as in the patients who did not agree that "home-visit services cannot respond to sudden changes in a patient's condition" and "being taken care of at home puts a burden on the family" (Table 4).

In addition, higher senses of security levels were significantly associated with an older age, male gender, lower pain intensity, and higher patient-reported quality of palliative care (Table 3).

#### Discussion

This is the first large-scale survey designed to clarify knowledge about opioids, beliefs about palliative care, and concerns about homecare in advanced cancer patients as a representative sample of multiple regions, in addition to the sense of security; the factors associated with knowledge, beliefs and concerns; and associations between the sense of security levels and knowledge and beliefs. The most important findings of this study involved clarification of the patients' knowledge about opioids, beliefs about palliative care, and concerns about homecare.

First, about 30% of advanced cancer patients believed that opioids are addictive and/or shorten life. This figure is very close to that in previous surveys of the general population in Japan and other countries (i.e., 30–40%) [2, 5, 7]; and somewhat lower than some studies (i.e., 70%) [4, 6]. In addition, this study revealed that older and male patients were significantly more likely to have incorrect knowledge about opioids. As many studies have identified misconceptions about opioids as dominant barriers to optimal pain control [3, 5], these results confirm that providing appropriate information about opioids, especially to older and male patients, is of considerable importance to achieve maximum pain control.



 $<sup>^{\</sup>rm b}$  n=827, due to missing values

Table 2 Knowledge about opioids, beliefs about palliative care, and concerns about receiving care at home

	All subjects	Age (years)			P value Sex			P value
		<60	60-74	75+		Male	Female	
Knowledge about opioids								
Opioids can relieve most pain caused by cancer $(n=743)$	545 (73%)	143 (71%)	272 (75%)	130 (74%)	0.620	320 (77%)	225 (69%)	0.018
Opioids are addictive and/or shorten life $(n=718)$	202 (28%)	40 (20%)	105 (30%)	57 (34%)	0.007	126 (32%)	76 (24%)	0.002
Beliefs about palliative care								
Palliative care relieves pain and distress ( <i>n</i> =753)	570 (76%)	155 (77%)	280 (75%)	135 (76%)	0.905	313 (74%)	257 (79%)	0.105
Palliative care is provided along with chemotherapy and/or radiation therapy ( <i>n</i> =742)	474 (64%)	124 (62%)	230 (63%)	120 (69%)	0.278	147 (35%)	121 (37%)	0.578
Palliative care is only for terminally ill patients ( $n=727$ )	377 (52%)	97 (48%)	187 (52%)	93 (55%)	0.436	216 (53%)	161 (50%)	0.508
Concerns about receiving care at home								
Pain can be alleviated as effectively through home-visit services as it can at the hospital $(n=748)$	286 (38%)	67 (33%)	144 (39%)	75 (42%)	0.203	171 (41%)	115 (35%)	0.006
Home-visit services cannot respond to sudden changes in a patient's condition ( $n$ =744)	452 (61%)	103 (52%)	241 (66%)	108 (61%)	0.004	256 (62%)	196 (59%)	0.442
It is hard to find home-visiting physicians $(n=742)$	419 (57%)	113 (57%)	215 (59%)	91 (51%)	0.191	227 (55%)	192 (58%)	0.354
Being taken care of at home puts a burden on the family $(n=748)$	557 (75%)	152 (76%)	274 (75%)	131 (73%)	0.811	303 (73%)	254 (76%)	0.309
Sense of security score $(n=833)$	$27.0\pm5.6 \ (n=833)$	$25.5\pm5.5 \ (n=208)$	$27.3\pm5.6\ (n=405)$	$27.8\pm5.1 \ (n=220)$	< 0.001	$27.4\pm5.4\ (n=473)$	$26.4\pm5.8~(n=360)$	0.009

Each column indicates the number (percentage) of respondents who agreed or strongly agreed with the statement, except for the last column, which indicates the mean ± S.D. (number of subjects)

Table 3 Factors associated with knowledge and beliefs about palliative care, and sense of security by multivariate analysis

