

regional resources to reduce actual family burden, and providing psychological support for patient-perceived burden.

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Public awareness, knowledge of availability, and readiness for cancer palliative care services: A population based survey across four regions in Japan

ABSTRACT

This study explores the distribution of public awareness, knowledge of availability, and readiness for palliative care services, and the perceived reliability of information resources as part of a nation-wide palliative care implementation intervention in Japan (OPTIM). A cross-sectional anonymous questionnaire survey was conducted, and 3,984 responses were used in the final analysis. 63.1% of respondents admitted having no knowledge about palliative care, while 0.5% of respondents were using palliative care services. Respondents who were familiar with palliative care, yet did not recognize the availability of palliative care in their living area included 18.8% of all respondents. Findings show that the public awareness of palliative care is insufficient and the availability of palliative care services remains very low.

Introduction

Palliative care for cancer patients in Japan has rapidly progressed in the past decade, but many critical issues still need to be resolved. To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare particularly focuses on palliative care concerns, and has launched a multiple nation-wide project, as described via the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study [1]. The OPTIM study aims to improve palliative care throughout Japan and implement a community-based intervention trial targeting four areas across Japan. The mission of the study also includes the diffusion of proper knowledge relevant to specialized palliative care programs, since the general public does not have adequate knowledge about palliative care concepts [1]. For example, only 34% of the general population knows about palliative care units in Japan, whereas the rate of knowledge in the UK is 70% [2, 3]. Of note is that although 32% of the Japanese general public believes that palliative care units are a place where patients simply wait for death, these aberrant perceptions are significantly decreased after individuals actually use a specialized palliative care service [3, 4]. Thus, the lack of knowledge and general misinterpretations regarding palliative care is a considerable barrier to palliative care and appropriate pain control, and further education of the general public would be of great value.

To improve overall cancer care (including palliative care) throughout Japan, the Cancer Control Act was established in April 2007. To facilitate the dissemination of palliative health services, the Ministry of Health, Labour, and Welfare particularly focuses on palliative care concerns, and has launched a multiple nation-wide project, as described via the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study [1]. The OPTIM study aims to improve palliative care throughout Japan and implement a community-based intervention trial targeting four areas across Japan. The mission of the study also includes the diffusion of proper knowledge relevant to specialized palliative care programs, since the general public does not have adequate knowledge about palliative care concepts [1].

However these researches concerned about general knowledge and perceptions for barriers, and have not clarified intentions or acceptances for actual usage and knowledge of the availability of palliative care services in local region, which enable the general people seek the information about or access the service. To develop effective strategies to promote the enhanced utilization of palliative care services as called for in the OPTIM study, we must explore the demographics related to not only general public awareness of palliative care, but also intention for use, knowledge of the availability, and actual rate of service utilization. Therefore, we carried out a survey of a general sample across four regions as part of the OPTIM study.

This article, therefore, has the following aims: 1) to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services, 2) to clarify the differences in awareness and readiness between healthy individuals and those who have cancer-related experiences (either personally or via family).

Methods

Subjects

This study was a part of OPTIM, and the overall protocol has been given in detail [1]. Our investigation was a survey of the general population, including cancer patients. We initially selected four regions from the OPTIM study. These consisted of a large urban area (Chiba), an urban area (Shizuoka), and two rural areas (Nagasaki and Yamagata). The first three areas are places where palliative care services are available and the last one (Yamagata) is, in comparison, a location where such services are practically unavailable.

A cross-sectional anonymous questionnaire survey was conducted in a sample of the general population selected by stratified two-stage random sampling in each area (2,000 subjects in each of four regional areas). As a result, this sample included cancer patients (outpatients receiving or having received cancer treatment). We mailed a total of 8,000 questionnaires to these potential participants in June 2007 and on a later date sent a reminder postcard. On the questionnaire, we explained the aim of the study and regarded completion and return of the questionnaire as consent for participation in this study. The institutional review boards of Tokyo University confirmed the ethical and scientific validity.

Questionnaire

We developed our own questionnaire on the basis of the aims of OPTIM and through literature reviews, existing surveys, and consensus among the authors as follows. On the cover page of the questionnaire, palliative care was defined as follows: attempts to make cancer patients and their family less anxious or to experience less pain, to immediately start consultations about anxiousness and pain regardless of the state of cancer development, and alongside treatment, to facilitate the teamwork of doctors and nurses in the practice of treating patients who are suffering from the physical and/or emotional effects of cancer.

The questionnaire included three parts. First, it included questions covering the demographic information of the subjects (age, gender, length of living in each area) and whether subjects are undergoing (or have undergone) cancer treatment or have family members who have experiences of undergoing cancer treatment. Second, it included an item originally designed to determine the distribution of public awareness, knowledge of availability, and readiness and actual utilization of palliative care service. To measure these concepts, we partly used applied behavioral scientific theory, in particular, a model related to the notion of “stage of change” as used in the trans-theoretical model (TTM) [5]. This theory is widely used to assess behavioral intentions and is often applied for various behavioral situations such as use of complementary and alternative medicine [6]. We asked the participants to choose only one option from six sequential options regarding palliative care and such services: 1) no knowledge (I have no knowledge regarding palliative care; I); 2) lack of knowledge of availability (I have heard of palliative care, but I don’t know if there are any available facilities in my municipality; II); 3) no interest (I know about palliative care and its availability in my residential area, but I have no interest in the service; III); 4) no intention (I know about palliative care and its availability in my residential area, and have an interest, but I have no intention of using the service as a patient or for a family member; IV); 5) preparation (I am preparing to use palliative care services; V); 6) under utilization (I currently use palliative care services; VI) (Figure 1). We transformed the subjects’ responses for these responses (I to VI) into a numeric scale ranging from 1 to 6 points. Finally, three items related to palliative care beliefs/concepts (“Palliative care relieves pain and distress”; “Palliative care is used

