

[Original Research]

Patients' Awareness of Palliative Care in a Community Pharmacy

Yumi SATOH and Masahiro OHSAWA

Department of Neuropharmacology, Graduate School of Pharmaceutical Sciences,
Nagoya City University

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Abstract: Several reports have pointed to the importance of early palliative care (PC) for patients with cancer, but the understanding of PC might be impeded by late introduction during treatment. This study aims to survey the knowledge and expectations for the timing of explanation of PC in cancer treatment among patients visiting a community pharmacy. A cross-sectional study was performed by distributing questionnaires to outpatients, who had received a prescription and had visited a community pharmacy to fill that prescription. A total of 201 responses were analyzed. In total, 22.9% of participants were unaware of PC. Approximately 25% of the participants indicated that they thought PC was for terminal illness at end of life. An additional 44.8% thought that PC for cancer treatment should begin at the time of diagnosis with cancer. About 60% had hoped to receive an explanation of PC at the time of diagnosis. More than 60% thought that PC was provided in a PC unit, while 3% thought that the PC was provided at community pharmacies. Our results indicated that people's understanding of PC is still insufficient. Further, the results of this study identified that people would like to receive an explanation of PC at the time of diagnosis itself. Many people might not be aware that PC can be offered at home, in outpatient clinics, and at community pharmacies.

Key words: palliative care, community pharmacy, patients' awareness, questionnaire, pharmacist

INTRODUCTION

Palliative care (PC) refers to improving QOL of patients facing life-threatening diseases and their families.¹⁾ Many efforts have been made to enhance the understanding of PC for cancer patients. Previously, early PC was indicated to improve QOL and mood in patients with metastatic non-small cell lung cancer,²⁾ suggesting the importance of early PC in cancer patients. The Japanese Basic Plan to Promote Cancer Control Programs in 2012 included a chapter on the early introduction of PC in cancer treatment.^{3, 4)} It was also reported that patients who received outpatient PC had improved end-of-life care compared with those who received inpatient PC.⁵⁾

Despite its importance, the awareness of PC is still inadequate, and the term "palliative care" is not correctly understood. A community-based cross-sectional survey in Northern Ireland revealed that public awareness of PC, and its availability, remains insufficient for widespread, effective, and appropriate PC to be accepted as the standard.⁶⁾ Many people still believe that PC is a medical treatment provided for terminal or elderly individuals.⁷⁾ In a survey of awareness of PC in Italy, about 60% of people had heard the term "palliative care," and 23.5% of them did not know or misunderstood its

meaning.⁸⁾ Similarly, according to a study in Japan, about 63% of people did not know what PC is, and public belief of PC is that it is an end-of-life medical care.⁹⁾

The reasons for the lack of understanding of PC might be the taboo surrounding discussions of the subject of death, lack of information on PC, misunderstanding PC, and a belief that PC resources are concentrated in urban areas and difficult to receive in rural areas.^{6-8, 10)} In addition, a major problem preventing the correct understanding of PC might be the inadequate timing of introducing and providing PC for cancer treatment. Morita et al. have reported that introduction of PC by an oncologist was late or very late compared to family members' expectations.¹¹⁾ This study raised the possibility that an obstacle to introducing PC at an early stage is limited opportunities to discuss PC among physicians, patients, and family members in the hospital. Factors that contribute to family perception of late referral included family belief before admission that PC shortens the patient's life, insufficient discussion in advance regarding preferred end-of-life care with physicians, families' insufficient preparation for changes in patient conditions, and treatment settings.¹¹⁾

Although there are several reports studying the awareness and understanding of PC in the general public and in cancer patients,^{7, 8, 12)} and the timing of introducing PC for cancer patients,¹¹⁾ no investigation has been done into when patients would like this information from medical staff, in the case of outpatients in particular. Therefore, in the present study, we conducted a questionnaire survey among patients visiting a community pharmacy

Corresponding author: Masahiro OHSAWA, Department of Neuropharmacology, Graduate School of Pharmaceutical Sciences, Nagoya City University, 3-1, Tanabe-dori, Mizuho-ku, Nagoya 467-8603, Japan
E-mail: ohsawa@phar.nagoya-cu.ac.jp

regarding knowledge of PC and ideal timing of explanation about PC in cancer treatment.

METHODS

This study was conducted in accordance with the ethical guidelines for medical and health research involving human subjects. The study was approved by the Ethics Committee of Nagoya City University Graduate School of Medical Sciences and the Nagoya City University Hospital Institutional Review Board (#60160040).