	Age (years)		Sex Pain		Care evaluation score (total)					
	<59	60–74	75+	Male	Female	Pain score	-49	50-79	80+	Trend P
Knowledge about opioids										
Opioids can relieve most pain caused by cancer $(n=743)$	1	1.1 0.7–1.6	0.9 0.6–1.5	1	0.6* 0.4-0.8	1.1 0.6–2.0	1	1.1 0.7–1.7	2.3* 1.4–3.7	<i>P</i> <0.001
Opioids are addictive and/or shorten life $(n=718)$	1	1.8 1.1–2.7	2.4* 1.4-4.0	1	0.7* 0.5-0.9	1.3 0.7–2.2	1	$0.6 \\ 0.4-1.0$	0.6* 0.4-0.9	P=0.04
Beliefs about palliative care										
Palliative care relieves pain and distress ( <i>n</i> =753)	1	0.9 0.6–1.4	1.1 0.6–1.9	1	1.2 0.8–1.7	0.9 0.5–1.5	1	1.4 0.9–2.3	2.4* 1.5–4.0	P<0.001
Palliative care is provided along with chemotherapy and/or radiation therapy (n=742)	1	1.0 0.7–1.5	1.4 0.9–2.2	1	0.9 0.7–1.3	0.8 0.5–1.3	1	1.1 0.7–1.6	1.4 0.9–2.2	P=0.11
Palliative care is only for terminal patients ( <i>n</i> =727)	1	1.2 0.8–1.7	1.4 0.9–2.2	1	0.9 0.7–1.3	0.9 0.9–1.5	1	0.8 0.5-1.2	0.8 0.5-1.2	P=0.39
Concerns about receiving care at	home									
Pain can be alleviated as effectively through home-visit services as it can at the hospital $(n=748)$	1	1.1 0.7–1.6	1.2 0.7–1.9	1	0.8 0.5–1.0	0.6 0.3–1.0	1	0.8 0.5–1.3	1.7* 1.1–2.6	P=0.002
Home-visit services cannot respond to sudden changes in a patient's condition $(n=744)$	1	2.1* 1.4–3.0	1.8* 1.1–2.8	1	1.0 0.8–1.4	0.9 0.5–1.5	1	1.1 0.7–1.8	0.7 0.5–1.1	P=0.07
It is hard to find home-visiting physicians $(n=742)$	1	1.2 0.8–1.7	0.9 0.6–1.3	1	1.0 0.8–1.4	1.0 0.6–1.6	1	1.1 0.7–1.6	0.8 0.5-1.3	P = 0.22
Being taken care of at home puts a burden on the family $(n=748)$	1	0.9 0.6–1.4	0.9 0.6–1.5	1	1.1 0.8–1.6	1.5 0.8–2.7	1	1.2 0.7–1.9	1.1 0.7–1.7	P=0.92
Sense of security score (n=833)	_	+1.5* 0.6, 2.3	+2.4* 1.3, 3.4	-	-0.8* -1.5, -0.1	-1.8* -2.9, -0.7	-	+0.9* -0.1, 1.8	+4.4* 3.4, 5.3	P<0.001

Values in the table indicate odds ratios and 95% confidence interval. Multiple logistic regression analysis for knowledge about opioids and beliefs about palliative care indicates adjusted odds ratio and P value; multiple linear regression analysis for sense of security score indicates adjusted difference in score; all models include age (<60, 60-74, 75+; <60 as reference category), sex (male as reference category), region of residence, family living with participant, physical activity status, current medical status, average pain score in previous 24 h, and care evaluation score (<50, 50-79, 80+; <50 as reference category)

Second, this study revealed that about half of the patients believed that palliative care is only for terminally ill patients, while similar percentages of the patients believed that palliative care is provided along with chemotherapy and/or radiotherapy. The findings are consistent with previous studies that revealed a negative image of palliative care among both patients and healthcare professionals [8–11]. In Japan, a strong policy change from end-of-life care to "early" palliative care resulting in the involvement of palliative care teams was significantly associated with patient- and family-perceived appropriate referrals to specialized palliative care services [12, 28]. These findings suggest that along with ongoing efforts of disseminating palliative care teams not only for terminally ill patients but also those with intense symptoms and suffering irrespective

of disease stages, providing information about the emerging concept of palliative care to patients themselves is another area to be improved to maximize palliative care use for enhancing patients' quality of life

Third, this study revealed a high level of concern among advanced cancer patients about receiving homecare. The concerns most commonly reported included family burden, being unable to adequately respond to sudden changes in out-of-hours care, and availability of family physicians visiting the home. These figures are very close to data provided by the Ministry of Health, Labour, and Welfare, whereby the most common difficulties with homecare surround concerns about the burden to the family and sudden changes in physical conditions [15], and this is also consistent with Western studies which identified that



<sup>\*</sup>p<0.05

Table 4 Associations between the levels of feeling secure and knowledge about opioids, beliefs about palliative care, and concerns about homecare

		Number	Mean $\pm$ S.D.	P value
Knowledge about opioids				
Opioids can relieve most pain caused by cancer	Yes No	545 198	$27.9\pm6.5$ $25.8\pm5.9$	< 0.001
Opioids are addictive and/or shorten life	Yes No	202 516	$27.2 \pm 5.8$ $27.3 \pm 6.9$	0.857
Beliefs about palliative care				
Palliative care relieves pain and distress	Yes No	570 183	28.3±8.0 25.6±6.1	< 0.001
Palliative care is provided along with chemotherapy and/or radiation therapy	Yes No	474 268	$28.1\pm6.5$ $25.9\pm6.1$	< 0.001
Palliative care is only for terminal patients	Yes No	377 350	27.3±6.4 27.2±6.4	0.684
Concerns about receiving care at home				
Pain can be alleviated as effectively through home-visit services as it can at the hospital	Yes No	286 462	$29.3 \pm 5.7$ $26.1 \pm 6.4$	<0.001
Home-visit services cannot respond to sudden changes in a patient's condition	Yes No	452 292	$27.1\pm6.4$ $27.9\pm6.1$	0.026
It is hard to find home-visiting physicians	Yes No	419 323	27.2±6.5 27.7±6.1	0.193
Being taken care of at home puts a burden on the family	Yes No	557 191	27.1±6.8 28.1±5.7	0.027

