at home as much as possible, and (7) asked the patients about their preferred place of death as much as possible.

Reasons why patients did not receive palliative care services

We first asked the patients and family members who reported "strongly disagree", "disagree," or "slightly disagree" for the Good Death Inventory item "free from physical discomfort" about whether they received specialized palliative care services [15]. We then asked those who did not receive palliative care services about the potential reasons, including (1) minimal interference with daily life, (2) no recommendation from physicians, (3) no information about how to consult palliative care services, (4) explained to that symptoms would continue only for short periods, (5) time and cost spent for consultation, (5) negative image of palliative care services (palliative care is only for dying patients), and (6) long-standing symptoms before diagnosis of cancer. Respondents were asked to choose all relevant items.

We also asked physicians who reported that they consulted no patients regarding palliative care services during this study periods about the reasons for no referral, including (1) encountered no patients with unpalliated symptoms, (2) encountered patients with unpalliated symptoms but was unaware that palliative care services were available in the region, (3) burdensome procedures to receive consultation, (4) cannot easily seek consultation, and (5) patients and/or family did not want services when recommended.

Reasons why the patients did not evaluate quality of palliative care as high

We asked patients and bereaved family members who reported "improvement is necessary", "considerably necessary," or "highly necessary" for the Care Evaluation Scale item "doctors tried to relieve physical discomfort" about the reasons [15] including (1) physicians did not respond at all to the patient symptoms, (2) physicians tried to relieve symptoms but had limited effects, (3) no opportunity to talk with physicians, (4) physicians were reluctant to talk, (5) insufficient time, and (6) different physicians on every visit. Patients were asked to choose all relevant items.

We also asked all physicians and nurses about the level of agreement for each statement based on their clinical experience during the study periods with the 5-point Likert-type scale from disagree to agree (1) insufficient time for responses to patient needs acknowledged, (2) tried to relieve symptoms but limited effects, (3) patients and/or families did not want symptom palliation even if recommended, (4) tried to relieve symptoms as much as possible, and (5) asked the patients if they had symptoms or concerns.

Perceived changes in physicians and nurses

We asked all physicians and nurses about the level of agreement for each statement using the 5-point Likert-type scale from disagree to agree about the perceived changes in their clinical experience during the study period. Items are listed in Table 4.

Statistical analyses

Analyses were mainly descriptive, and 95 % confidence intervals were calculated. The frequency of the participants who chose "the others" was small (less than 5 %), and we did not calculate the frequencies for the others responses. Perceived changes were compared among hospital physicians, general practice physicians, hospital nurses, and district nurses using analysis of variance with the Scheffe test as a post hoc test. All statistical procedures were performed using the IBM SPSS statistical software package 19.

Results

Why patients did not die at home?

Among all bereaved family members, 315 families (28 %) reported that patients did not die in their preferred place (Table 1). Of them, the preferred places of death were homes (76 %, $n=239$), hospitals (6.7 %, $n=21$), palliative care units (4.8 %, $n=15$), others (3.8 %, $n=12$), and unsure (8.9 %, $n=28$). The patients whose family members reported that they had wanted to die at home but actually did not thus accounted for 21 % (239/1,137) of all deaths.

The main reasons for not achieving home deaths included unexpected rapid deterioration, caregivers unavailable, physical symptoms uncontrolled, and concerns about adequate responses to sudden changes. Less than 10 % of the families listed lack of physician availability at home and lack of information from physicians. More than 70 % of the physicians reported that they tried to ask the patients about their preferred place of death and respond to patient desire to stay at home.

Why patients did not receive palliative care services?

Among the 857 patients and 1,137 families, 111 patients (13 %) and 345 families (30 %) reported slightly disagree, disagree, or strongly disagree for the item "free from physical distress" (Table 2). Of them, 20 patients and 114 families reported that they had received specialized palliative care services, and 34 patients and 108 families reported that they were unsure. Thus, the remaining 57 patients (51 %) and 123 families (36 %) reported that they did not receive specialized

Table 1 Reasons why patients did not die at home

	Families (*n*=239)		Physicians (*n*=706)		Nurses (*n*=2,236)	
	% (95 % CI)	n	% (95 % CI)	n	% (95 % CI)	n
Caregivers unavailable	20 % (15, 25)	47	37 % (33, 40)	259	36 % (34, 48)	800
Unexpected rapid deterioration	45 % (39, 52)	108	31 % (28, 35)	219	42 % (39, 44)	928
Home-visit or nurses physicians unavailable	6.3 % (4, 10)	15	13 % (11, 16)	92	8.1 % (7, 9)	180
Physical symptoms uncontrolled	48 % (42, 54)	115	16 % (14, 19)	116	25 % (23, 26)	551
Concerns about adequate responses to sudden changes	42 % (36, 49)	101	NA		NA	
Belief that the patient would become better	15 % (11, 20)	35	NA		NA	
No information from physicians	6.3 % (4, 10)	15	NA		NA	
Patients and/or families did not desire death at home	NA		38 % (35, 42)	269	35 % (33, 37)	784
Tried to respond to patient need to stay at home	NA		78 % (74, 81)	548	69 % (67, 71)	1,545
Asked the patients about their preferred place of death	NA		71 % (67, 74)	499	53 % (51, 55)	1,193

For physicians and nurses, values are total number of responses of agree or slightly agree

CI confidence intervals

palliative care services. Of the 706 physicians, 199 (28 %) reported that they had consulted no patients regarding palliative care services during this study period.

The main reasons for not receiving specialized palliative care services observed in patients and families were the lack of recommendations from physicians and no information about how to consult palliative care services. In addition, 40 % of the patients listed minimal interference with daily life and 25 % received an explanation that symptoms would continue only for short periods as a reason. About 60 % of the physicians reported that they encountered no patients with unpalliated symptoms, and 15 % reported that they were unaware palliative care services were available.

Table 2 Reasons why patients did not receive palliative care services

	Patients (*n*=57)		Families (*n*=123)		Physicians (*n*=199)	
	% (95 % CI)	n	% (95 % CI)	n	% (95 % CI)	n
Minimum interference with daily life	40 % (29, 53)	23	11 % (6, 17)	13	NA	
No recommendation from physicians	33 % (22, 46)	19	56 % (47, 65)	69	NA	
No information about how to consult palliative care services	33 % (22, 46)	19	28 % (21, 37)	35	NA	
Explained that symptoms would continue only for short periods	25 % (15, 37)	14	0		NA	
Time and cost for consultation	12 % (6, 23)	7	0.8 % (0, 5)	1	NA	
Negative image of palliative care services	12 % (6, 23)	7	14 % (9, 21)	17	NA	
Long-standing symptoms before cancer	11 % (5, 21)	6	3.3 % (1, 8)	4	NA	
Encountered no patients with unpalliated symptoms	NA		NA		62 % (55, 69)	124
Being unaware palliative care services were available	NA		NA		15 % (10, 20)	29
Burdensome procedures for consultation	NA		NA		7.5 % (5, 12)	15
Cannot easily seek consultation	NA		NA		7.0 % (4, 12)	14
Patients and/or families did not want services when recommended	NA		NA		3.0 % (1, 6)	6

For physicians, values are total number of responses of agree or slightly agree

CI confidence intervals

Why the patients did not evaluate the quality of palliative care as high?