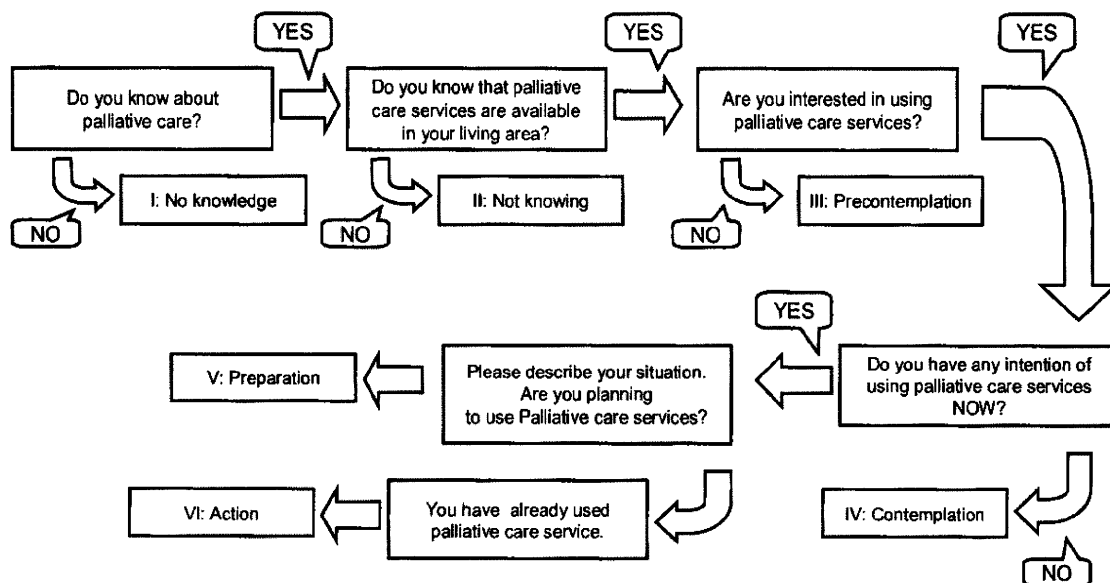


Figure1 Public awareness and readiness for palliative care services

with chemotherapy and radiotherapy”; “Palliative care is for patients close to death.”) [3, 7] were presented, and responses were measured on a five point Likert-type scale from 1) strongly disagree to 5) strongly agree.

Analysis

Descriptive analyses were carried out summarizing the subjects’ backgrounds, awareness of palliative care and utilization of such services, and scores for reliable media source opinions for total and each sampled area. Then we explored the distribution of knowledge and readiness of palliative care and utilization of the service associated with each sampled area and experiences of having cancer. These analyses were performed after dividing subjects into two groups (the general population and cancer patients/survivors) and we used the chi-square test and Cramer’s V to clarify relations between categorical variables and using coefficient correlation and relations between two categorical variables and ordered variables two-way analysis of variance (ANOVA). We conducted all statistical analyses using the Statistical Package for the Social Sciences (version 15.0.1.1 J) software package. The significance level was set at $P < 0.05$ (two-tailed).

Results

Of the 8,000 questionnaires delivered to the sampled subjects, 26 were returned as undeliverable and 3,984 were returned (response rate 49.8%). Of those returned, 3,190 were considered valid for statistical analyses. The rest ($n=794$) were invalid and were excluded from the analyses since major information was lacking. Thus, the final rate of valid replies was 39.9%.

1,860 respondents (58.3% of all respondents) were identified as ‘those having experienced cancer’ and the rest were identified as belonging to the ‘general population.’ Table 1 summarizes the background of respondents.

Public Awareness, knowledge, and readiness for palliative care

63.1% of respondents admitting to having “no knowledge” of palliative care while 0.5% of respondents were actually using palliative care services. Respondents who knew about palliative care yet did not know about the availability of palliative care in their living area included 18.6% of all respondents. Female respondents were more likely to know about palliative care

Table 1 Demographic background of the respondents

	General Population		Those Who Have Experienced Cancer	
	(n=1,200)		(n=1,677)	
	n	%	n	%
Age Years				
40-49	295	24.6	398	23.7
50-59	383	31.9	563	33.6
60-69	339	28.3	452	27.0
70-	183	15.3	264	15.7
Gender				
Male	603	50.2	700	41.7
Female	597	49.8	977	58.3
Region (Prefecture)				
Chiba	377	31.4	496	29.6
Shizuoka	326	27.2	381	22.7
Nagasaki	254	21.2	404	24.1
Yamagata	243	20.3	396	23.6
Length of living in each area				
<1 year	20	1.5	12	0.7
1-5 year	55	4.4	67	4.0
>5 year	1,125	94.1	1,598	95.3

than male respondents ($\chi^2=55.09$, d.f.=1, $P<.001$, Cramer's $V=.131$), while age and length of living in each area were not significantly associated with either awareness, knowledge or readiness. Respondents who had cancer-related experiences (either themselves or via family members) were more likely to be aware of palliative care compared to the general population ($\chi^2=27.24$, d.f.=1, $P<.001$, Cramer's $V=.092$). Also among people who knew palliative care, there was a significant association between cancer experience and knowledge for availability or readiness ($\chi^2=4.83$, d.f.=1, $P=.028$, Cramer's $V=.064$). Table 2 also shows that awareness and knowledge of and readiness for palliative care was significantly different among each area ($\chi^2=16.84$, d.f.=3, $P<.001$, Cramer's $V=.073$). Particularly, respondents in Chiba-city have more knowledge about palliative care than individuals from the other three areas.