1. Participants

A cross-sectional study was performed by distributing questionnaires to outpatients who had received a prescription and had visited Sky Pharmacy in Hongo to fill a prescription. Data were collected from May to June 2015 and again from October to November 2015.

Exclusion criteria included: (1) inability of patient to complete questionnaire due to physical condition, level of literacy, or other factors, and (2) age over 20 years. In this study, participants were independent from disease or prescription content.

2. Questionnaires

In this survey, a questionnaire was created by referenced to the Public Opinion Survey on Cancer Control by Cabinet Office, Government of Japan in 2014.¹³⁾ The questionnaires were distributed to patients who had agreed to participate. Questionnaires were self-report, completed anonymously, and contained details regarding the aim and ethical considerations of the study. The following questions were included in the questionnaire. (1) Awareness of PC: Choose the category that best corresponds to your level of awareness of PC (only one answer): very aware, aware, and unaware. (2) Purpose of PC: Choose the statement that corresponds to your idea of PC: alleviation of physical distress, relieving emotional distress, for medical service at end of life, social support for patients undergoing treatment, or no idea. (3) Target population of PC: Who do you think PC is for? Select from among the following (multiple answers permitted): patient, patient's family, and unknown. (4) Possible time to start PC in cancer treatment: When do you think PC could be started as part of cancer treatment? Choose from among the following (only one answer): when diagnosed with cancer, together with other cancer treatments (i.e., chemotherapy, radiation therapy), and when it becomes difficult to treat actively (i.e., at the end of life). (5) Ideal time for providing an explanation of PC in cancer treatment: When would you want to receive a detailed explanation of PC in cancer treatment? Choose from among the following (multiple answer): when the cancer is diagnosed, when you start to feel physical pain, when you start to feel psychological distress, when active treatment becomes difficult, and a detailed explanation is not needed. (6) Ideal time to start PC in cancer treatment: When do you want to start PC in cancer treatment? Choose from among the following (multiple answer): when diagnosed with cancer, when you start to feel physical pain, when you start to feel psychological dis-

tress, when active treatment becomes difficult, and PC in cancer treatment is not needed. (7) Location of PC for cancer patients: Where do you think PC in cancer treatment will be provided? Choose from among the following (multiple answer): general hospital, PC unit, at home, outpatient clinic, community pharmacy, others, and unknown. Age and gender were obtained from prescription.

3. Analysis

We conducted the Fisher's exact test for all statistical analyses. A value of $p < 0.05$ was considered significant in all analyses. All analyses were carried out using R software.

RESULTS

The questionnaires were distributed to 209 patients. Since two participants did not answer any questions, their questionnaires were excluded from the analysis. While we had asked for only one answer in question 4, multiple answers were obtained from six participants, so we excluded these data. Therefore, the analysis was conducted on 201 responses. The characteristics of participants are summarized in Table 1.

1. Awareness of PC

Among the 201 participants, 43 (21.4%) reported that they were familiar with PC (very aware group), 112 (55.7%) reported that they were aware (aware group), and 46 (22.9%) reported that they were unaware (unaware group).

2. Purpose of PC

The purpose of PC was reported to be alleviation of physical distress in 60.7% ($n = 122$) of the participants, relieving emotional distress in 58.2% ($n = 117$), for medical service at the end of life in 24.9% ($n = 50$), and social support for patients undergoing treatment in 4.5% ($n = 9$) (Table 2, Q2). Few participants answered that the purpose of PC was social support for patients, as compared to the other answer choices, in all three groups. The number of participants who answered that the purpose of PC was alleviation of physical distress was significantly lower in the unaware group, compared to the other two groups. Although about 75% of all participants mentioned that PC is not meant to provide medical service at the end of life, 40% of the very aware group considered the purpose of PC to be end-of-life care.