Among the total of 857 patients and 1,137 families, 132 patients (15 %) and 210 families (18 %) evaluated palliative care as improvement necessary, considerably necessary, and highly necessary, and, of these, 62 patients and 153 families gave valid answers as to why (the remainder gave no responses, probably because of the complex questionnaire layout) (Table 3).

The main reasons for evaluating the quality of palliative care as not high were clinicians tried to relieve symptoms but had limited effects and insufficient time. This result was consistently observed across patients, families, physicians, and nurses.

Perceived changes of physicians and nurses

The majority of physicians and nurses across all working situations reported that they became more aware of palliative care and valued multidisciplinary teams (Table 4). Half or more participants also reported that the availability of palliative care specialists and knowledge about palliative care improved; and 80 % of the hospital physicians reported that they consulted a palliative care team earlier than before. About 30 to 50 % of all respondents reported that they cooperated with other regional health care providers more easily. About half of the general practice physicians reported that they became to accept caring for cancer patients at home more confidently. In general, these perceived changes were more often reported by the district nurses, followed by hospital physicians, rather than general practice physicians and hospital nurses.

Discussion

The strengths of this study are twofold: one is clarification of the potential reasons why the expected outcomes were not achieved in individual levels based on the comprehensive assessment of patients, families, physicians, and nurses; and the other is the clarification of physician- and nurse-perceived changes during the study periods. Both contribute to a better understanding of the overall results of this regional intervention trial.

Why patients did not die at home?

This study revealed that about 30 % of the patients died in places other than their preferred place, and they had mostly wanted to die at home. The reasons reported were unexpected rapid deterioration, caregivers unavailable, physical symptoms uncontrolled, and concerns about adequate responses to sudden changes. On the other hand, the lack of physician availability at home and insufficient information about home care were not listed as major reasons. These findings suggest that the intervention was likely to succeed in increasing physician availability at home and improved information about home death potentially through region-wide support for general practice physicians and education about the importance of the preferred place of death for health care professionals. The findings that half of the general practice physicians and district nurses reported that they were more likely to accept caring for cancer patients at home more confidently through increased knowledge and support, and the fact that 71 % of the physicians reported that they had asked the patients about their preferred place of death supports this interpretation. The identified reasons of unexpected

Table 3 Reasons why patients did not evaluate the quality of palliative care as high

	Patients (*n*=62)		Families (*n*=153)		Physicians (*n*=706)		Nurses (*n*=2,236)	
	% (95 % CI)	n	% (95 % CI)	n	% (95 % CI)	n	% (95 % CI)	n
Tried to relieve symptoms but limited effects	65 % (52, 75)	40	66 % (58, 73)	101	24 % (21, 28)	171	36 % (34, 38)	807
Insufficient time	29 % (19, 41)	18	29 % (23, 37)	45	28 % (25, 32)	198	41 % (39, 43)	911
Physician reluctant to talk	18 % (10, 29)	11	12 % (8, 18)	18	NA		NA	
Physicians did not respond at all	8.1 % (3, 18)	5	5.2 % (3, 10)	8	NA		NA	
No opportunity to talk with physicians	8.1 % (3, 18)	5	10 % (6, 16)	15	NA		NA	
Different physicians at every visit	4.8 % (2, 13)	3	2.0 % (0, 4)	3	NA		NA	
Patients and/or family did not want services	NA		NA		7.2 % (6, 9)	51	9.8 % (9, 11)	220
Tried to relieve symptoms as much as possible	NA		NA		75 % (72, 78)	530	72 % (70, 74)	1,614
Asked the patients if they had symptoms or concerns	NA		NA		75 % (72, 78)	532	74 % (72, 76)	1,648

For physicians, values are total number of responses of agree or slightly agree

CI confidence intervals

Table 4 Perceived changes of physicians and nurses in daily practice

	Hospital physicians (n=486)	General practice (n=220)	Hospital nurses (n=2,026)	District nurses (n=210)	P
Become more aware about palliative or home care in daily practice	75 %, 364	53 %, 117	68 %, 1,377	82 %, 173	<0.001[a]
Respect patients' hopes, feelings, and values	79 %, 386	69 %, 152	82 %, 1,658	88 %, 184	<0.001[c]
Pay greater attention to families	75 %, 366	69 %, 151	81 %, 1,638	88 %, 184	<0.001[c]
Recognize greater value of interdisciplinary team	84 %, 406	61 %, 135	84 %, 1,693	88 %, 184	<0.001[c]
More specialists available for consultation in palliative care	77 %, 373	45 %, 98	68 %, 1,383	56 %, 117	<0.001[b, c]
Consult palliative care team earlier	81 %, 395	NA	74 %, 1,496	NA	<0.001
More accurate knowledge about palliative care through education programs	64 %, 312	49 %, 107	51 %, 1,041	63 %, 132	<0.001[f, g, h]
Cooperate with other health care providers in the region more easily through getting to know persons involved in palliative care	47 %, 229	36 %, 79	30 %, 609	47 %, 99	<0.001[g, h]
More opportunities to meet multidisciplinary professionals beyond facilities	39 %, 189	32 %, 70	33 %, 667	50 %, 105	<0.001[g, i]
Provide more specific information through getting to know resources	50 %, 245	41 %, 91	29 %, 587	46 %, 96	<0.001[d]
More recognize that cancer patients could die at home if desired	65 %, 315	45 %, 98	66 %, 1,337	84 %, 176	<0.001[c, e]
More routinely determined procedures for sudden changes in advance for patients discharge to home	52 %, 253	39 %, 86	43 %, 874	77 %, 161	<0.001[e, h]
Plan hospital care to make it available and simple at home	66 %, 320	NA	62 %, 1,265	NA	0.19
Accept caring for cancer patients at home more confidently through increased knowledge and support	NA	40 %, 89	NA	65 %, 137	<0.001

Values are total number of responses of agree or slightly agree

NA not available

[a] Among all professions

[b] Hospital physician (HP) vs. all other professions

[c] GP vs. all other professions

[d] Hospital nurse (HN) vs. all other professions

[e] District nurse (DN) vs. all other professions

[f] HP vs. GP

[g] HN vs. DN

[h] HP vs. HN

[i] GP vs. DN

rapid deterioration and caregivers unavailable are understandable because no intervention is specifically aimed to facilitate an education program about survival estimation for physicians and to enhance informal caregiver resources [16]. As multiple studies have demonstrated that clinicians are significantly likely to overestimate the prognosis of terminally ill patients [18] and that the presence of formal and informal caregivers is one of the most important determinants of home death [8, 9], systematic efforts to improve physician prognostication, such as the dissemination of validated prognostic tools and facilitating proactive strategies throughout the region [19–21], and reconstructing social resources to optimize formal and informal caregivers, are necessary to achieve more home death. Against uncontrolled physical symptoms as a reason for discontinuing staying at home, this study encouraged community palliative care team and a continuing effort to establish community palliative care services is highly valuable [22–24]. To lessen concerns about adequate responses to sudden changes, the health care system of 24-h 7-day service is more encouraged.

