

Table 3
Perceptions of PCUs

	General Population				Bereaved Families from PCUs				P-Value ^a	ES
	(n = 2,548)				(n = 513)					
	Agree (%)	Somewhat Agree (%)	Mean	SD	Agree (%)	Somewhat Agree (%)	Mean	SD		
Supports patients in living peacefully	37	35	4.03	1.06	45	30	4.12	1.23	0.067	0.09
Supports patients in living with dignity	32	38	3.94	0.93	38	38	4.12	0.84	<0.0001	0.19
Provides care for families	29	38	3.90	1.32	54	33	4.38	1.38	<0.0001	0.53
Provides compassionate care	28	39	3.88	1.18	56	30	4.36	1.21	<0.0001	0.52
Alleviates pain	32	36	3.87	1.03	57	30	4.40	0.85	<0.0001	0.52
Expensive	30	31	3.79	0.94	18	23	3.14	0.98	<0.0001	-0.58
Provides no medical treatments	12	20	3.00	1.03	29	25	3.59	1.32	<0.0001	0.49
Isolates patients from the community	7.5	21	2.80	0.90	8.4	21	2.75	0.81	0.40	-0.04
A place where people only wait to die	11	20	2.76	1.19	18	22	3.03	1.24	<0.0001	0.20
Shortens the patient's life	2.8	5.3	2.27	0.92	7.4	9.2	2.44	0.87	0.006	0.15

PCUs = palliative care units; SD = standard deviation; ES = effect size.
^at-test.

levels of awareness and perceptions of PCUs in Japan. Interpretation of the findings depends first on an understanding of the health care system and palliative care system in Japan.

In Japan, each person is obligated to enroll in a national health insurance system. The system is designed so that if a person moves, the insured person is expected to pay the same amount for the same amount of care. Medical fees are set and regulated by the government, and the maximum out-of-pocket cost for the patient is 30% of any such fee. In addition, to curb the expense of high-cost care, the government has instituted a monthly cap of 80,100 yen (670 US\$) co-payment. Meals and extra charges for private rooms are not

covered by the national health insurance system. The system provides the insured person with total freedom to choose any physician, hospital, or clinic.

Enhancement of palliative care for any Japanese citizen with cancer is a priority in Japan; thus, the Ministry of Health, Labor and Welfare supports dissemination of specialized palliative care services, with services provided by PCUs. PCUs have been covered by national medical insurance since 1991. To be approved as a PCU, institutions must fulfill the ministry's requirements regarding staff numbers, facilities, and equipment.

PCUs provide intensive symptom control and end-of-life care for patients with incurable cancer and their families, and the amount of money paid by national health insurance to medical institutions is fixed, irrespective of the treatment provided to patients. An approved PCU is reimbursed at the rate of 37,800 yen (315 US\$) per patient per day by the health insurance system. The maximum out-of-pocket cost for the patient is 30%, 11,340 yen (95 US\$). The majority of PCUs belong to general hospitals and have interdisciplinary teams, including attending physicians, nurses, and other specialists.¹⁸

Consistent with previous findings in Canada in 2004,⁹ public awareness of specialized palliative care services has remained insufficient in Japan. Moreover, experience of bereavement

Table 4
Association Between Overall Satisfaction with Received Care and Perceptions of PCUs

	n = 513	
	R ^a	P-value
Provides compassionate care	0.49	<0.0001
Provides care for families	0.49	<0.0001
Supports patients in living peacefully	0.43	<0.0001
Supports patients in living with dignity	0.40	<0.0001
Alleviates pain	0.30	<0.0001
Isolates patients from the community	-0.27	<0.0001
A place where people only wait to die	-0.27	<0.0001
Shortens the patient's life	-0.23	<0.0001
Expensive	-0.11	0.01
Provides no medical treatments	-0.06	0.19

^aSpearman's rank correlation coefficient.

due to cancer was not significantly associated with awareness of PCUs, possibly suggesting that health care professionals do not adequately explain PCUs as an option for end-of-life care to patients with cancer and their families.

Of note, the PCU-bereaved families were likely to have better perceptions of PCUs as providers of comprehensive and human-focused care, that is, compassionate care, symptom control, and care for families. They were also less likely to perceive PCUs as being expensive than the general population. These findings highlight the need for a greater effort to inform the general population that the present palliative care system offers comprehensive and human-focused care, and that the cost of its services is covered by the national health insurance system.

In our preceding analysis of the same survey, perceptions of PCUs as "alleviates pain" and "provides care for families" were significantly associated with preferences for PCUs as place of end-of-life care.¹⁹ It is, therefore, particularly important to disseminate adequate information about empirical evidence for effective pain control and the palliative care concept, including treatment of the patient and their family as the unit of care. Future research is needed to clarify the most effective strategy to improve public awareness of palliative care.