Typical images of palliative care

Table 3 indicates the results of two-way ANOVA using awareness and cancer experiences as dependent variables, when age, gender and area were controlled. Firstly the analysis revealed the differences in perception for three common images of palliative care between individuals having no knowledge of palliative care and those who had knowledge. Significant differences were observed between them in terms of images of palliative care in the following dimensions: "Palliative care relieves pain and distress" (General population; $f(1, 3186)=33.02$, $p<.001$, Those Having Experienced Cancer; $f(1, 3186)=60.85$, $p<.001$) and "Palliative care is for patients close to death" (General population; $f(1, 3186)=13.62$, $p<.01$, Those Having Experienced Cancer; $f(1, 3186)=13.00$, $p<.01$). People who know about palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the patients, and is specialized for terminally-ill patients. There were no significant differences between the general population and cancer-experienced individuals on the three typical images of palliative care, and there were no significant interactions between cancer experience and knowledge of palliative care.

Table 2 Public awareness and readiness for palliative care service

	Total		General Population		Cancer Patient and Family		Chiba		Shizuoka		Nagasaki		Yamagata	
	(n=3,190)		(n=1,330)		(n=1,860)		(n=945)		(n=785)		(n=733)		(n=727)	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I: No knowledge	2,012	63.1	909	68.3	1,103	59.3	546	57.8	518	66.0	482	65.8	466	64.1
Having Knowledge	1,178	36.9	421	31.7	757	40.7	399	42.2	267	34.0	251	34.2	261	36.0
II: Not knowing	593	18.6	230	17.3	363	19.5	201	21.3	96	12.2	115	15.7	181	24.9
III: Not interested	24	0.8	13	1.0	11	0.6	5	0.5	12	1.5	5	0.7	2	0.3
IV: No Intention	499	15.6	167	12.6	332	17.8	171	18.1	142	18.1	116	15.8	70	9.6
V: Preparation	46	1.4	10	0.8	36	1.9	18	1.9	14	1.8	10	1.4	4	0.6
VI: Under Utilization	16	0.5	1	0.1	15	0.8	4	0.4	3	0.4	5	0.7	4	0.6

Cancer experience × Awareness (No knowledge vs. Having knowledge):

$\chi^2=27.24$, d.f.=1, $P<.01$, Cramer's V=.092

4 areas × Awareness (No knowledge vs. Having knowledge):

$\chi^2=16.83$, d.f.=3, $P<.01$, Cramer's V=.073

Within people who knew palliative care

Cancer experience × Availability: $\chi^2=4.83$, d.f.=1, $P<.028$, Cramer's V=.064

4 areas × Availability: $\chi^2=61.88$, d.f.=3, $P<.01$, Cramer's V=.229

Availability: No awareness of availability vs. Awareness of availability

Table 3 Mean scores of images of palliative care by awareness and experience of cancer

Experience of Cancer	Awareness		General population				Those Experienced Cancer				Main effect					
	Total		No knowledge		Having Knowledge		Total		No knowledge		Having Knowledge		Exp. Cancer		Awareness	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	F	P	F	P
Palliative care relieves pain and distress	3.81	0.80	3.72	0.83	4.00	0.70	3.88	0.85	3.76	0.88	4.06	0.76	2.75	.07	74.73	.00
Palliative care is used with chemotherapy and radiotherapy	3.51	0.90	3.53	0.85	3.47	1.00	3.51	0.97	3.50	0.94	3.52	1.02	0.18	.68	0.04	.85
Palliative care is for patients close to death	3.19	1.22	3.12	1.12	3.34	1.26	3.22	1.29	3.15	1.27	3.32	1.30	0.01	.91	15.30	.00

The results by two-way ANOVA were shown when age, gender and area were controlled as covariates.

Discussion

This study is the first attempt to understand the public awareness of palliative care and utilization of services based on a nation-wide sample in Japan. A clarification of these findings will hopefully contribute to understanding general perception of cancer palliative care and its variations by experiences related to cancer.

The primary aim of this study was to clarify the distribution of public awareness, knowledge of availability, and readiness for palliative care services. Per the results of the survey, 63.1% of all the participants had no knowledge of palliative care services. These results demonstrate a low public awareness of the Japanese palliative care services compared with other countries [2, 3]. Moreover, among those who did possess knowledge about palliative care in general, 18% did not know about the specific availability of the service in their region. These results indicate that over 80% of people do not have sufficient knowledge of palliative care to take advantage of its services, and it is therefore important to promote a more comprehensive understanding of palliative care (including availability) to the general population.

Second, our data clarified that cancer experiences were related to a greater knowledge of and readiness for palliative care, but did not significantly relate to specific images commonly associated with palliative care. From our data it is difficult to strictly compare cancer patients with the overall population since the sample surveyed in this study was from the general population, and therefore only a small number of cancer patients were included. However, people who had experiences with cancer (either personally or via family members) recognized both the term and meaning of palliative care. Also, people who had knowledge of palliative care have an overall positive image of it, tend to think that palliative care brings symptom control to the cancer patients, and is specialized for terminally-ill patients. Generally, as the images will be reinforced by actual experiences, those who experienced as cancer patients or as family members might see or hear the care at late stage of the cancer process. This indicated current situation that palliative care for cancer patients in general Japanese hospitals were mainly provided for late stage-cancer and that contributed to form the general images of palliative care. Also, the perception that palliative care is primarily for terminally-ill patients care may cause late referrals to palliative care services [7]. These suggest that images derived from actual experiences will have strong impact for actual decision-making for choosing or readiness for the services when the patients need. Therefore, it is important to provide proper and detailed information about palliative care services, as well as information regarding the availability of services, within areas of residence. We still have very big challenges to modify general perception for cancer palliative care, because there is no known effective method to achieve that. Educational approaches in community may become one of the solutions, and will especially be needed to help people recognize that palliative care services accept even early-stage cancer patients.