Table 1 Characteristic of patients

	$n = 201$	(%)
Age		
< 40	69	(34.3)
40 ~ 69	105	(52.2)
70 <	21	(10.4)
No answer	6	(3.0)
Gender		
Male	28	(13.9)
Female	167	(83.1)
No answer	6	(3.0)

Table 2 Knowledge and beliefs about palliative care in cancer treatment (answers to question 2 ~ 6)

	All	Very aware ^c	Aware ^c	Unaware ^c	<i>p</i> value
	<i>n</i> = 201	<i>n</i> = 43	<i>n</i> = 112	<i>n</i> = 46	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Q2) Purpose of palliative care ^a					
Alleviation of physical distress	122 (60.7)	34 (79.1)	68 (60.7)	20 (43.5)	< 0.01
Relieving emotional distress	117 (58.2)	31 (72.1)	73 (65.2)	13 (28.3)	< 0.001
For medical service at end of life	50 (24.9)	17 (39.5)	27 (24.1)	6 (13.0)	< 0.05
Social support for patients undergoing treatment	9 (4.5)	1 (2.3)	8 (7.1)	0 (0.0)	0.11
No idea	26 (12.9)	1 (2.3)	7 (6.3)	18 (39.1)	< 0.001
Q3) Target population of palliative care ^a					
Patient	169 (84.1)	40 (93.0)	100 (89.3)	29 (63.0)	< 0.001
Patient's family	75 (37.3)	22 (51.2)	46 (41.1)	7 (15.2)	< 0.001
Unknown	21 (10.4)	1 (2.3)	6 (5.4)	14 (30.4)	< 0.001
Q4) Possible time to start palliative care ^b					
When diagnosed with cancer	90 (44.8)	14 (32.6)	50 (44.6)	26 (56.5)	0.075
Together with other cancer treatments	32 (15.9)	6 (14.0)	17 (15.2)	9 (19.6)	0.787
When it becomes difficult to treat actively	69 (34.3)	22 (51.2)	41 (36.6)	6 (13.0)	< 0.001
Q5) Ideal time for providing an explanation of palliative care ^a					
When diagnosed with cancer	118 (58.7)	17 (39.5)	67 (59.8)	34 (73.9)	< 0.01
When you start to feel physical pain	55 (27.4)	19 (44.2)	29 (25.9)	7 (15.2)	< 0.05
When you start to feel psychological distress	40 (19.9)	14 (32.6)	24 (21.4)	2 (4.3)	< 0.01
When it becomes difficult to treat actively	26 (12.9)	13 (30.2)	11 (9.8)	2 (4.3)	< 0.01
Detailed explanation is not needed	7 (3.5)	2 (4.7)	2 (1.8)	3 (6.5)	0.215
Q6) Ideal time to start palliative care ^a					
When diagnosed with cancer	93 (46.3)	15 (34.9)	48 (42.9)	30 (65.2)	< 0.01
When you start to feel physical pain	65 (32.3)	15 (34.9)	42 (37.5)	8 (17.4)	< 0.05
When you start to feel psychological distress	60 (29.9)	13 (30.2)	39 (34.8)	8 (17.4)	0.093
When active treatment becomes difficult	36 (17.9)	14 (32.6)	18 (16.1)	4 (8.7)	< 0.05
Palliative care is not needed	5 (2.5)	1 (2.3)	1 (0.9)	3 (6.5)	0.081

^a Multiple answer. ^b Percentage do not add up 100% because of no answer. ^c Awareness of palliative care (answer of question 1). *p* values were determined with Fisher's exact test.

3. Target population of PC

Among all participants, 84.1% answered that PC is provided for the patient. On the other hand, only 37.3% answered that PC is provided for the patient's family (Table 2, Q3).

4. Possible time to start PC in cancer treatment

With regard to when patients believe that they are able to start PC as part of cancer treatment, 44.8% (*n* = 90) answered that the appropriate time is when cancer is diagnosed, 15.9% (*n* = 32) answered that it could be provided together with other cancer treatments, and 34.3% answered that it could be provided when it becomes difficult to treat the cancer actively (i.e., at end of life) (*n* = 69) (Table 2, Q4). The very aware group answered, "When it becomes difficult to treat actively," significantly more than the other groups.

5. Ideal time for explanation of PC in cancer treatment

Among all participants, 58.7% (*n* = 118) reported that they hoped to be introduced to PC at the same time as cancer diagnosis (Table 2, Q5). According to the participants, the ideal time to be informed about PC was when they started to feel physical pain (27.4%, *n* = 55), when they start to feel psychological distress (19.9%, *n* = 40), when it becomes difficult to treat actively (12.9%, *n* = 26), and no explanation is needed (3.5%, *n* = 7) (Table 2, Q5). The rate of answering that they would prefer to receive

an explanation of PC at the time of cancer diagnosis was highest in the unaware group (73.9%). In contrast, the rate of answering that they would prefer to receive an explanation of PC when it became difficult to continue active cancer treatment was the highest in the very aware group (30.2%).