On the other hand, the general population is concerned that the PCU is "a place where people only wait to die," and "shortens the patient's life." It is of note that PCU-bereaved families were more likely to agree with both statements than the general population, despite the fact that palliative care aims to help patients live as actively as possible until death and intends neither to hasten nor postpone death,²⁰ and the reality that patients receive their usual medical treatments in many PCUs.²¹

Moreover, it is important that both perceptions were significantly associated with overall satisfaction with care and differed considerably among institutions. In Japan, there are significant differences in medical and nonmedical care performed in certified PCUs,²¹ possibly due to each institution's economic and staffing pressures, and their staff's philosophy of what constitutes palliative care. Recent literature suggests that terminally ill cancer patients

choose palliative chemotherapy as a means of maintaining a sense of hope,²²⁻²⁴ and thus the fact that no anticancer treatments are available at PCUs can make patients and families feel abandoned.¹⁴ This can become a barrier to providing palliative care. More discussion is needed about the most appropriate medical system for a certain group of patients who receive chemotherapy and have difficult symptoms requiring a specialized inpatient palliative care service. That is, because patients and families may have equal access to quality specialized palliative care whether or not they receive anticancer treatment, we believe that PCU administration criteria should change from focusing on disease incurability to degree of need for specialized palliative care, and functional classification of specialized palliative care services (i.e., primary, secondary, and tertiary PCUs) should be established.^{25,26} In addition, further efforts to minimize the real differences in provided care among PCUs are essential. This would enable patients receiving anticancer therapy to temporarily receive quality symptom control in PCUs, reflecting a continuum of cancer care.

This study had several limitations. First, because the respondents were not terminally ill cancer patients, results cannot be automatically applied to patients. We believe that this study is valuable, nonetheless, because PCU-bereaved families could provide worthwhile suggestions on the basis of their actual experience. Second, as the response rate among the general population was not high, response bias could exist. Third, we did not explore the possible associations between actual treatment received and perceptions of PCUs among PCU-bereaved families. A more detailed survey is necessary to clarify what kind of care had led to the difference in perceptions and overall satisfaction.

In conclusion, public awareness of PCU remains insufficient in Japan. PCU-bereaved families were generally likely to have better perceptions of PCUs than the general population, but both groups shared concerns that the PCU is a place where people only wait to die. More efforts to inform the general population about the actual palliative care system are needed, and it is necessary to reconsider the role of the PCU within the continuum of cancer care.

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Short report

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The relationship between health-related quality of life and social networks among Japanese family caregivers for people with disabilities

Hirokazu Arai^{*1}, Miwa Nagatsuka² and Kei Hirai^{3,4,5}

Address: ¹Department of Health Psychology, Osaka University of Human Sciences, Osaka, Japan, ²National Hospital Organization Osaka Medical Center, Osaka, Japan, ³Center for the Study of Communication Design, Osaka University, Osaka, Japan, ⁴Department of Psychology and Behavioral Sciences Graduate School of Human Sciences, Osaka University, Osaka, Japan and ⁵Department of Complementary and Alternative Medicine, Graduate School of Medicine, Osaka University, Osaka, Japan

Email: Hirokazu Arai^{*} - ICB53570@nifty.com; Miwa Nagatsuka - miwa-n@onh.go.jp; Kei Hirai - khirai@grappo.jp

^{*} Corresponding author

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Abstract

Aims: The purpose of this study was to examine HRQOL depending on whether the participants have family members with disabilities or not. In addition, we examined the relationship between HRQOL and social networks among family caregivers in Japan.

Methods: The study has a cross-sectional design. Survey forms were distributed to 9205 people aged 30 and older who visited a dispensing pharmacy within fifteen areas of Japan. We collected data on gender, age, job status, and care giving status for persons with disabilities. Moreover, we assessed support size, social support, and HRQOL. Out of the 2029 questionnaires returned, 1763 (male: 663, female: 1100, mean age = 63.06 ± 13.34) were valid for statistical analyses (the available response rate was 19.15%).

Results: A significant difference in HRQOL was identified between family caregivers and non-family caregivers. Further, in males (N = 101), the results confirmed that only social support predicted the PCS and MCS scores, while other variables did not predict either score. On the other hand, in females (N = 144), it was found from the second step of hierarchical multiple regression analysis that only age explained the PCS score, while job status and support size explained the MCS score.

Conclusion: It is reasonable to conclude that the HRQOL of family caregivers was lower than that of non-family caregivers, and that the HRQOL of family caregivers was estimated by their social networks.