This study had several limitations. First, this study did not include measurements for the effectiveness of each medium and we cannot discern which media sources and what kind of information directly led individuals to be more aware of palliative care and to use these services. Second, we did not explore the possible associations between the awareness of palliative care and amounts of actual cancer treatment undergone. A more detailed survey will need to be conducted in order to clarify the above items. Moreover, it would be useful to better explore the insights of specific populations. In future surveys, it should be possible to design more directed questionnaires to support hypothesis-based studies.

In conclusion, the public awareness of palliative care is insufficient and the utilization of palliative care services remains low. Although those experienced with cancer treatment (either directly or via family members) were more aware of palliative care than the general population, they did not have an intention of using such services. Approaches to inform the general population (including those with cancer-related experiences) about palliative care have already been taken in Japan. However, more effective methods should be developed. We feel that it is possible to eliminate many existing barriers to the improvement of end-of-life quality, and the dissemination of knowledge related to such care and treatment in Japan should be a top priority.

Author Disclosure Statement

No competing financial interests exist.

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A scale for measuring feelings of support and security regarding cancer care in a region of Japan: A potential new endpoint of cancer care

Abstract

Context: Having a sense of security is important for cancer patients and their families.

Objectives: To develop a scale for the general population to evaluate feelings of support and security regarding cancer care, and to identify factors associated with a sense of security.

Methods: A cross-sectional, anonymous questionnaire was administered to 8,000 subjects in four areas of Japan. The sense of security was measured using five statements and employing a seven-point Likert scale: If I get cancer, (1) "I would feel secure in receiving cancer treatment", (2) "my pain would be well relieved", (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 performed exploratory factor analysis, and uni- and multivariate analyses to examine factors associated with such a sense of security.

Results: The five items regarding the sense of security were aggregated into one factor, and Cronbach's α was 0.91. In the Yamagata area, where palliative care services were not available, the sense of security was significantly lower than in the other three areas. A female gender ($p=0.035$), older age ($p<0.001$), and having cancer ($p<0.001$) were significantly associated with a strong sense of security.

Conclusion: A new scale that evaluates the sense of security was developed. Future studies should examine whether establishing a regional healthcare system that provides quality palliative care could improve the sense of security of the general population.

Introduction

Cancer is a serious disease, affecting the lives of many people. In Japan, cancer affects half of the population (55% of males and 41% of females) throughout their lifetime¹, and causes about 30% of all of deaths². Therefore, it is important to provide quality care for cancer patients. Outcomes of care for cancer patients have been measured using various indicators such as symptoms^{3, 4}, the prognosis, quality of life^{5, 6}, quality of care^{7, 8}, patient satisfaction^{9, 10}, and family satisfaction¹¹; however, there are no indicators that cover the overall aspects of care in a region.

Having a sense of security is very important for cancer patients and their families.¹² A sense of security should be evaluated from the perspective of the general population living in a region, in addition to cancer patients and their families. These perspectives reflect the quality of the regional system for providing healthcare services and the awareness among the population of the services provided by the system. As part of quality assurance of regional cancer care, a sense of security among the general population is important.

Regarding the concept of a sense of security, Funk and colleagues indicated that a feeling of security among family caregivers of cancer patients consisted of trust in competent professionals; timely access to needed care, services, and information; and a sense of their own identity and self-worth as caregivers and individuals.¹² The domain of "access to care" encompasses a sense of feeling supported as well as the perceived access to care.¹² Milberg and colleagues also suggested that having competent staff with a good attitude, access to care 24 hours a day, and being at home contributed to a feeling of security among family caregivers.^{13, 14} According to these proposed concepts, security is not just trust in an individual healthcare professional, but also a generalized sense of institutional trust in the healthcare system that makes people feel supported.¹² However, the concept of a sense of security has not been explicitly validated.

The aims of this study were: (1) to develop a scale for the general population in a region of Japan that evaluates the sense of feelings of support and security regarding cancer care, and (2) identify factors associated with a sense of security in that region. This study is new in that the scale to assess the sense of security is measured from the perspective of the general

population in a region, and includes both trust in competent healthcare professionals and in the regional healthcare system, as proposed by Funk.¹²

Methods

This study was conducted as a part of the Outreach Palliative Care Trial of Integrated Regional Model (OPTIM) study, launched by the Ministry of Health, Labor, and Welfare in Japan.^{15, 16} The OPTIM study is a regional intervention trial with the aim of establishing a regional palliative care model in four areas of Japan: a large urban area (Chiba: Kashiwa, Nagareyama, and Abiko City), a smaller urban area (Shizuoka: Hamamatsu City), and two rural areas (Nagasaki: Nagasaki City, and Yamagata: Tsuruoka and Mikawa City). In the first three areas, palliative care services are available, while, in the last one (Yamagata), such services are sparse.

We administered a cross-sectional, anonymous questionnaire survey. In the questionnaire, we explained the aim of the study and regarded the completion and returning of the questionnaire as consent to participate. The ethical and scientific validity of this study was confirmed by the institutional review board independently from the research project, which was organized by the Japan Cancer Society, the organization responsible for conducting the OPTIM study.

Population and procedures

We identified 8,000 subjects within the general population from 40 to 80 years old using a stratified, two-stage random sampling of residents in the four areas (2,000 subjects in each area). We mailed questionnaires to potential participants in July 2007, and, if the questionnaire was not returned, we sent a reminder postcard.

Measurements

We developed a questionnaire regarding the sense of security through discussions based on previous studies.¹²⁻¹⁴ The questionnaire consisted of five statements about the characteristics of healthcare professionals who provide adequate treatment and care (“competent professionals”) and adequate access to healthcare resources to feel supported (“timely access to needed care”), which are components indicated by Funk.¹² We did not include the “caregiver’s identity and self-worth”¹² in the questionnaire because the intended use of this scale in the OPTIM study was to measure the change in the level of competency of professionals and timely access to needed care as a result of the intervention for improving regional palliative care. The face validity of the questions was assessed based on full agreement of the authors.