concern about burden is a major factor affecting a cancer patient's decision regarding homecare [18, 29, 30]. The family burden is one of the most relevant issues in this population, and this includes the patient-perceived burden and actual family burden in caregiving. Multiple studies have indicated that the patient-perceived burden has one of the largest impacts on suffering in terminally ill cancer patients, even if family members do not report an actual caregiving burden [31, 32]. These findings indicate that clinicians should alleviate patient concerns about burden when they receive homecare through the provision of psychological support for patients themselves, as well as arranging regional resources to reduce the actual family burden.

Another important finding of this study was clarification of the levels of a sense of security and the significant association between the sense of security and patients' knowledge, beliefs, and concerns. To our best knowledge, this is the first reported study to demonstrate the significant association between the sense of security and patients' knowledge, beliefs, and concerns. This finding suggests that a sense of security is shaped at least partly by knowledge and beliefs, and providing appropriate information could be of marked importance to enhance patients' sense of security.

Despite the strengths of this study, including obtaining a relatively large number of patients from multiple regions of Japan and regional representative sampling, there are some limitations. First, it was a cross-sectional study, and, thus,

the observed associations among variables might not be causal. Second, the response rate was moderate and no data were collected from the non-respondents. This could be a potential selection bias which may distort the study results. Third, unmeasured confounding factors, such as educational levels and family forms, could have distorted the study results, although adjustment was made for the confounders measured in the multivariate analyses. Finally, patients' knowledge, beliefs, and concerns are inevitably influenced by the social and cultural views in the societies they live in.

In conclusion, advanced cancer patients frequently had incorrect knowledge about opioids, a belief that palliative care is only for terminally ill patients, and concerns about homecare, especially the family burden and responses to sudden changes. The knowledge, beliefs, and concerns were significantly associated with the sense of security levels regarding receiving cancer care in the region. Providing appropriate information about the safety of opioids, availability of palliative care during the entire course of a disease, and realistic information about homecare is of marked importance to achieve the optimal quality of life for cancer patients.

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# 患者・遺族調査の結果に基づいた 緩和ケアセミナーの有用性



Idea

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#### 要旨

本研究の目的は、① 患者・遺族調査の結果に基づいた緩和ケアセミナーの有用性を評価すること、② セミナー参加者が重要であると認識したケアを収集することである。緩和ケアセミナーに参加した延べ274名のうち、260名(95%)から有効回答を得た。96%がセミナーを「とても役に立った、役に立った」と回答した。フォーカスグループでは、重要なケアとして、「患者・家族が伝えようとしているメッセージを聴く」、「ありのままの患者・家族を受け入れそばにいる」、「コミュニケーションをとり信頼関係を構築する」、「一緒に考えサポートを保証する」が認識されていた。患者・遺族調査の結果に基づく緩和ケアセミナーは、地域の緩和ケアの促進に有用な可能性が示唆された。

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キーワード:疼痛, 地域緩和ケア, 教育プログラム

# I. 背景・目的

緩和ケアの知識,技術を地域全体に普及することは重要である。なぜならば,がん患者や一般市民が希望する療養の場所や看取りの場所は,病院のみならず,自宅や福祉施設などを含み、患者の希望を達成するための体制の整備が

(Idea)

Palliative care education program based on the survey of cancer patients and bereaved family members

Chizuru Imura, et al

Seirei Mikatahara General Hospital, Hamamatsu Cancer Support Center 求められているからである<sup>1.2)</sup>. しかし, 医療福祉従事者の緩和ケアについての知識や自信は必ずしも高くはなく, 困難感を持ちやすいことが示唆されている<sup>3.4)</sup>. したがって, 医療福祉従事者の緩和ケアの知識, 技術を向上させることは, がん患者とその家族の quality of life の向上に有用な可能性がある. わが国の緩和ケア教育においては, 医師や看護師を対象とした, 構造化された教育プログラムが導入され始めているが<sup>5.6)</sup>, プログラムの有用性を評価した実証研究はほとんどない.

一方,緩和ケア領域においては、患者・家族によるケアの評価が重要であり、わが国においても大規模な遺族調査が行われてきた<sup>7)</sup>.遺族

調査は緩和ケアの教育プログラムを策定する上で「患者・家族の声」という重要な情報を含んでいるが、われわれの知る限り、調査結果に基づいて作成された緩和ケアセミナーなどの教育プログラムを評価した研究はない。したがって、患者・遺族調査の結果に基づいた緩和ケアセミナーの効果を評価することには意義があると考えられる。

本研究の目的は、① 患者・遺族調査の結果に基づいた緩和ケアセミナーの有用性を評価すること、② セミナー参加者が重要であると認識したケアを収集することである.