Why patients did not receive palliative care services?

This study revealed that 30 % of terminally ill patients might suffer from considerable levels of symptoms, and 30 % to half did not receive palliative care services. For outpatients, the frequency of unpalliated symptoms was generally low, and patient-reported reason for not receiving palliative care services was minimal interference with daily life, which are understandable, because this population showed a generally good performance status, and their symptoms were likely to be transient associated with anticancer treatment. Contrary to previous surveys [10–12], this study revealed that a negative image about palliative care in patients and families was not reported as the main reason for nonreferrals. The findings from the qualitative analyses that the intervention improved perception about palliative care of core health care professionals [17], and that more than 80 % physicians surveyed reported that they referred patients to a palliative care team earlier than before, support the idea that intervention succeeded in improving general perceptions of palliative care of health care professionals. On the other hand, the main reasons for no use of palliative care services by patients and families included no recommendation from physicians and no information about how to consult palliative care services, and the majority of the physicians who did not use specialized palliative care services reported that they encountered no patients with unpalliated symptoms. On considering previous findings that the assessment of symptom intensity demonstrated low-level agreement between physicians and patients [25], and physician recommendation is one of the strongest determinants in referral to specialized palliative care services [10], this can be interpreted as the physician's inability in identifying patients who receive some benefits from palliative care services and/or a lack of awareness of palliative care services available in the region. Potential resolutions to overcome this barrier may be using a simple visible and routine need assessment tool with clear instruction of when and how to consult palliative care services in the region [26, 27].

Why patients did not evaluate the quality of palliative care as high?

This study revealed that about 20 % of patients and families evaluated the quality of palliative care as still requiring improvement. The major reasons were clinicians actually tried to relieve symptoms but limited effects and insufficient time; that is, negative attitudes of clinicians were rarely reported by patients and families. The majority of physicians and nurses surveyed reported that they respected patients' hopes and paid greater attention to families. A possible interpretation of this result is that physicians and nurses actually made maximum efforts to relieve patients' distress within the limited time allowed, but patient distress often demonstrated no apparent improvement due to (1) the refractory nature of the symptom (e.g., fatigue, anorexia, neuropathic or incidental pain); (2) nonreferral to palliative care services, resulting in failure to optimize symptom palliation; or 3) lack of time to address complex psychological, social, and spiritual issues, resulting in unsatisfactory outcomes. Potential systematic resolutions include (1) research to identify effective palliative treatment of difficult symptoms [28–30] and (2) ensuring enough time for each clinician to address patients' concerns.

Physician- and nurse-perceived changes during the study period

The findings were generally consistent with the accompanying qualitative study and confirmed some generalizability [17]. The value of this quantitative study is clarifying the relative frequency of each perceived change of health care professionals. Physicians and nurses reported increased perception of the importance of palliative care most frequently, followed by the improved availability of palliative care specialists and improved knowledge about palliative care, and improved perception about home care. Of interest is that improved communication and cooperation among regional health care professionals are relatively less frequent. This is in somewhat contrast to the finding of the accompanying qualitative study that strongly emphasized improved communication and cooperation [17]. The interpretation of this finding is that the regional palliative care program did improve communication and cooperation among health care professionals, and the effect was strongly observed especially in people in a leadership role, rather than clinicians working in general positions.

Despite the strength of this study regarding the success in obtaining data from comprehensive data sources at regional levels, this study has several limitations. First, response bias was not so high and no formal testing of the questionnaire's reliability and validity was performed. Second, substantial number among the patients and family members who reported disagree for the item free from physical distress answered that they were unsure whether they received specialized palliative care services (34/111, 108/345, respectively). This is because (1) we had decided not to combine patient-reported data with medical record data (i.e., use of palliative care services) due to technical difficulties, and (2) patients and family members often did not recognize the participation of specialized palliative care services when they provided consultation services (did not directly see the patient and family members). This could make a bias, but we cannot assume the direction of the bias. Third, there were relatively frequent missing values in some questions. This is probably because we had located these additional questions in the last of pages of the questionnaire, distant from the original questions, due to the lack of space. This could be a bias, but we believe that missing occurred randomly and the major results would be the same. Finally, we concluded the intervention was likely to succeed in increasing physician availability at home because the lack of physician availability at home was not listed as the major reason for not staying at home. However, as there are no preintervention data to directly support this, the conclusion needs to be carefully interpreted.

In conclusion, this analysis suggests, to achieve better outcomes, some medical system interventions can be promising on the basis of a comprehensive regional palliative care program: (1) routine proactive care planning based on validated prognosis estimation, (2) reconstructing social resources to increase informal caregivers, (3) establishing formal community palliative care services as easily available and a 24-h 7-day service, (4) using a simple visible and routine-need assessment tool with clear instruction of when and how to consult palliative care services in the region, (5) ensuring enough time for each clinician to address patients' concerns, and (6) research to explore more effective palliative treatment of frequent but difficult symptoms.

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Original Article

How and Why Did a Regional Palliative Care Program Lead to Changes in a Region? A Qualitative Analysis of the Japan OPTIM Study

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Abstract

Context. Improving palliative care is one of the major issues throughout the world.

Objectives. The primary aim of this study was to explore how and why a regional palliative care program led to changes in a region.

Methods. As part of a nationwide mixed-methods study of a regional palliative care program, a qualitative study was performed with 101 health care professionals involved in the implementation of the program. In-depth interviews were done, focusing on perceived changes and the perceived reasons for the changes. We used thematic analyses.

Results. Seven themes were identified as follows: 1) improved communication and cooperation among regional health care professionals; 2) increased confidence in the system to care for cancer patients at home; 3) improved knowledge/skills, practice, and perception of palliative care; 4) contribution to self-growth; 5) wide variability in perceived changes in the knowledge and perception of patients, family members, and the general public; 6) wide variability in the perceived regionwide effects of the project; and 7) unresolved issues.

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Participants emphasized improved communication and cooperation among regional health care professionals and stated a variety of ways of how communication and cooperation influenced daily practice. The main reasons for changes included regionwide interdisciplinary conferences and informal interactions at a variety of meetings.

Conclusion. This study advances understanding of how the regional palliative care program created a change in the region. The findings are useful for developing a conceptual framework and identifying key interventions to improve regional palliative care for clinicians, researchers, and policy makers. J Pain Symptom Manage 2013;■:■–■. © *2013 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Region, palliative care, home, community, social capital

Introduction

Developing a regional palliative care system is an urgent task in many countries, and an increasing number of outcome studies have reported the beneficial effect of regional palliative care intervention trials.[1–4] However, to develop a feasible and effective regional palliative care system as a complex intervention, understanding how regional palliative care interventions work in the real world would be of great value.[5,6]

In the U.K., the Gold Standards Framework has been implemented, stressing communication and coordination in the community through developing a palliative care patient registry and holding regular meetings; multiple qualitative studies have examined how the program was implemented and what changes occurred.[7–11] These studies, as well as several works that addressed the effects of a palliative care network in Australia, The Netherlands, and Canada,[12–14] suggested that the most important perceived benefit of a regional palliative care program is facilitating communication among health care professionals.