The statements were: If I get cancer: (1) “I would feel secure in receiving cancer treatment”, (2) “my pain would be well relieved”, (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.” The translation from Japanese to English was done by a translation-back-translation procedure as follows: the questions were translated into English by a proficient translator; this translation was supervised by a bilingual person and modified. Subsequently, this prototype was translated into Japanese by two researchers other than the authors. The back-translation was compared with the original Japanese questionnaire, and the authors approved it. We asked participants to rate their level of agreement with the statements on a seven-point Likert scale (1: strongly disagree, 2: disagree, 3: slightly disagree, 4: not sure, 5: slightly agree, 6: agree, 7: strongly agree).

The demographic data, such as area where the respondent lived, age, gender, duration of residence in the region, current treatment of health problems, diagnosis of cancer (during or after treatment), and family members’ experiences of cancer, as well as knowledge about palliative care, were also included in the questionnaire.

Statistical analyses

First, we conducted descriptive analyses of demographic data and responses regarding the sense of security regarding cancer care in the designated region.

Scale development

To examine feasibility, we considered the rate of missing data for question items regarding the sense of security. We then used exploratory factor analysis employing the principal factor method for question items on the sense of security; the factorial validity of the scale was examined. To assess the reliability of the scale, we calculated Cronbach's α coefficients.

The scale score was calculated by summing the points for the five items because the score was regarded as normally distributed. We set 25 points, which is the sum of five number 5 ratings ("slightly agree"), or more as the cut-off of the sense of security scale to identify persons who felt secure.

Related factors

To identify factors associated with the sense of security, univariate analyses were conducted using analysis of variance, the unpaired *t*-test, Pearson's product-moment correlation coefficient, and Spearman's rank correlation coefficient, where appropriate. Thereafter, the association of each hypothesized factor with the sense of security score was determined using multiple regression analysis.

Statistical analysis was performed using SAS version 9.1 (SAS Institute, Inc., Cary, NC, USA). The significance level was set at <0.05 (2-tailed).

Results

Characteristics of participants

Of the 8,000 questionnaires sent out, 26 were undeliverable and 3,984 were returned. Among the respondents, 254 were excluded due to missing all data for items regarding the sense of security, and 3,730 responses were analyzed (effective response rate: 46.8%). There was a significant difference in the response rate among the areas (Yamagata, 47%; Chiba, 53%; Shizuoka, 44%; Nagasaki, 42%; chi-square test, $p < 0.001$).

Table 1 summarizes the characteristics of the respondents.

[Table 1]

Distribution of the sense of security in the region

Table 2 shows the distribution of responses regarding the sense of security. While about 60% of the respondents (sum of "strongly agree," "agree," and "slightly agree") believed that they would be treated appropriately for cancer, less than half of the respondents believed that treatment for pain and distress and the availability of healthcare services, including home care, would be sufficient (Table 2).

[Table 2]

Feasibility

The rate of missing values for the five items regarding the sense of security was 1.5 – 3.5%.

Exploratory factor analysis

According to the results of exploratory factor analysis, the five items regarding the sense of security were aggregated into one factor (Table 3). Cronbach's α was 0.91.

[Table 3]

Related factors

Univariate analysis

The association of each demographic factor with the sense of security score, which was calculated by summing the points of the five items, was examined employing univariate analyses, and the results are shown in Table 4. The difference in the sense of security among the areas was significant ($p < 0.001$). Other factors associated with a higher score for the sense of security were an older age ($p < 0.001$), current treatment for a health problem ($p < 0.001$), having cancer ($p < 0.001$), and no family history of cancer ($p = 0.005$). When examining correlations among variables, a family history of cancer was associated with the gender (females had more experiences of family cancer), and having a health problem was associated with the age and having cancer ($p < 0.001$, respectively).

[Table 4]

Multiple regression analyses

The results of multiple regression analyses are shown in Table 5. The Yamagata area showed a significantly smaller score for the sense of security compared to the other areas ($p < 0.001$). A female gender ($p = 0.035$), older age ($p < 0.001$), and diagnosis of cancer ($p < 0.001$) were associated with a high score for the sense of security. The associations of these variables, other than the area and age, were not strong, and the determination coefficient was small (0.068).

[Table 5]

Discussion

In this study, we developed a scale to evaluate the general population in a region of Japan to assess their feelings of support and security regarding cancer care. The scale was constructed using one factor, and showed good face validity with the full agreement of the authors, and factorial validity and internal consistency on factor analysis. The sense of security in the Yamagata area was poor compared to that in the other three areas. Being female, of an older age, and having cancer were associated with a strong sense of security. Additionally, more than half of the respondents felt uneasy (i.e., "strongly disagree", "disagree", "slightly disagree", and "not sure") about the availability of adequate treatment for pain and distress caused by cancer and of the types of healthcare services available (e.g., home care). These responses suggest that many people were unsure about the adequacy of regional cancer care.

To our knowledge, this is the first study to evaluate the sense of security regarding cancer care from the perspective of the general population. In the Yamagata area, where specialized palliative care services were not available at the time of the survey, the sense of security was poor, whereas other factors associated with the sense of security were adjusted. This result suggests that the scale could reflect the adequacy of the regional system for providing healthcare services, thus suggesting good known-group validity. In the scale developed in this study, the sense of security of the general population consists of trust in healthcare professionals to adequately respond to patients' pain and distress from cancer, and feeling

that various medical and care services are readily available, even at home.¹² To improve the sense of security in a region, it is important for the general population to feel supported; thus, healthcare professionals should be educated in cancer and palliative care, palliative and other care services should be available, and these services should be accessible to the general population. This new scale would be a useful endpoint for evaluating the comprehensive sense of security in the general population of a region. It may also be used as an indicator of the adequacy of healthcare services (including the competency of healthcare professionals and accessibility to care) provided in the region and awareness of the services among the general population.