# Ⅱ. 対象・方法

# 1) 患者・遺族調査の結果に基づいた緩和ケアセミナー

緩和ケアの普及を目的とした地域介入である「緩和ケア普及のための地域プロジェクト(OPTIM)」の一環として、患者・遺族調査の結果に基づいた緩和ケアセミナーを策定した。

#### ① 緩和ケアセミナーの教材

緩和ケアセミナーの教材として. 5病院の緩 和ケアチームの医師9名、看護師8名、薬剤師 1名からなるフォーカスグループにより、冊子 「浜松市1,000件の調査に基づくがん患者さ ん・ご家族の声」、「緩和ケアについての必須の 知識」を作成した8)、前者では、患者・遺族調 査の自由記述の内容分析により明らかにされた 5つの患者・家族の希望それぞれについて、患 者・家族の声、医療者にできることを整理した (「患者・家族の気持ちに寄り添って一緒に考え て欲しい」、「患者・家族が後悔しないようにし て欲しい」「苦痛を最小限にして欲しい」「生き る希望を支えて欲しい」「医療用麻薬について の不安をやわらげて欲しい」). 後者では、「医 療用麻薬を長期間使用すると、薬物中毒がしば しば生じる」などの設問に対して、実際の浜松 市の医療者対象調査での正答率とともに一問一 答式の解説を行った.

#### ② 緩和ケアセミナーの構成

緩和ケアセミナーの構成は, 講義 (20分),

フォーカスグループとまとめの講義 (135分), 模擬患者・家族とのコミュニケーションのデモ ンストレーション (15分) とした. 講義では, 患者・遺族調査結果の報告と, 調査結果から医 療福祉従事者に求められるケアを説明した.

フォーカスグループでは、1グループ6~8名に設定し、1名のファシリテーターを置いた. 共通事例を提示し、アセスメント、具体的なケア・コミュニケーションについて議論した.特に、①気持ちをわかってもらえたと思えるためのケアとして何をするか、②生きる希望を持ちながら、かつ、心残りもないためのケアとして何をするか、③苦痛をやわらげ、かつ、医療用麻薬についての誤解もないためのケアとして何をするか、を扱った、議論を促進する目的から、付箋や模造紙を用いて、アセスメントやケアを1枚の付箋に①項目ずつ記載し、模造紙に並べながら議論を進めた.

# 2)調査対象および方法

### ①質問紙調査

緩和ケアセミナーの参加者全員を対象として、自記式質問紙調査を行った。終了後に質問紙を配布し、回収箱に回収した。主要評価項目は、緩和ケアセミナーの有用性および実践の自己評価と知識である。

有用性については、全般的有用性1項目(「総合的に役に立ったか」)、領域ごとの有用性3項目(①気持ちをわかってもらえたと思えるようにサポートする方法を知る・考えること、②生きる希望を持ちながら、かつ、心残りもないようにサポートする方法を知る・考えること、③苦痛をやわらげ、かつ、医療用麻薬についての誤解もないようにサポートする方法を知る・考えること)について「とても役に立った」から「役に立たなかった」の5件法で尋ねた.

実践の自己評価については、セミナー前後で、「診療やケアはどのように変わるか」を「医療用麻薬の使用は生命予後に影響しないことをはっきりと説明する」など12項目について、「とても減ると思う」から「とても増えると思う」の5件法で尋ねた9.10.

表1 実践の自己評価

	とても減ると思う/ 減ると思う	変わらないと 思う	増えると思う	とても増える と思う
医療用麻薬の使用は、患者の生命予後に影響 しないことをはっきりと説明をする	0% (n = 0)	5.8% (n = 15)	54% (n = 141)	38% (n = 99)
患者や家族が医療用麻薬を使用するとよくないと思っている時、過去にきっかけとなった 体験があるかを聞く	0% (n = 0)	3.1% (n = 8)	61% (n = 158)	35% (n = 91)
患者や家族から不安の表出があった時,説明 をするのではなく、「苦しいですね」、「心配 ですね」など感情に焦点をあてた受け答えを する	0.4% (n = 1)	4.6% (n = 12)	60% (n = 155)	35% (n = 90)
患者・家族が伝えようとしているメッセージ は何かを考えながら話を聴く	0.4% (n = 1)	4.2% (n = 11)	63% (n = 163)	32% (n = 84)
家族に質問をする時、「何かご心配はありま すか」のような自由に回答できる質問をする	0% (n=0)	6.5% (n = 17)	62% (n = 160)	32% (n = 82)
患者に質問をする時、「何かご心配はありま すか」のような自由に回答できる質問をする	0% (n=0)	6.9% (n = 18)	62% (n = 160)	31% (n = 81)
「家族としてどう看てあげたいと思っている か」を聞く	0% (n = 0)	2.7% (n = 7)	69% (n = 180)	28% (n = 72)
患者・家族と重要な話をする時、静かでプラ イバシーが保てる場所で話をする	0% (n = 0)	11% (n = 29)	61% (n = 159)	27% (n = 70)
患者・家族の希望が現実的ではなくても「できません」と否定せず、「できるといいですね」など、気持ちを支えるように対応する		5.4% (n = 14)	70% (n = 182)	24% (n = 63)
患者・家族に質問を促すなどして, 病状の理解度について確認する	0% (n = 0)	7.7% (n = 20)	69% (n = 178)	23% (n = 59)
医療用麻薬の使用や病状の進行のために眠気が出てコミュニケーションが十分に取れなくなることが予測される時は、家族にコミュニケーションを取れる時間が限られていることを伝える	0% (n = 0)	6.2% (n = 16)	72% (n = 186)	20% (n = 52)
思者・家族が心の準備ができていないと思う時,「もしよくならないとしたら」を用いて,「もし悪くなったとしても後悔しないためには今何をしておいたらいいか」を早めに聞くようにする	0.4% (n = 1)	3.8% (n = 10)	77% (n = 199)	19% (n = 48)