Although these studies yielded important findings about the development of a regional palliative care service, to date, to our best knowledge, no such studies have been designed along with regionwide quantitative evaluations. No studies have been reported from Asian countries.

The primary aim of this study was to explore how and why a regional palliative care program led to changes as a part of a regionwide intervention study.

Methods

This is a detailed description of the qualitative arm of a mixed-methods study of a regional palliative care intervention program, the OPTIM (Outreach Palliative care Trial of Integrated Model) study.[15–17] This study explored how and why a regional palliative care program led to changes in a region. The study methodology is described in detail elsewhere.[16] Ethical and scientific validity was confirmed by the institutional review board for this study and all participating hospitals.

Summary of the OPTIM Study and Outcomes Obtained[17]

The OPTIM study was a mixed-methods study performed in four regions of Japan. We surveyed participants, introduced interventions, and then surveyed participants again. The intervention program was implemented from April 2008 to March 2011. The primary end points were home death, use of a palliative care service, and patient- and bereaved family-reported quality of palliative care. Secondary end points included physician- and nurse-reported difficulties and patient quality of life. After interventions, the percentage of home deaths increased, and this increase was significantly greater than that reported in national data. Moreover, almost all family members confirmed that patients who died at home had preferred a home death, and the care burden showed no significant increase. The ratio of patients who received palliative care services increased significantly. The patient- and family-reported quality of care was significantly better after the intervention (effect size 0.14 and 0.23, respectively). Physician- and nurse-reported difficulties, especially about communication and coordination, decreased significantly (effect size 0.52 and 0.59, respectively).

Interventions

The interventions comprised the following four types: 1) interventions to improve knowledge and skills of palliative care (disseminating manual and assessment tools, interactive workshops), 2) interventions to increase the availability of specialized palliative care services (establishing a new community palliative care team, outreach educational visits), 3) interventions to coordinate community palliative care resources (regional palliative care centers, regionwide interdisciplinary conferences, patient-held records, and introduction of a discharge planning system), and 4) interventions to provide appropriate information about palliative care to the general public, patients, and families. To deliver the intervention, each region identified a team of local leaders, including a physician, a nurse, and a social worker, responsible for implementation. To deliver the program, the team further recruited 10 to 40 core link staff members from health care professionals who had already been working in the region; they were usually experienced physicians, nurses, pharmacists, medical social workers, and care managers, involved in both clinical and managerial activities. To monitor and help with the implementation of interventions, a certified community nurse visited every region and followed-up by telephone and e-mail consistently throughout the study period.

Sampling and Subjects

All 103 core link staff members in four regions, that is, health care professionals who had roles in the implementation of interventions, were recruited. We assumed that core link staff members were suitable data sources for this study because 1) they could observe changes through their daily clinical practice, as they were working as clinicians in the area, and 2) their managerial position was appropriate to gather a variety of data across the region. In the initial phase of sampling, after several successful interviews with core link staff members, we piloted interviews with five other health care professionals who were not core link staff members, for example, general nurses working in a hospital or home care, and confirmed that they were not suitable sources because they generally acknowledged only the circumstances around them and had a limited outlook of how changes occurred. We thus determined that core link staff members were appropriate study subjects. After the first 40 interviews, data saturation was reached, because there were few new topics identified; however, we continued to perform interviews with all 103 participants to explore potential unexpected observations.

Interviews and Analyses

Two trained research nurses conducted face-to-face semistructured interviews with the use of an interview guide and under the supervision of one of the authors (C. I.). Both interviewers were women, were employed for this study, and had no personal relationships with the study subjects before the study. Interviews were performed from January to March 2011, at the work place of the participant. All were single interviews, and the participants were told the aim of this study. Questions focused on the perceived changes and experiences during the study period and perceived reasons for the changes. All interviews were audiotaped, transcribed verbatim, and subjected to thematic analysis in the grounded theory tradition.[18,19] Field note documents were not analyzed, and transcribed interviews were not returned to the participants for comments. Two nurse researchers, different from the nurses who conducted the interviews, used a consistent comparison method to independently code interviews for major themes. For coding, a coding notebook was created through the initial 40 interviews, and then the subsequent interviews were coded with adjustments and modifications. Coding frameworks and assignments were thereafter discussed under the supervision of an experienced palliative care specialist (T. M.). Discussions between researchers resulted in full agreement about the codes and themes that emerged. In the final stage of the analyses, four health care professionals on the local project teams (one for each region) and the certified community nurse who visited and monitored the implementation of interventions provided comments and agreed on the final results of the analyses. We did not calculate inter-reliability statistics, and no software was used. For the presentation of this study, we use visual presentation for three major themes.

Results

Among the 103 core link staff members we recruited, all agreed to participate, but two interviews could not be performed for practical reasons. Thus, a total of 101 core link staff were interviewed, for a mean (standard deviation) of 135 (39) minutes. The backgrounds of the study subjects are summarized in Table 1.

Seven themes were identified for the perceived changes as follows: 1) improved communication and cooperation among regional health care professionals; 2) increased confidence in the system to care for cancer patients at home; 3) improved knowledge/skills, practice, and perception of palliative care; 4) contribution to self-growth; 5) wide variability in perceived changes in the knowledge and perception of patients, family members, and the general public; 6) wide variability in the perceived regionwide effects of the project; and 7) unresolved issues.

Table 1
Study Subjects' Background Characteristics

Background Characteristic	Value
Region (*n*)	
Tsuruoka	15
Kashiwa	31
Hamamatsu	44
Nagasaki	11
Sex (*n*)	
Male	33
Female	68
Specialty (*n*)	
Physician	23
Nurse	46
Pharmacist	13
Care manager	9
Medical social worker	5
Dietitian	2
Administrative official	1
Occupational therapist	1
Medical clerk	1
Working site (*n*)	
Hospital	56
Clinic	13
District nurse service	14
Home care support service/office	8
Community pharmacy	7
Nursing home, public health office, community general support center	3 (1 for each)
Clinical experience (years, mean, standard deviation)	19.3 (8.9)
Number of cancer patients (per year)	
None	2
1–9	13
10–49	33
50–99	10
≥100	40