Furthermore, the scale, which was developed to target the general population, could also cover cancer patients and their families. Although the questionnaire queried the general population about a hypothetical diagnosis of cancer, surveys of cancer patients and their families employing this instrument could collect more practical data on the sense of security based on care already received.

We also identified factors other than “area” that are associated with the sense of security in order to apply the OPTIM model effectively to other areas of Japan in the future. An older age, the gender (female), and a diagnosis of cancer were associated with a strong sense of security; having health problems and a family member’s experience of cancer, which were associated with a sense of security on uni- but not multivariate analysis, might be confounding factors of age and having cancer, and gender, respectively.

First, the results for age and gender were comparable to previous studies regarding patient satisfaction with healthcare, which indicated that older patients were more satisfied with their care than younger ones, but the association of gender and satisfaction differed.¹⁷⁻¹⁹ Our results showing that older people had a strong sense of security are supported by the results of a previous study in which older individuals remembered an earlier, less accessible healthcare system and so were less ready to criticize, and that they did not have high expectations.¹⁸ Additionally, because many older persons lead a community-based life compared to younger ones, they may have easy access to regional healthcare; consequently they may feel more secure regarding the accessibility of healthcare. For gender, a previous study put forward a reason why females may be more satisfied with the healthcare they have received than males: the level of communication with healthcare staff affected patient satisfaction, and females communicated more with staff than males.²⁰ In this study, however, the scores for the sense of security were almost equal between males and females, and the standardized partial regression coefficient of the multiple regression analysis was small. Further analyses regarding the influence of gender are needed.

Second, the subjects with cancer felt more secure regarding cancer care than those without cancer. This result suggests that, whereas a person without cancer may feel a vague anxiety about cancer and its care, once a person gets cancer and has experienced receiving care, he or she may feel secure because the level of individual treatment and care in Japan is of a relatively high quality. On the other hand, subjects with a family member who had cancer had a poor sense of security compared to those without such experience, although the difference was not significant on multivariate analysis. This situation might be a result of experiencing early cancer care in Japan, which was poor. Doctors did not tell patients they had cancer, and pain control was inadequate. Consequently, many patients died a painful death. The result may suggest that individuals who lost a family member (mostly parents) to cancer in times past saw their pain and distress; therefore, they have an impression that cancer causes great distress, and so a poor sense of security regarding cancer care. However, in Japan, palliative care teams became covered by National Medical Insurance in 2002, and the Cancer Control Act was established in 2007; as a result, palliative care has progressed so that more effective treatments are available.

Nonetheless, the association of each variable with a sense of security was not strong, and the determination coefficient was small. There should be factors associated with a sense of security other than those measured in this study. To identify effective strategies for improving the sense of security in the general population within a region, future studies should look at the association of more detailed characteristics of the respondents with the sense of security. For example, if persons

with negative perceptions about palliative care (such as “a place where people only wait to die”)²¹ have a low sense of security, strategies that specifically educate about palliative care and improve the perceptions of such persons would be needed. Also, if persons who do not know of the availability of specialized palliative care services and other care resources (e.g., home care) in the region have a low sense of security, strategies that disseminate knowledge on the availability of services would be needed.

This study had several limitations. First, the content validity and test-retest reliability were not confirmed; further study is needed. Generally, the reliability of a scale should be verified employing the test-retest method. However, Cronbach’s α (internal consistency) can also be used as an indicator of reliability; if Cronbach’s α is high, the coefficient of test-retest reliability would also be high. In this study, because Cronbach’s α of the scale was very high, it is possible that the test-retest reliability would also be high.

Second, although we considered that the scale for the sense of security could be a measure of the adequacy of the system for providing healthcare services and the awareness among the population of the services, the construct validity has not been confirmed. Future studies should compare the sense of security with other indicators regarding the quality of the regional healthcare system, such as death at home, the number of patients receiving specialized palliative care, and evaluation of patients and the bereaved family, which were not measured during the study period but are measured now in the OPTIM study.¹⁵

Third, the response rate of the survey was not high, the difference in response rate among the areas was significant, and we could not clarify the characteristics of non-responders; therefore, a response bias may exist. However, because the response rate of opinion surveys in the general population in Japan is generally about 50%,^{8, 22-24} the response rate of the study may be acceptable.

In conclusion, this study developed a new scale to evaluate feelings of support and security regarding cancer care in a region of Japan. This scale may be a useful endpoint for studies on the comprehensive sense of security, as well as adequacy of the system for providing healthcare services for cancer in a region, and awareness among the general population of the services. The OPTIM study is an intervention trial for improving these endpoints; we are awaiting the results of this intervention.

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Table 1. Characteristics of respondents (n= 3,730)

		n	%
Area	Yamagata	943	25
	Chiba	1,061	28
	Shizuoka	877	24
	Nagasaki	849	23
Gender	Male	1,648	45
	Female	2,012	55
Age, y, mean (± SD)		59.6 (± 10.5)	
Duration of residence in the region	Less than 1 year	42	1
	1-5 years	141	4
	More than 5 years	3,457	95
Treated for health problems		1,959	54
Have cancer		177	5
Family members' experiences of cancer		2,008	55
Awareness of palliative care		523	15

SD, standard deviation

Percentages for each item were calculated after excluding missing values.

Table 2. Distribution of responses for sense of security regarding cancer care (n = 3,730)

If I get cancer:	Strongly disagree %	Disagree %	Slightly disagree %	Not sure %	Slightly agree %	Agree %	Strongly agree %	Total agreement ^a %
(1) I would feel secure in receiving cancer treatment.	3	10	9	17	26	30	6	61
(2) My pain would be well relieved.	4	18	13	24	23	17	2	41
(3) Medical staffs will adequately respond to my concerns and pain.	3	14	13	23	26	19	2	46
(4) I would feel secure as a variety of medical care services are available.	5	17	14	29	21	12	2	35
(5) I would feel secure in receiving care at home.	9	26	16	26	15	7	1	23

Percentages for each item were calculated after excluding missing values.