欠損値のため合計が100%にならない箇所がある

知識については、「医療用麻薬の使用は、患者の生命予後に影響しない」など 9 項目について、「正しい」「間違っている」「わからない」で尋ねた $^{11}$ ).

参加者の背景については、職種、勤務場所、 臨床経験年数、OPTIM 主催のセミナーへの参 加回数を尋ねた。

倫理的配慮として、対象者の自由意思に基づき、匿名性に配慮して行った。

# ② セミナー参加者が重要であると認識したケアの収集

フォーカスグループで挙げられた。① 気持ちをわかってもらえたと思えるためのケア、② 生きる希望を持ちながら、かつ、心残りもないためのケア、③ 苦痛をやわらげ、かつ、医療用麻薬についての誤解もないためのケア、を記録した付箋の内容を分析対象とした.

表2 緩和ケアの知識

	正解	不正解	わからない
医療用麻薬の使用は、患者の生命予後に影響しない〔正〕	97% (n = 251)	1.9% (n=5)	0.8% (n=2)
「しておいた方がよいことについて早い時期に相談にのる」, 「代替療法の相談にのる」ことで、家族が「希望を持ちなが ら、心の準備ができる」と思えることに役立つ〔正〕	97% (n=251)	0% (n=0)	0.8% (n = 2)
「何もすることがない」というかわりに「今後の達成可能な 目標を具体的に言う」ことで、終末期のコミュニケーション についての満足度が上がる〔正〕	94% (n = 245)	0.4% (n=1)	3.1% (n = 8)
がん患者の呼吸困難はモルヒネでやわらげることができる〔正〕	94% (n = 245)	2.3% (n = 6)	1.5% (n = 4)
緩和ケアの対象は、根治的治療法のない患者のみである〔誤〕	94% (n = 243)	2.3% (n=6)	2.7% (n = 7)
医療用麻薬を長期間使用すると、薬物中毒がしばしば生じる〔誤〕	90% (n = 234)	3.8% (n = 10)	5.0% (n = 13)
患者の息苦しさと酸素飽和度は比例する〔誤〕	85% (n = 222)	5.4% (n = 14)	8.1 % (n = 21)
痛みに関して医療用麻薬を定期的に使用している場合,呼吸 困難を緩和するために医療用麻薬を追加すると,呼吸抑制が 起こりやすい〔誤〕	85% (n = 220)	6.5% (n = 17)	6.9% (n = 18)
主治医が予測した予後より、実際の予後は短いことが多い〔正〕	84% (n = 217)	8.5% (n = 22)	7.7% (n = 20)

欠損値のため合計が100%にならない箇所がある

[ ] 内は質問内容の正誤を示す

# 3)解析

量的データは度数分布を集計した.質的データについては、内容分析を行った $^{12)}$ . ケアに関する1つの意味内容を含む文章を1単位とし、分割された意味単位の類似性に従い、帰納的に分類、抽象化し、カテゴリー化した. 2名の研究者が独立に内容分析を行った後、緩和ケア領域における同様の研究経験を豊富に有する緩和ケア専門家(T.M.)のスーパービジョンを基に、3名の合意が得られるまで議論を行った.以下、カテゴリーを【 】で、サブカテゴリーを< >で、具体的な表現を「 」で示した.

### Ⅲ. 結 果

緩和ケアセミナーは4回実施し、参加者は延べ274名であった。質問紙は260名(95%)から有効回答を得た。職種は、看護師75%(n=194)、介護支援専門員10%(n=27)、医師5.8%(n=15)、薬剤師3.1%(n=8)、医療ソーシャルワーカー0.4%(n=1)、その他4.6%(n=12)であった。勤務場所は、一般病院55%(n=144)、緩和ケア病棟・緩和ケアチーム13%

(n=34), 居宅介護支援事業所 10% (n=27), 訪問看護ステーション 7.3% (n=19), 診療所 6.9% (n=18), 保険薬局 2.3% (n=6), その他 4.2% (n=11) であった。平均臨床経験年数は  $12\pm8.7$ 年,OPTIM のセミナーへの参加回数は中央値 1 (範囲: $1\sim18$ ) であった。