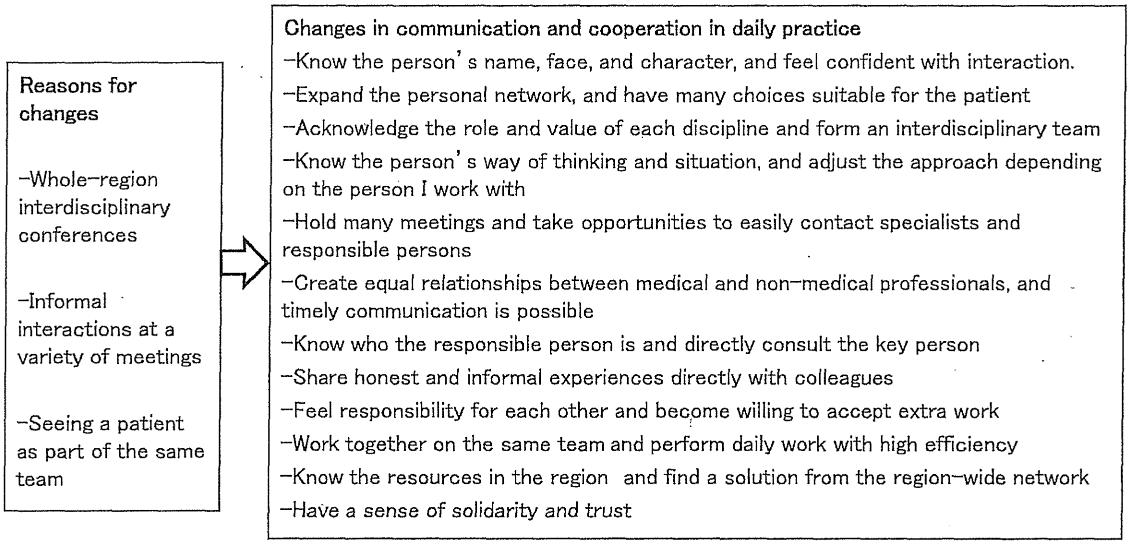
Improved Communication and Cooperation Among Regional Health Care Professionals

Many participants enthusiastically referred to improved communication and cooperation among regional health care professionals, and they stated a variety of ways of how communication and cooperation worked in daily practice (Fig. 1). As the reason for improved communication and cooperation, they listed an opportunity for face-to-face, small-group discussions in the regionwide interdisciplinary conferences, informal interactions at a variety of meetings, and viewing the patient as part of the same team. The face-to-face, small-group discussions in the regionwide interdisciplinary conferences were especially welcomed, because these never had been held in all areas, and were perceived as key for developing the network.

Know the Person's Name, Face, and Character and Feel Confident With the Interaction. Many participants stated that they had not known each other even when working in the same region and seeing the same patients, but, in the project, they had their first opportunity to talk with colleagues and know who is who. They stated that this led to confidence in daily interactions and, further, to timely information-sharing and consultation.

> As I had met with a number of health care professionals at project meetings, remembered their names and faces, and understood their characters, it became easier for me to talk with them. Even on the phone, I talked with them in a relaxed manner because I could imagine their faces and what they were thinking about during the conversation. I could comfortably ask them even possibly irrelevant questions without fear of being embarrassed. (General Practitioner)

Expand Personal Network and Have Many Choices Suitable for the Patient. Some participants reported they had more choices through various encounters during a variety of meetings and



Reasons for changes

-Whole-region interdisciplinary conferences

-Informal interactions at a variety of meetings

-Seeing a patient as part of the same team

Changes in communication and cooperation in daily practice

-Know the person' s name, face, and character, and feel confident with interaction.
-Expand the personal network, and have many choices suitable for the patient
-Acknowledge the role and value of each discipline and form an interdisciplinary team
-Know the person' s way of thinking and situation, and adjust the approach depending on the person I work with
-Hold many meetings and take opportunities to easily contact specialists and responsible persons
-Create equal relationships between medical and non-medical professionals, and timely communication is possible
-Know who the responsible person is and directly consult the key person
-Share honest and informal experiences directly with colleagues
-Feel responsibility for each other and become willing to accept extra work
-Work together on the same team and perform daily work with high efficiency
-Know the resources in the region and find a solution from the region-wide network
-Have a sense of solidarity and trust

Fig. 1. Improved communication and cooperation among regional health care professionals.

that they experienced the value of choosing the best from regionwide resources for the patient.

> Through participating in a variety of meetings, I met with many persons and obtained much information about resources available in this region, about which I had been unaware. Having many choices is beneficial for patients, and I can choose one resource for my patient from a variety of resources. (General Practitioner)

Acknowledge the Role and Value of Each Discipline and Form an Interdisciplinary Team. Many participants stressed that, as they acknowledged the role and value of other disciplines through directly talking with each other, they formed a team for the patients.

> I have developed a team with a number of disciplines through this program. I have many opportunities to talk with hospital physicians, district nurses, and care managers, and talking with them helps me understand the problems faced by patients. The greatest thing about this program is that it encourages physicians to collaborate and communicate with other health care professionals. (General Practitioner)

Know the Person's Way of Thinking and Situation, and Adjust the Approach Depending on the Person I Work With. Other than the role as a professional, many participants greatly emphasized the value of knowing the way of thinking, because this makes communication and cooperation much easier through adjusting the approach, depending on the person and situation.

> Small-group discussions were held once every two months over the past three years, through which I became acquainted with almost all health care workers in this region. Having understood their values, way of thinking, attitudes toward work, and viewpoints, it became easier for me to collaborate with them. I have come to take various things into account and modify my approach. (Medical Social Worker)

Hold Many Meetings and Take the Opportunity to Easily Contact Specialists and Responsible Persons. Many participants reported that many meetings, whatever the main purpose, provide an opportunity to easily contact specialists, responsible persons, or clinicians caring for the same patient.

> Following a scheduled conference, we can talk face to face with other participants to report on progress regarding various topics. We attend the meetings for other purposes, but many colleagues are there. This way, we have many opportunities to meet key health care professionals involved with a certain patient. We can share experiences and exchange information on such occasions, just

> like a kind of small conference. (Care Manager)

Create Equal Relationships Between Medical and Non-Medical Professionals, and Timely Communication Is Possible. Non-medical participants, such as medical social workers and care managers, often stated that the barrier between medical and non-medical professionals diminished through this project. They typically stated they first noticed that medical professionals did want to cooperate with non-medical professionals to provide better care for patients, and this awareness led to easier communication with each other.

> As I communicated with medical professionals a number of times to prepare for workshops, I came to understand that they are the same as us. They are thinking a great deal about their patients and have the same feelings. Before the project, I felt our relationship was unequal, and I hesitated to give my opinions to physicians and nurses. However, now, I can easily talk to them when necessary. (Care Manager)

Know Who the Responsible Person Is and Directly Consult the Key Person. Some participants stated that, before the project, they had no information about who the responsible or key person was, but the many interactions enabled them to know who the responsible person was to resolve the matter.

> Owing to this project, I now know the main person to contact when we have a problem. Because all key persons of health institutions in this region attend the conferences, all we have to do to obtain advice is to contact one of these persons. We can continue every plan; before this project, we had to abandon some plans because we did not know who the responsible person was. (Dietician)

Share Honest and Informal Experiences Directly With Colleagues. Some participants, especially palliative care clinicians, home care clinicians, and discharge nurses, who were usually working in the institution with a few colleagues or even alone, reported that sharing honest and informal experiences directly with colleagues in other institutions was a wonderful benefit of this project.

> This project allows me to seek honest opinions on new therapeutic options directly from other specialists. Academic meetings organized at a national level or other large networks usually cannot provide such honest information. In a closed, small meeting, we are allowed to share informal opinions, asking, "Do you really think that this new drug is effective?" (Palliative Care Physician)

Feel Responsibility for Each Other and Become Willing to Accept Extra Work. Some participants stated that they became more willing to ask for and accept extra work because they had a shared responsibility in the same region. They reported that they actually asked and/or accepted favors from each other, which they had never done before.