^a Sum of "slightly agree", "agree", and "strongly agree"

Table 3. Exploratory factor analysis (n=3,587)

If I get cancer:	Factor 1	Communality
(1) I would feel secure in receiving cancer treatment.	0.82	0.67
(2) My pain would be well relieved.	0.88	0.77
(3) Medical staffs will adequately respond to my concerns and pain.	0.91	0.83
(4) I would feel secure as a variety of medical care services are available.	0.90	0.82
(5) I would feel secure in receiving care at home.	0.77	0.59

Proportion of variance explained, 73.5%

Table 4. Factors related to sense of security according to univariate analyses (n = 3,587)

Variable		Sense of security score, mean (SD)	p-value
Area	Yamagata	17.7 (7.1)	<0.001 ^a
	Chiba	19.8 (6.3)	
	Shizuoka	21.3 (6.2)	
	Nagasaki	19.9 (6.6)	
Gender	Male	20.0 (6.2)	0.571 ^b
	Female	20.1 (6.3)	
Age		0.225 ^c	<0.001
Duration of residence in the region		-0.015 ^d	0.373
Treated for health problems	Yes	20.6 (6.3)	<0.001 ^b
	No	19.5 (6.2)	
Have cancer	Yes	23.1 (5.7)	<0.001 ^b
	No	19.9 (6.3)	
Family members' experiences of cancer	Yes	19.5 (6.4)	0.005 ^b
	No	20.1 (6.2)	
Awareness of palliative care	Yes	20.1 (6.7)	0.666 ^b
	No	20.0 (6.2)	

SD, standard deviation

^a Analysis of variance ^b t-test ^c Pearson's product-moment correlation coefficient ^d Spearman's rank correlation coefficient

Table 5. Factors related to sense of security according to multi-regression analysis (n =3,419)

Independent variable		β	p-value
Area	Yamagata	Reference	-
	Chiba	0.143	<0.001
	Shizuoka	0.242	<0.001
	Nagasaki	0.140	<0.001
Gender	Male	Reference	-
	Female	0.035	0.035
Age		0.155	<0.001
Duration of residence in the region	Less than 1 year	Reference	-
	1-5 years	0.023	0.436
	More than 5 years	-0.004	0.898
Treated for health problems		0.015	0.389
Have cancer		0.090	<0.001
Family members' experiences of cancer		-0.028	0.096
Awareness of palliative care		-0.011	0.528

Determination coefficient: R²=0.068

市民公開講座の受講前後の緩和ケアに対するイメージの変化

Abstract

緩和ケアや医療用麻薬に対する誤ったイメージは未だ根強く、緩和ケア普及を妨げる一因となっている。緩和ケア普及のための地域プロジェクト（OPTIM）では、鶴岡市と浜松市の一般市民を対象に緩和ケアに関する教育講座を行い、受講前後での緩和ケアに対するイメージの変化を調査した。質問紙調査の結果、両方の地域で、参加者は受講前よりも受講後にポジティブな認識を持っていた。また、性別による認識の差は見られなかったが、年齢別、地域別、立場別でいくつかの特徴が見られた。市民講座は緩和ケアに関する正しいイメージを普及する上で重要であるといえる。

はじめに

緩和ケアや医療用麻薬に対する誤ったイメージは、緩和ケア普及の妨げとなることが示唆されている（文献：1-3）。しかしながら、我が国では3-5割の国民あるいはがん患者が「医療用麻薬は命を縮める」や、「緩和ケアは末期だけのものである」といったイメージを持っており（文献：4-5）、このような誤解を取り除くための対策が必要とされている。緩和ケアや医療用麻薬に関する正しい知識を得てもらうために、一般市民やがん患者を対象とした教育講座やセミナーが各地で開かれているが、効果について評価した研究はほとんどない。1地域の民生委員を対象とした研究では、緩和ケアについての講演会は緩和ケアに対する誤ったイメージを取り除くために、短期的に有効であることが示されている（文献：6）。しかし、複数の地域の一般市民を対象とした研究はこれまでに報告されていない。本調査は、複数の地域の一般市民を対象に、市民講座の受講前後での緩和ケアに対するイメージの変化を検証することを目的とする。

対象・方法

緩和ケア普及のための地域プロジェクト（OPTIM）（文献：7）の介入の一部として、平成20年度から22年度にかけて、山形県鶴岡市と静岡県浜松市の一般市民を対象に緩和ケアに関する市民講座を行った。市民講座のテーマは、鶴岡では「地域で支えるがん緩和ケア ～あなたらしく生きるために～」（平成20年11月15日実施：講義・パネルディスカッション）、浜松では「上手に使おうホスピス・緩和ケア」（平成20年9月27日実施：講義）、「安心できるがん緩和医療をめざして～患者さんとご家族の明日のために～」（平成21年9月26日実施：講義）、「がんと向き合う 地域で支える」（平成22年7月18日：講義）であった。いずれも講演の中で、「緩和ケアは、化学療法や放射線治療などがんに対する治療と一緒に進む」、「モルヒネなど医療用麻薬は、麻薬中毒になったり命を縮める作用はない」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」ことを伝え、また、地域で利用できる緩和ケアの資源を具体的に紹介することによって「がんであっても、苦痛や心配には十分に対処してもらえると思う」、「がんであっても、安心して自宅で療養できる」ことを伝えた。

参加者1,200名を対象に調査を行った。鶴岡地域の参加者は319名、浜松地域の参加者は、平成20年度は72名、21年度は600名、22年度は209名の計881名であった。質問紙は、講座開始前に全員に配布し、終了後に任意で回収した。回収は匿名で行った。