6. Ideal time to start PC in cancer treatment

As shown in Table 2, Q6, the largest number of ratings was for the response, "when diagnosed with cancer" (46.3%, *n* = 93). The ideal time to start PC was rated as follows, when they start to feel physical pain (32.3%, *n* = 65), when they start to feel psychological distress (29.9%, *n* = 60), when it becomes difficult to treat actively (17.9%, *n* = 36), and PC is not needed (2.5%, *n* = 5) (Table 2, Q6). The rate of response for starting PC at the time of cancer diagnosis was 34.9% in the very aware group, a significantly lower rate than in the other two groups. This time was rated by 42.9% of participants in the aware group, and 65.2% in the unaware group (*p* < 0.01). For the "PC is not needed" response, there were no significant differences between groups.

7. Location of PC for cancer treatment

As shown in Table 3, the largest number of responses was for the PC unit location (62.7%, *n* = 126) across all participants. The responses were rated as follows: unknown (24.4%, *n* = 49), at home (23.9%, *n* = 48), at a general hospital (23.4%, *n* = 47), at an outpatient clinic

Table 3 The idea of a place where providing palliative care (answers to question 7)

	All	Very aware ^a	Aware ^a	Unaware ^a	<i>p</i> value
	<i>n</i> = 201	<i>n</i> = 43	<i>n</i> = 112	<i>n</i> = 46	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
general hospital	47 (23.4)	13 (30.2)	24 (21.4)	10 (21.7)	0.504
palliative care unit	126 (62.7)	35 (81.4)	74 (66.1)	17 (37.0)	< 0.001
at home	48 (23.9)	17 (39.5)	27 (24.1)	4 (8.7)	< 0.01
outpatient clinic	16 (8.0)	8 (18.6)	7 (6.3)	1 (2.2)	< 0.05
community pharmacy	6 (3.0)	3 (7.0)	3 (2.7)	0 (0.0)	0.144
unknown	49 (24.4)	5 (11.6)	26 (23.2)	18 (39.1)	< 0.01

^a Awareness of palliative care (answers of question 1). Fisher's exact test was performed to identify differences based on awareness of palliative care.

(8.0%, *n* = 16), at a community pharmacy (3.0%, *n* = 6). In the very aware and aware groups, the highest rates of response were for the PC unit (81.4% and 66.1%, respectively). However, the highest rate of response was "unknown" (39.1%) in the unaware group. On the other hand, the lowest rate of response was for community pharmacies in all groups, and rates for this response did not differ by group. The unaware group had fewer responses of "at home" (8.7%), compared to the very aware group (39.5%), and the aware group (24.1%).

DISCUSSION

In 2002, the World Health Organization defined PC as an approach to improve the QOL of patients facing life-threatening illness and their families, through the prevention and relief of suffering by means of early diagnosis and impeccable assessment, and treatment of pain and other physical, psychosocial, and spiritual problems.¹⁾ However, the essential understanding of PC among citizens around the world is still inadequate.⁶⁻⁹⁾ Our study indicated that most participants (77%) were aware of the term "palliative care." This result is consistent with a previous report that indicated that 76% of participants were aware of the term "palliative care."⁶⁾ Even though there is awareness of the term, only 27.7% of participants in our study knew its meaning. Moreover, we found that people with low awareness of PC tended to not understand who would receive PC, and that less than 40% of participants considered families as targets for PC. In this study, only 4.5% of participants considered PC as a means of providing social support to patients during cancer treatment. According to a study in South Korea, many patients lost their jobs after being diagnosed with cancer.^{14, 15)} In Japan, support for cancer patients who experience employment difficulties is very rare, and government initiatives to support these problems have only recently been developed.^{14, 16)} This limited support for the employment issues faced by cancer patients might be reflected in the low knowledge regarding PC for employment support. Therefore, although the term "palliative care" is recognized by people in Japan, understanding of PC is insufficient.

It has been reported that PC is perceived as end-of-life medical care.^{6, 9, 12)} In this study, we found that about 75% of people do not perceive PC as an end-of-life medical

treatment. In addition, almost half answered that patients would be able to receive PC from the time that cancer was diagnosed. On the other hand, people who rated themselves "very aware" of PC considered PC as end-of-life care, and those with higher awareness of PC were more likely to select the terminal stage of cancer treatment as the ideal time to begin PC. In contrast with highly aware people, those who reported lower awareness of PC showed a tendency to believe that PC can start at an earlier stage. In addition, the response that PC could be carried during cancer treatment, had the lowest response rate across all groups. There were no significant differences in the awareness of PC among three groups. These results indicate that PC is not recognized as a treatment that can begin at the time of diagnosis with cancer.