### 1)緩和ケアセミナーの評価

「総合的に役に立ったか」に対して、96%(n = 250)が「とても役に立った」「役に立った」と回答した、領域ごとに、「とても役に立った」「役に立った」と回答したものは、それぞれ、「気持ちをわかってもらえたと思えるようにサポートする方法を知る・考えること」(93%)、「生きる希望を持ちながら、かつ、心残りもないようにサポートする方法を知る・考えること」(92%)、「苦痛をやわらげ、かつ、医療用麻薬についての誤解もないようにサポートする方法を知る・考えること」(92%)であった。

実践の自己評価については、12項目のうち 11項目において、90%以上が「とても増える と思う」「増えると思う」と回答した(表1). 緩和ケアの知識の正答率は、緩和ケアセミナー

表3 「気持ちをわかってもらえたと思える」ためのケア

${\cal H} = {\cal J} = {\cal J}$	サブカテゴリー
患者・家族が伝えようとしてい るメッセージを聴く	<ul> <li>・タイムリーに一人ひとりの気持ち(不安や気がかり、困っていること、つらいこと、対応して欲しいことなど)を聴く(120)</li> <li>・十分にコミュニケーションできる環境(時間・場所・雰囲気・態度)を整える(17)</li> <li>・援助的コミュニケーションを用いてキーワードやサインをキャッチする(10)</li> <li>・解決のみを目標とはせず、気持ちをわかろうと関わる(7)</li> <li>・身体的なアプローチを通じて気持ちをわかろうと関わる(1)</li> <li>・患者・家族が話せるようになるまで待つ(1)</li> </ul>
ありのままの患者・家族を受け 入れそばにいる	<ul> <li>・そばにいる存在となり、寄り添う(44)</li> <li>・ありのままの患者・家族を受け入れる(23)</li> <li>・患者・家族が頑張ってきたこと・頑張っていることを認め、ねぎらう(37)</li> <li>・共感的支持的に関わる(19)</li> </ul>
コミュニケーションをとり信頼 関係を構築する	・自ら声をかけコミュニケーションを継続する(18) ・日々の関わりを積み重ね、信頼関係を築いていく(12) ・笑顔で、安心感や大切に思う気持ちが感じられるよう関わる(3) ・医療福祉従事者自身の気持ちを伝えていく(2)
一緒に考えサポートを保証する	<ul><li>・サポートの準備があること・一人ではないことを伝える(22)</li><li>・一緒に考え、ともに最善の方法を見つけていく(10)</li><li>・サポートできる具体的な内容を伝えていく(3)</li></ul>

サブカテゴリーの ( ) 内の数値は単位数を示す

後では85~95%であった(表2).

# ① セミナー参加者が重要であると認識したケア

フォーカスグループで収集されたケアの内容 分析では、合計 1,013 の意味単位から 21 のカ テゴリーが抽出された.

# i)「気持ちをわかってもらえたと思える」 ためのケア

349 の意味単位から【患者・家族が伝えようとしているメッセージを聴く】、【ありのままの患者・家族を受け入れそばにいる】、【コミュニケーションをとり信頼関係を構築する】、【一緒に考えサポートを保証する】の4つのカテゴリーが抽出された(表3).

参加者から最も多く挙げられたケアは、〈タイムリーに一人ひとりの気持ち(不安や気がかり、困っていること、つらいこと、対応して欲しいことなど)を聴く〉ことであった.参加者は、患者・家族の苦しみや気がかりに焦点を当て、「何かをしようとするのではなく、聴くこ

との重要性をわかって関わる」ケアに言及した. さらに、患者・家族の生き方を尊重し、そばにいる存在となるケアが挙げられた。多くの参加者は、「患者・家族の頑張りを認める」、「患者・家族のゆらぎに添う」のように【ありのままの患者・家族を受け入れそばにいる】ケアを挙げた。

# ii)「生きる希望を持ちながら、かつ、心残りもない」ためのケア

353の意味単位から、【患者・家族の価値観や人生についてわかろうとする】、【希望についてともに考え、何をしておけば心残りがないかを話し合う】、【希望を支持し実現できるよう一緒に取り組む】、【患者・家族の病状認識を知り、心の準備に合わせた関わりを行う】、【患者・家族のコミュニケーションを促進する】、【家族の力をサポートする】、【身体や心の苦痛をやわらげる】、【チームをコーディネートする】、【医療福祉従事者自身が希望を維持する】の9つのカテゴリーが抽出された(表4).