> Because the project provides us with many opportunities to communicate with community health care workers, I now know them well and can negotiate with them honestly and frankly. I clearly assume the responsibility of being ready to respond promptly should something occur. (Hospital Nurse)

Work Together on the Same Team and Perform Daily Work With High Efficiency. Some participants reported that the more they worked on the same team, the more efficient their daily activities became, and less time and effort were wasted.

> I realized that I could coordinate care services in a much shorter time, because I had seen health professionals on a regular basis. We usually have to exchange greetings before discussing a patient's care plan. The project allowed us to immediately start a meaningful discussion and to finish a care coordination plan efficiently. We had the advantage of skipping the introductory part. (Care Manager)

Know the Resources in the Region and Find a Solution From the Regionwide Network. Participants stated they had many opportunities to know the resources available in the region, and it became easier to find a solution through the regionwide network.

> I have realized that a variety of health professionals are involved in palliative care here.

> I have long thought that there is no better or more advanced care than what we provide in the hospital. However, a community care provider can do more things than I had thought. (Hospital Nurse)

Have a Sense of Solidarity and Trust. Many stated they built a sense of solidarity and trust through this project.

> I became acquainted with a large number of people with the same motives. In this interprofessional project, we talked about our dreams while sometimes drinking beer and developed personal relationships with trusted people. (Hospital Physician)

Increased Confidence in the System to Care for Cancer Patients at Home

A large number of participants stated that the system to care for cancer patients at home had been developing or developed during this study period. The participants attributed this to the following four main changes: 1) changes in perception, 2) changes in hospitals, 3) changes in the community, and 4) changes in outcomes (Fig. 2). Improved communication and collaboration was the basis of these changes.

Changes in Perception. Many participants reported the following two changes in perception: 1) recognize the importance of the place of death, and ask the patients and families the preferred place, and 2) recognize that dying at home is possible. Through educational workshops, interactions, and actual experiences, they reported that they recognized the importance of the place of death and recognized that dying at home is possible even for terminally ill cancer patients.

> At educational seminars and interdisciplinary conferences, I have learned from other health care professionals that the appropriate arrangement of various services greatly helps patients stay at home, even those who require artificial hydration or parenteral

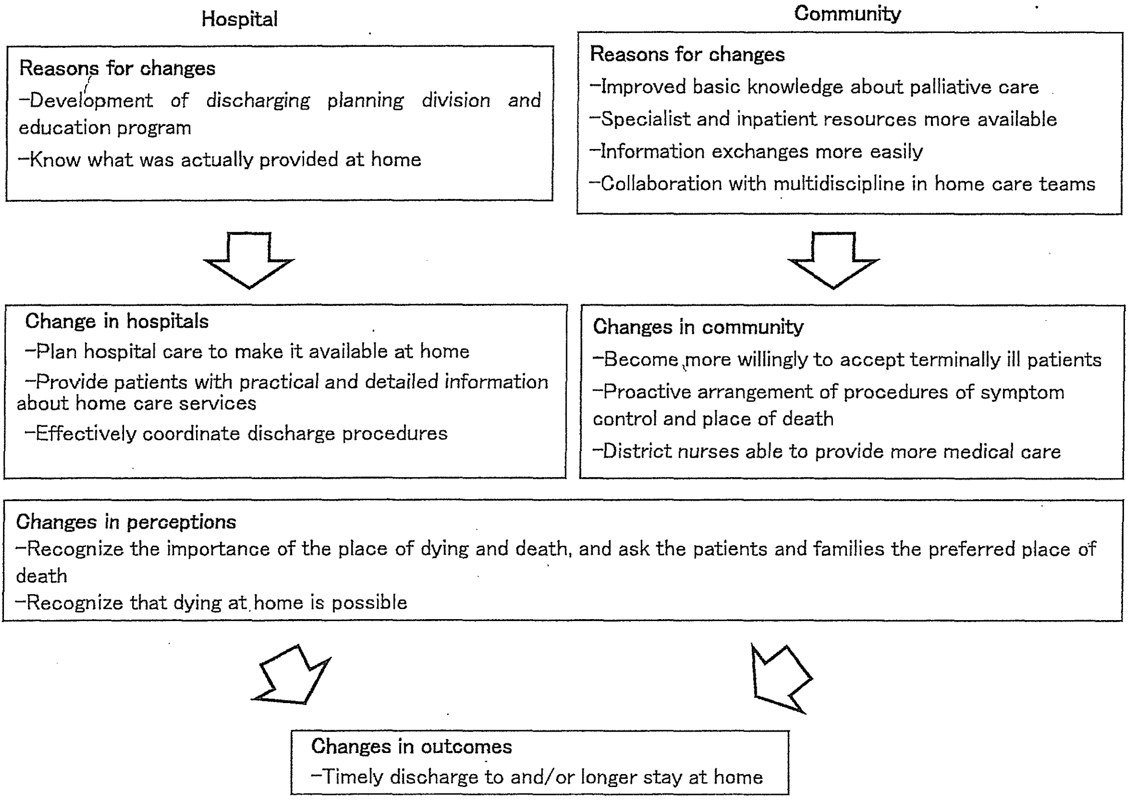


Fig. 2. Increased confidence in system to care for cancer patients at home.

> opioids or those without families. So, I now believe that many cancer patients can stay at home if they desire. (Hospital Nurse)

Changes in Hospitals. In hospitals, clinicians became able to 1) plan hospital care to make it available at home (e.g., simple medications, assessment of home environment, and reduce the caregiving burden), 2) provide patients with practical and detailed information about home care services, and 3) effectively coordinate discharge procedures (conferences, availability of inpatient resources, and information exchanges). The perceived reasons for these changes were development of a discharge planning division and education program and knowledge of what was actually provided at home through small group discussions, visits, and informal communication (e.g., photos from home).

> Patients with bone metastasis often do not feel much pain in the hospital, but, at home, these patients often experience pain when walking to the toilet. On the basis of conferences with community health care professionals, we have come to do a predischarge assessment to determine whether the home environment is appropriate. I have, similarly, come to arrange medications to be as simple as possible, with fewer drugs and a simple administration schedule, so that they can easily be followed by patients at home. (Palliative Care Physician)

> With this program, it is easier to provide patients with accurate information about home care services: "The doctor is around XX years old and values XX. With his personality, I think that he will get along with you." If patients are simply told, "You are going home," they cannot imagine what their lives will be like. Now, we can explain to them more concretely who is going to provide what type of support and help patients in that way. (Hospital Physician)

Changes in the Community. Community health care providers became more willing to accept terminally ill cancer patients and proactively arranged the procedures of symptom control and place of death, and district nurses became able to provide more medical care (e.g., arrangement of opioid dose). The perceived reasons for the changes included the following: 1) improved basic knowledge about palliative care was available through manuals and workshops, 2) specialist and inpatient resources were more available, 3) information exchange was made easier through developing formal and informal networking, and 4) more multidisciplinary collaboration occurred by home care teams, such as collaboration between district nurses and community pharmacies.