The present study clarified the stage at which patients at a community pharmacy would like to receive an explanation of PC. Approximately 60% of participants thought that PC should be introduced at the initial stage of diagnosis with cancer, and this preference was more pronounced in the group with lower awareness of PC. On the other hand, few thought that an explanation of PC is unnecessary. In response to the statement, "when do you want to start PC in cancer treatment" (Table 2, Q6), 46.3% of people answered, "When the cancer is diagnosed." Open discussion of the process of death or of death itself is often discouraged.^{6, 7)} A report by McIlfratrick et al. noted that the recognition of PC has not improved owing to the lack of sufficient discussion with medical providers, either when patients are diagnosed with cancer, or after treatment has begun.⁹⁾ It was reported that PC is often introduced late.⁴⁾ The bereaved families of 50% of the cancer patients surveyed in one study in Japan reported that PC is introduced very late.¹¹⁾

In this study, many people answered that the location to receive PC might be a specialized medical facility (Table 3). Only 24% of participants reported that PC can be received at home. People who reported a lower awareness of PC showed a lower rate of answering "home" as a place to provide PC. Moreover, more than 20% did not know where PC can be delivered. Previous reports showed that there is a tendency to hope to receive PC at home.⁶⁻⁸⁾ Although specialized facilities for PC are increasing in Japan, the development of specialized

palliative home care has been relatively slow.¹¹ This slow growth of specialized palliative home care in Japan may be one reason for the low rate of awareness of the potential for PC in the home, as reported in this survey. On the other hand, cancer patients also tend to believe that the burden on patients' families will increase when patients receive home PC.^{12, 17} In addition, it is reported that many cancer patients think that home PC does not ensure adequate response to sudden changes in the patient's condition.¹² These are reasons participants in this survey gave to explain why they felt that the best location to provide PC was a specialized medical facility.

The present study highlighted that many people do not think that outpatient clinics and community pharmacies are places to provide PC. Because of advances in cancer chemotherapy, the number of patients with cancer treated in outpatient clinics has rapidly increased.¹⁷ At the same time, patients with cancer not only have problems with cancer treatment but also experience psychological distress, job loss, and difficulty getting re-employed.^{12, 18} It is also reported that about 20% of patients with advanced metastatic cancer during outpatient visits feel mild to severe pain.¹⁷ Thus, outpatients must resolve these various problems by themselves, while hospitalized patients can receive help from medical personnel. Since Japan has become a rapidly-aging population country, maintaining the dignity of the elderly is an important issue. It is essential to support elderly people so they can be independent where they are accustomed to living until the end of their lives. To achieve this purpose, the Ministry of Health, Labour and Welfare is promoting the establishment of a comprehensive support and service provision system in the region (community-based integrated care systems).¹⁹ Since community pharmacies were not recognized as the place to provide PC in this study, it is difficult to conclude that community pharmacies have contributed significantly to regional PC. Since pharmacists in community pharmacies are medical providers close to local residents, community pharmacists might play a key role in managing PC to the outpatient with cancer. In order to improve the patients' QOL, it is important to strengthen the cooperative relationship with pharmacists working at community and hospital pharmacies.

There is some limitation in this study. As the participants of this survey were patients of only one community pharmacy, the results cannot be generalized. Since the location of the pharmacy where this study was conducted was close to gynecology and breast surgery clinics, the ratio of female participants was relatively high, and this biased population in participants might affect the results. Further survey of a wider range of participants from many locations and clinics will be required to obtain more comprehensive knowledge regarding PC. It is also necessary to survey the stage at which people would like to be introduced to the idea of PC in various situations.

In conclusion, although the term "palliative care" is becoming more familiar, the understanding of PC is still

insufficient. This study indicates a tendency in participants to expect information and an introduction of PC at an early stage after diagnosis of cancer. Many people did not think that homes, outpatient clinics, and community pharmacies are ideal places to provide PC. These findings suggest that it is necessary to improve awareness of, and to provide timely information about, PC to patients and their families.

Conflict of Interest: The authors declare no conflict of interest.

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