緩和ケアのイメージについて、「緩和ケアは、化学療法や放射線治療などがんに対する治療と一緒に進む」、「モルヒネなど医療用麻薬は、麻薬中毒になったり命を縮める」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」という緩和ケアの知識に関する3項目と、「がんであっても、苦痛や心配には十分に対処してもらえると思う」、「がんであっても、安心して自宅で療養できる」という安心感に関する2項目で尋ねた。それぞれの項目ごとに、受講前のイメージと受講後のイメージを、1) そう思っていなかった・そう思わない、2) そう思っていた・そう思う、

3) ととてもそう思っていた・とてもそう思う、の3件法で尋ねた(文献:4,8)。一回の質問紙で受講前後のイメージを尋ねた。

緩和ケアの受講前後でのイメージについて paired t 検定を行った。受講前後でイメージに変化が見られた群と見られなかった群に分けて、カイ二乗検定を行った。イメージに変化が見られた群とは、受講前は各項目に対し「そう思わなかった」と答えたが、受講後は「そう思う、とてもそう思う」と答えた、否定的だったイメージが肯定的に変化した参加者を指す。イメージに変化が見られなかった群とは、受講前に「そう思わなかった」、受講後に「そう思わない」を選択し、否定的なイメージを持ち続けた参加者、または受講前は「そう思っていた、とてもそう思っていた」を選択したが、受講後は「そう思わない」を選択した、肯定的なイメージが否定的に変化した参加者を示す(いずれの群も、逆転項目の場合は反対の処理を行った)。

結果

858名(回収率71.5%)から回答を得た。年代別では、60代(27.3%)が最も多く、続いて50代(22.9%)、70代以上(21.3%)、40代(17.6%)、30代(7.3%)、20代(3.6%)であった。男女比は1:4であった。参加者の内訳は、一般市民(55.1%)が最も多く、続いて医療関係者(18.5%)、患者の家族(10.2%)、患者(8.4%)、その他(7.8%)であった。

全体として、市民講座の受講前後での緩和ケアに関するイメージを比較したところ、「緩和ケアは、化学療法や放射線治療などがんに対する治療と一緒に進む」、「がんであっても、苦痛や心配には十分に対処してもらえると思う」、「モルヒネなど医療用麻薬は、麻薬中毒になったり命を縮める」、「がんであっても、安心して自宅で療養できる」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」のすべての項目で有意な変化が得られた(表1)。

地域別でも、いずれの地域においても、すべての項目において、受講前より受講後の方が緩和ケアや医療用麻薬に対するイメージは肯定的に変化した(表1)。

また、受講前後で否定的なイメージが変化する割合は、性別による有意差は見られなかった。年齢別では、「モルヒネなど医療用麻薬は、麻薬中毒になったり命を縮める」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」の、知識についての項目で優位傾向が見られた。地域別では、「緩和ケアは、化学療法や放射線治療などがんに対する治療と一緒に進む」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」の、知識に関する項目で有意差があった。立場別では、「がんであっても、苦痛や心配には十分に対処してもらえると思う」、「がんであっても、安心して自宅で療養できる」の、安心感に関する項目で有意差があった(表2)。

考察

本調査の結果から、緩和ケアに関する市民対象の教育講座は、市民の緩和ケアのイメージを少なくとも短期的に変化させる可能性が示唆された。「緩和ケアは、化学療法や放射線治療などがんに対する治療と一緒に進む」、「ホスピスは『末期』だけでなく、在宅療養を支える役割もある」という項目について、受講後に「とてもそう思う・そう思う」と答えた参加者が増加したことから、緩和ケアに関する講座は「緩和ケア=末期」というイメージを取り除き、早期からの緩和ケアを推進するために効果的であることが示唆される。同様に、「モルヒネなど医療用麻薬は、麻薬中毒になったり命を縮める」、という項目では、受講後に「とてもそう思う・そう思う」と答えた参加者が減少したことから、緩和ケアに関する講座は麻薬に関するそのような間違ったイメージを払拭するために有効であることが示唆される。また、「がんであっても、苦痛や心配には十分に対処してもらえると思う」、「がんであっても、安心して自宅で療養できる」という項目についても、受講後に「とてもそう思う・そう思う」と答えた参加者が増加したことから、参加者が講座を受講することで、がんに罹患しても住んでいる地域や自宅で治療を受けながら生活できるという安心感が得られていると考えられる。

今回対象とした二地域では同じようなイメージの変化が見られたことから、このような市民講座はいずれの地域でも有効であると考えられる。

受講前後でのイメージに変化があった群となかった群で、対象者の性別に差が見られなかったことから、男女の違いによるイメージの認識に大きな変わりはないことが示唆されると考えられる。また、年齢別では、60歳以上の高齢者の方が、緩和ケアの知識についての認識が変わりにくい傾向がでている。高齢者向けの講演を行う場合には、知識に関する説明だけでなく、高齢者の経験や生活に即した情報提供を行うことがより効果的ではないかと考えられる。地域別に見ると、知識に関する項目で差は見られたが、これは鶴岡地域にもともと緩和ケアに肯定的なイメージを抱いていた参加者が多かったため、このような結果になったと考えられる。同様に、参加者の立場別に見て、医療関係者の方が安心感に関するイメージが変わりにくいとの結果が得られたが、知識に関しては市民と差がなかった。これは、医療関係者は実際に現場を知っており、現実的な経験に基づいたイメージを持っているためであると考えられる。

このように、市民に緩和ケアに関する正しいイメージを提示し、今後の緩和ケアの利用につなげるためにも、緩和ケアに関する教育講座は重要であるといえる。

本調査の限界として、市民講座を受講した前と後にイメージを聞いておらず、受講をした後に、受講前後のイメージを聞いているため、対象者の認識にバイアスがかかっている可能性が指摘される。また、本調査では市民講座の長期的な効果を検討していないため、今後、そのような調査を行うことも重要である。

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