表4 「生きる希望を持ちながら、かつ、心残りもない」ためのケア

カテゴリー	サブカテゴリー
患者・家族の価値観や人生に ついてわかろうとする	・価値観やこれまでの生き方を知る(8) ・人生や家族にとっての存在の意味、病気体験の意味について話し合う (5)
希望についてともに考え,何をしておけば心残りがないかを話し合う	<ul> <li>・患者・家族が何を望み、どこでどのように過ごしたいのかとその理由を知る(77)</li> <li>・どうすれば心残りがないか、やっておきたいこと・話しておきたいことを話し合う(40)</li> <li>・希望となるもの(病気が良くなるかもしれないという希望を持つこと・治療・今できること・代替療法)を支え、見守っていく(38)</li> <li>・希望となるものを一緒に見い出していく(9)</li> <li>・病気がよくなった時・悪くなった時についての考えを聞く(5)</li> </ul>
希望を支持し実現できるよう 一緒に取り組む	・小さな具体的で達成可能な目標設定をサポートする(13) ・希望を実現するための患者の気持ち・考え・選択を支持する(10) ・希望を実現できるよう、タイムリーに必要な情報提供を行う(6) ・やっておきたいこと・希望する療養場所・希望する最期が達成されるよう障害を取り除いていく(22) ・患者・家族の個別の希望をケアに取り入れる(1)
患者・家族の病状認識を知り、心の準備に合わせた関わりを行う	
患者・家族のコミュニケー ションを促進する	患者・家族が気持ちを共有し、ともに過ごす時間をサポートする(20)
家族の力をサポートする	・家族が患者を支えられる(本人らしく生きることを支える、家族がやってあげられることができる)ようサポートする(19) ・家族の負担に配慮(休める声かけや環境整備、家族が気持ちを共有できる場の紹介、利用できる社会資源の紹介など)する(23)
身体や心の苦痛をやわらげる	・症状マネジメントを行う(8) ・精神的苦痛をやわらげる(5)
チームをコーディネートする	・いつ, だれが, どのように関わるのか役割分担を行う (5) ・共通の認識を持ち, チームで関わる (2)
医療福祉従事者自身が希望を 維持する	医療福祉従事者自身が希望を失わない(2)

サブカテゴリーの()内の数値は単位数を示す

参加者は、〈価値観やこれまでの生き方を知る〉、〈人生や家族にとっての存在の意味、病気体験の意味について話し合う〉ことを通じて、一人の人間としての患者をわかろうと関わるケアを挙げた、さらに、多くの参加者は、患者・家族と希望について話し合い、希望を育み、維持していこうとするケアを挙げた、参加者は、「希望の背景を知る」ことや「良くなりたいと

いう気持ちをわかろうと関わる」、「患者自身が 納得できる(過程を歩める)よう様々な試みを 行うことを支持する」のように、〈希望となる もの(病気が良くなるかもしれないという希望 を持つこと・治療・今できること・代替療法) を支え、見守っていく〉ケアを挙げた.

また、参加者は、〈どうすれば心残りがないか、やっておきたいこと・話しておきたいこと

表5 「苦痛を緩和し、かつ、医療用麻薬についての誤解がない」ためのケア

$\lambda$ $\gamma$ $\gamma$ $\gamma$	サブカテゴリー
医療用麻薬に対する誤解や不安 の背景をわかろうとする	・医療用麻薬に対する誤解や不安の背景にある過去の体験など理由を尋ねる (29) ・無理に誤解を解こうとするのではなく、医療用麻薬に対する不安や葛藤を受けとめる (12)
	これまでの医療用麻薬に関連した体験から、どのようなケアを望むかを 聞く(1)
気持ちに配慮しながら正しい情 報を伝える	・医療用麻薬や医療用麻薬に関連した体験に関する正確な情報を伝える (75) ・これまでに使用してきた薬の種類や薬の効果を一緒に確認する(4)
医療用麻薬の副作用に見える身体状況の変化は、医療用麻薬の ためではなく、病状が進行して いるためであることを説明する	・現在の状況をどう捉えているかを聞く(10) ・医療用麻薬のせいではなく,病状が進行しているために変化が起こる ことを伝える(7)
医療用麻薬の使用に関する意思 決定ができ、家族が自分を責め る気持ちにならないようサポー トする	・現状や予測される状況,選択肢を患者・家族が理解できるように具体的に伝える(47) ・苦痛の緩和の方法について,患者・家族の意思が尊重されることを保証しながら,一緒に考え不安をやわらげる(11) ・医療用麻薬を使うことを決めたことで家族が自分を責める気持ちにならないように関わる(3)
患者・家族のコミュニケーショ ンを促進する	・患者・家族が気持ちを共有し、ともに過ごす時間をサポートする(35)・患者・家族が同じ気持ちで同じ目標に向かえるようサポートする(8)・大切にしたいこと、患者が家族に望むことを共有できる場を作る(5)
家族の力をサポートする	<ul><li>・家族背景を理解してサポートする(15)</li><li>・家族が患者のためにできることを伝え、一緒に考える(11)</li><li>・家族の心身の負担に配慮する(10)</li><li>・家族の悲嘆をケアする(4)</li></ul>
チームをコーディネートする	・共通の認識をもちチームで関わる (20) ・いつ, だれが, どのように関わるのか役割分担を行う (3) ・患者・家族と医師の橋渡しをする (1)

サブカテゴリーの ( ) 内の数値は単位数を示す

を話し合う〉、〈小さな具体的で達成可能な目標設定をサポートする〉、〈病気が良くなった時・悪くなった時についての考えを聞く〉ケアに言及した.ケアの具体的な内容としては、「早めにやっておきたいことを話し合う」、「家族は先々の予測が難しく、今がその時であることを伝えていく」、「病気をどうしたいかだけでなく、一日一日をどう過ごしていきたいかを話し合う」、「最大限の努力をしても『もし、状態が悪くなったとしたら』どうしたいかを聞く」などが挙げられた.