> Through this project, I have started to accept as patients persons I would otherwise have definitely rejected, as I have learned about symptom control, and I am sure that I will receive adequate support and cooperation from all involved in the project. After participating in the project, I have come to treat cancer patients at home, even for their first visit. (General Practitioner)

> In the past, patients receiving care at home would return to the hospital when their pain-relieving drugs no longer relieved pain. However, we now discuss with the physician before discharge: "Is there any possibility of the patient feeling severe pain at home?" Physicians provide us with orders we will be allowed to give to the patient. This way, we can make the decision to allow patients to continue to stay at home instead of returning to the hospital. (District Nurse)

Improved Knowledge/Skills, Practice, and Perception of Palliative Care

Many participants also referred to improved knowledge/skills, practice, and perception about palliative care (Fig. 3). The perceived reasons for the changes included regionwide standard tools, interactive workshops, and collaboration experience with palliative care specialists. In addition, they reported that, for collaboration with palliative care specialists, not only the presence of a consultation system itself but also an opportunity to talk is necessary for improved accessibility.

Knowledge/Skills and Practice About Palliative Care Are Improved. Many participants stated that practice, not only knowledge, changed in their clinical settings. Especially, they referred to palliative treatment for dyspnea and psychoexistential problems, beyond pain.

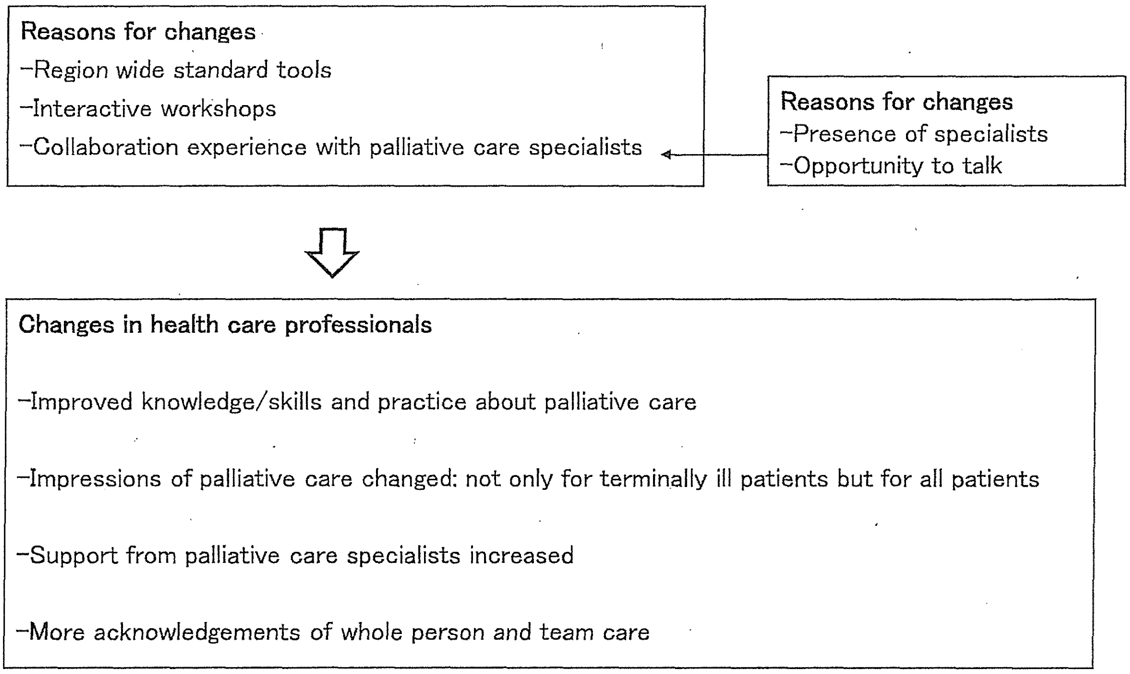


Fig. 3. Improved knowledge/skills, practice, and perception about palliative care.

> Until recently, opioids were not used to treat dyspnea in our unit. Now, everyone recognizes their effectiveness, which is a big change. Educational seminars, outreach programs of palliative care teams, and the fact that patients are actually obtaining relief from morphine use—all have changed physicians' attitudes. The information was not anecdotal information or indirect information from unreliable sources; instead, physicians obtained the information from educational sessions led by specialists. An authorized region-standard manual works well, because the rationale of opioid use is clearly described in a written format, rather than orally or via secondhand information. (Hospital Nurse)

Impressions of Palliative Care Changed, Not Only for Terminally Ill Patients But for All Patients. Some participants typically stated that palliative care is a standard and should be provided for all suffering patients and not just for terminally ill or cancer patients.

> After receiving a diagnosis of cancer at our clinic and being referred to a cancer hospital, patients often visit us for consultation. Recently, I have provided them with different advice. I had an image of palliative care as being only for the terminally ill. This is not true. Now, I explain to patients that they can receive palliative care from an early stage to minimize their distress, which makes a big difference. (General Practitioner)

Other Domains

Some participants reported the considerable effect of the project not only on the health care system in the region but also as a contributor to self-growth. They described this project as worthwhile, valuable, and a source of professional identity.

Regarding the knowledge and perception of patients, family members, and the general public, and the regionwide effects of the project, the participants reported various experiences. Some stated that their perception had totally changed or that the project had influenced the whole region, but some reported that patient perception did not change at all, and the effects of the project were limited to some parts of the region.

Finally, participants listed many points as showing no or minimum change during the study period, including palliative care for the non-cancer population and patients with a rare malignancy; pediatric palliative care; quality of care in home practice; earlier advance care planning; insufficient resources of physicians, nurses, and caregivers; gaps between urban and rural areas; more effective methods to share real-time patient information; and education on death for the general public. These were mainly expressed as the next challenges for each region.

Discussion

The first important finding of this study was the fact that, irrespective of the difference in interventions, emerging themes were similar to those in the Gold Standard Framework and other regional palliative care programs.[7,12–14] All studies identified improved communication and cooperation, increased understanding about available health care services, and greater access to specialists as the perceived benefits of regional palliative care programs, in addition to increased knowledge and awareness about palliative care. These findings, consistent with ours, strongly indicate that regional palliative care programs should include an intervention to facilitate communication and cooperation among multiple disciplines and institutions as an essential component to optimize available resources in the region. This could be interpreted as an improved network of health care professionals and is one of the most valuable aspects of "social capital" for regional palliative care.[20]

The second important finding was that this study reinforces measurable changes in quantitative studies, that is, increased home deaths and improved physician- and nurse-reported difficulties.[17] More importantly, this study deepens understanding of how and why these changes occurred, and the empirical basis for a conceptual framework. This study found major perceived reasons for the changes, and a variety of ways of how communication and cooperation worked in daily practice and probably influenced patient outcomes. Developing a complex intervention requires a careful conceptual framework,[5,6] and the findings of this study contribute to developing an empirically based conceptual framework for future region-based palliative care intervention trials.