さらに参加者は、〈現実を受けとめていくことをサポートする〉ケアとともに、〈患者・家族が現実を受け入れることと希望を持つことの両方の気持ちを持っていることをわかりながら関わる〉ケアを挙げた.

# iii)「苦痛をやわらげ、かつ、医療用麻薬についての誤解もない」ためのケア

311 の意味単位から【医療用麻薬に対する誤解や不安の背景をわかろうとする】、【医療用麻薬を使用するか使用しないかにあって、望むケアについて話し合う】、【気持ちに配慮しながら

正しい情報を伝える】、【医療用麻薬の副作用にみえる身体状況の変化は、医療用麻薬のためではなく、病状が進行しているためであることを説明する】、【医療用麻薬の使用に関する意思決定ができ、家族が自分を責める気持ちにならないようサポートする】、【患者・家族のコミュニケーションを促進する】、【家族の力をサポートする】、【チームをコーディネートする】の8つのカテゴリーが抽出された(表5).

多くの参加者は、「なぜそう思うのか不安の背景を聞く」、「医療用麻薬に関連した近親者の体験を聞く」のように、医療用麻薬に対する誤解を解くだけではなく、背景にある不安や葛藤に焦点を当てるケアを挙げた。さらに参加者は、医療用麻薬に関する説明について、「病状の変化は医療用麻薬のせいではないことをはっきりと説明する」、「自信を持って伝える」、「誰が何を使って、どのように説明するかを工夫する」のように、患者・家族の不安や葛藤に配慮したケアを挙げた。また、「具体的な選択肢を提示する」、「可能な対処について一緒に考える」のように、様々な選択肢を持ち、決定を家族のみに任せるのではなく、一緒に考え負担を分けあうケアが挙げられた。

### Ⅳ. 考察

本研究は、われわれの知る限り、患者・遺族調査の結果に基づいた緩和ケアセミナーの有用性を評価した初めての研究である.

本研究で重要な知見の一つは、患者・遺族調査の結果に基づいた緩和ケアセミナーは、参加者が患者・家族の求めるケアを実践しようとする意思を促進する可能性が示唆された点である.この解釈としては、患者・遺族調査で「患者・家族が求めていること」が実際の生の声として確認できたこと、実際の事例を通じて具体的にどのようにケアに取り入れるかを議論したことにより、あいまいな形ではなく具体的なケアの指針を得られたためと考えられる.患者・家族が求める緩和ケアを提供していくためには、知識の獲得を目的とした講義のみならず、

実際の患者・家族の評価, 医療福祉従事者に求められるケアについてのグループワークを含む教育プログラムが有用であることが示唆される<sup>13)</sup>

本研究でもう一つの重要な知見は、患者・遺 族調査の結果を知った参加者が重要だと考えた 具体的なケアが収集された点である。「生きる 希望を持ちながら、かつ、心残りもない」ため のケアでは、患者・家族の価値観の尊重を保証 すること, 希望を支持し達成可能な目標設定を サポートすること、患者・家族の心の準備に合 わせた情報提供、現実を受け入れることと希望 を持つことの両方の気持ちを理解することが含 まれた. これらは、これまでに患者・家族、医 療福祉従事者を対象とした研究から重要とされ たケアと類似しており14-17)、今後、「生きる希 望を持ちながら、心残りもない」ように過ごせ るためのケアの体系化が求められる。また、本 研究では、日々の生活に焦点を当てることに よって希望を見い出していくケアが多く挙げら れた. 希望を維持するためには, 医療的な側面 のみならず、日々の生活の視点から行うケアの 重要性が示唆される15).

一方、「苦痛をやわらげ、かつ、医療用麻薬についての誤解もない」ためのケアでは、正しい知識や情報を提供することとともに、不安や葛藤の背景を知ること、医療用麻薬の使用に関する意思決定の負担を分け合うこと、具体的な選択肢を提示することが挙げられた。これまでに、医療用麻薬についての負のイメージが患者の精神的負担となることが示されている<sup>18)</sup>.これらから、医療用麻薬の使用に関わる不安や葛藤は、単に知識の提供のみで解決されるものではなく、医療者が具体的な複数の選択肢を持ち、患者・家族の不安や葛藤に配慮することがより重要である可能性が示唆される.

本研究には、以下の限界がある。参加者を対象とした実践の自己評価や知識の評価は、緩和ケアセミナー直後の評価であり、長期的な効果や患者・家族にもたらされた効果を評価することはできない。今後、これらの課題を明らかにする研究が必要である。

# 結 論

本研究では、患者・遺族調査の結果を基にした緩和ケアセミナーの評価と、参加者が重要であると認識したケアが収集された。患者・遺族調査の結果をフィードバックするように策定された緩和ケアセミナーは、参加者から有用と評価され、患者・家族の求めるケアを実践しようとする意思を促進することに有用な可能性が示唆された。

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