This study had some limitations. It was performed in Japan; thus, the findings cannot be generalized to other countries where socioeconomic status and health care systems may differ. The qualitative analyses used in this study were thematic, and theory-generating analyses were not performed; to develop a theory, another qualitative analysis is necessary.

Conclusion

This study deepens understanding of how regional palliative care programs can change a region. The findings are useful for developing a conceptual framework and for identifying key interventions to improve regional palliative care areas for clinicians, researchers, and policy makers.

Disclosures and Acknowledgments

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Usefulness of the Leaflet-Based Intervention for Family Members of Terminally Ill Cancer Patients with Delirium

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Abstract

Background and Objective: Delirium in terminally ill cancer patients causes considerable distress to family members. The aim was to determine the family-perceived usefulness of a leaflet about delirium in terminally ill cancer patients.

Methods: Family members received a leaflet about delirium designed for this study as a part of routine practice. Questionnaires were mailed to bereaved family members of cancer patients recruited from three palliative care units, one hospital palliative care team, and three specialized home care teams in Japan.

Results: Among 235 family members, 16 questionnaires were returned as undeliverable, and responses were obtained from 169 bereaved family members (response rate 77%, 169/219). Of these, 22 were excluded because of missing data and 34 families reported they did not recognize that the patient had delirium, and thus 113 responses were finally analyzed. As a whole, 81% of the family members reported that the leaflet was "very useful" or "useful." Many respondents noted that the leaflet "helped them understand the dying process" (84%), "helped them identify what they could do for the patient" (80%), "helped them understand the patient's physical condition" (76%), and "was useful in preparing for the patient's death" (72%).

Conclusions: The leaflet about delirium was evaluated as useful for family members. This leaflet could help family members cope with a difficult situation by facilitating accurate understanding of the situation and by helping family members understand what they could do for the patient. More comprehensive intervention programs should be developed and tested in the future.

Introduction

Delirium occurs in 68% to 90% of terminally ill cancer patients just before death.[1,2] Delirium-related symptoms cause considerable distress to family members: They experience high levels of distress from both the agitation and cognitive symptoms of terminal delirium.[3–6]

To our knowledge, despite the many interventions that have been proposed for family caregivers of cancer patients,[7,8] few studies have explored the effectiveness of each intervention specifically for delirium in terminally ill cancer patients.[9] In previous studies,[10,11] we gathered potentially useful care strategies for relieving family distress of terminally ill cancer patients with delirium, including providing information about the pathology of delirium, explaining the expected course based on daily changes in the patient's condition, and relieving the family's care burden. Based on the results of these studies, we created a leaflet specifically designed to help families of terminally ill cancer patients with delirium (https://dl.dropbox.com/u/50169679/Figure.pdf).

The aim of this preliminary study was to determine the level of family-perceived usefulness of the leaflet about delirium in a terminally ill cancer patient.

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Methods

A cross-sectional survey was used to determine the level of family-perceived usefulness of the leaflet. Participating institutional groups across Japan included three palliative care units, one palliative care team, and three specialized home care teams. The ethical and scientific validity of the study were confirmed by the institutional review boards of each of the participating institution.

Intervention

In the study periods, from 2009 to 2010, in addition to the usual practice of verbal discussion with the family, clinicians in the participating institutions used the leaflets about delirium as a part of routine practice, especially about the nature, causes, and implications of delirium in terminally ill cancer patients. The leaflet was constructed by a multidisciplinary team including palliative care physicians and nurses, and psychiatrists, and it was based on the results of previous studies.[10,11] Before the multicenter implementation, one half-day interactive workshop using an educational video was held for medical health care professionals from participating institutions.

Procedure

Questionnaires were mailed along with the leaflet to bereaved families, at least 6 months after the patient had died, and again after one month to families that had not responded to the first mailing. If the families did not want to participate in the survey, they were asked to return the questionnaire with "no participation" indicated, and the second questionnaire was not mailed to them. Completion and return of the questionnaire were regarded as consent to participate in the present study. We chose this interval from patient death to questionnaire completion so that family members would be past the immediate stages of grief, yet the death would not be too distant, thereby minimizing the risk of introducing a recall bias. Similar time periods were used in previous studies.[12–14]

Primary treating physicians were asked to consecutively enroll families that met the following inclusion criteria: (1) bereaved adult family member of adult patients who died at the participating institutions from September 2009 to December 2010 and who had experienced delirium according to the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (DSM-IV) criteria[15] during the last2 weeks before death (one family member per patient); (2) capable of replying to a self-reported questionnaire; (3) informed of cancer; and (4) no serious psychological distress determined by the primary treating physician. Family members of patients with preexisting symptomatic organic brain pathology (i.e., brain metastasis, cerebral infarction) or psychiatric disorders (i.e., psychosis, dementia) were excluded, because the psychiatric symptoms of the comorbidity may have influenced the results.

Measurements

A questionnaire was developed based on a review of the literature,[7–9,16,17] the results of our previous studies,[10,11] and discussions among the authors. Face validity was assessed by complete agreement of the authors and a pilot test involving five bereaved family members.

The primary endpoint of this study was the family-perceived usefulness of the leaflet. The level of family-perceived usefulness was evaluated by the question, "As a whole, how useful did you feel the leaflet was when you were informed by the physician about delirium?" Answers to this question were rated on a 4-point Likert-type scale ranging from 1 (not at all useful) to 4 (very useful). "Delirium" was paraphrased in the questionnaire as "the rapid development of difficulty concentrating, forgetfulness, disorientation in time and place, hallucinations and delusions, incoherent speech, clouding of consciousness and difficulties communicating, emotional instability, reversal of daytime and nighttime activities (drowsy during the day and wakeful at night), and inconsistent behavior, with these conditions changing even within one day," similar to the definition used in our previous study.[10] We carefully developed this section based on the DSM-IV criteria through complete agreement with liaising psychiatrists and palliative care specialists.[10]

In the survey, families were asked to report on 13 items based on their experiences after receiving the leaflet (Table 1).

TABLE 1. FAMILY EXPERIENCES ABOUT USING THE LEAFLET ($N=113$)

	Agree or strongly agree N *(%)*	*95% confidence interval* (%)
The leaflet:		
Helped me understand the dying process	96 (84)	77–90
Helped me identify what I could do for the patient	91 (80)	72–87
Helped me understand the symptoms and why changes occur	89 (78)	70–85
Helped me understand the patient's physical condition	86 (76)	67–83
Was useful in preparing for the patient's death	82 (72)	64–80
Was useful in indicating when I should consult the doctor or nurse	79 (69)	61–78
Was useful in explaining the patient's condition to other family members	77 (68)	59–76
Was useful in indicating what I needed to do when the patient became more agitated	76 (67)	58–75
Explained what I wanted to know but found difficult to ask the nurse and/or doctor directly	69 (61)	52–70
Was useful in asking the doctor or nurse detailed questions while reading through it	66 (58)	49–67
Was useful in relieving my anxieties and worries	66 (58)	49–67
Was useful in making me feel that I had done all I could as a family member	66 (58)	49–67
Empathized with how I felt, such as acknowledging my fatigue and worries	63 (55)	46–65