Findings

It is important to assist family members in caring for persons with disabilities. The important role of family caregivers in maintaining their disabled members in the community is becoming increasingly recognized [1]. In

addition, Japan has various care requirements for persons with disabilities. It often becomes very important that support is available from family caregivers. Transitional community-based care has increased awareness of the extent of the importance of family caregivers [2].

Caring for persons with disabilities places a chronic physical and mental burden on family caregivers. Thus, it is important that physical, mental and social aspects, in other words, QOL of a family caregiver, are discussed. Canam and Acorn [2] suggest that QOL has emerged as an important concept for determining the impact of community-based care on family caregivers. However, few studies have attempted to explore how the QOL of family caregivers for persons with disabilities is different from the QOL of non-family caregivers. Any potential study should also identify whether there are gender differences in a caregiver's QOL because a caregiver's QOL can be influenced by gender [3].

Some studies have related HRQOL to social networks. Hellström et al. [4] described that the social network determined a high QOL among people aged 75 years and over. Another study has suggested that higher levels of social support increases the self-reported QOL of male workers [5]. Here we show that, as has previously been reported, the QOL of family caregivers might be explained by social network variables.

The purpose of this study was to examine differences in HRQOL depending on whether the participants have family members with disabilities or not. Moreover, we also examined the relationship of HRQOL and social networks among family caregivers.

This study was approved by the institutional review board of the Department of Psychology and Behavioral Sciences, Graduate School of Human Science, Osaka University. The study was a cross-sectional, anonymous mail survey. In this study, we used a convenient sampling technique (e.g. Syad et al., 2008 [6]). The survey forms, "the questionnaire about medicine and lifestyle", were distributed to 9205 people aged 30 and older who visited a dispensing pharmacy within fifteen areas of Japan. These areas included the twelve prefectures in the Kanto, Chubu, Kinki, Chugoku, Shikoku, and Kyushu regions. Staff members in the dispensing pharmacies handed out the questionnaires. If a person who came to a dispensing pharmacy looked like they were over 30 years old, the staff handed the questionnaire to that person. The staff explained the study to the person as follows: 1. Participation in this research is on a voluntary basis. 2. This survey is being conducted on medical care and lifestyle. 3. If you participate in this study by completing a questionnaire, you will receive incentives which include some flower seeds. Moreover, we explained the purpose of the study on the questionnaire and the fact that returning the questionnaire would be regarded as consent for participation, though we asked the participants to return the questionnaires anonymously. The study was carried out from November 2006 to January 2007.

We collected data on the gender, age, and job status of participants. In order to identify family caregivers, we also collected data about whether the participants had family members with disabilities or not. The relevant question was "Are you living with a family member who has a disability?" In this study, we defined somebody as a family caregiver if the response to the question was "Yes".

We used two scales to assess social support that was recognized by participants. One scale was the tangible social support scale [7] to rate support size, i.e. the quantitative amount of social support. The scale was "If you have problems, how many people around you do you have to help you?" The other scale was a social support scale [8], which was altered to suit people of all ages in order to assess the qualitative amount of social support. The scale was "If you have worries or problems how many of your family and friends will listen to you?", and was a 5-point Likert scale. Although these scales have not been validated in a Japanese population, some Japanese studies have used these scales (e.g. Shiozaki et al. [9] and Okabayashi et al. [8]).

For this study, we used the Japanese version of the MOS SF-8 which was administered to assess HRQOL. The SF-8 is divided into an 8 dimension health profile (PF, RP, BP, GH, VT, SF, RE, and MH) and 2 summary scores (PCS and MCS). The SF-8 is comprised of 8 items that are assessed by a 5 or 6-point Likert scale. The 8 domain scaled scores range from 0 to 100, with 100 representing optimal health and functioning. The Japanese version of the SF-8 has good reliability and validity among the Japanese population [10].

All data were analyzed using SPSS 15.0J. If missing data were found in the scale, the scores of the corresponding factors were excluded from the analysis. Out of the 2029 questionnaires returned, 1763 were valid for statistical analyses. The available response rate was 19.15% (male: 663, female: 1100, mean age = 63.06 ± 13.34). The rest (n = 266) were invalid due to a lack of major information (gender, age, or care giving status), or because the respondent was below thirty years old.

The results of the chi-squared tests for demographic data showed that more family caregivers were not holding a job than non-family caregivers (care giving status × gender: $\chi^2(1) = 1.47$, n.s./care giving status × job status: $\chi^2(1) = 8.00$, $p < .01$). The result of a *t*-test identified that the family caregivers' mean age (66.54 ± 12.11) was significantly higher than that of non-family caregivers (62.28 ± 13.48) ($t(1761) = 5.23$, $p < .001$).

With respect to whether the participants were family caregivers or not, the analyses indicated significant differ-

ences in all HRQOL scores (Table 1). However, support size and social support were not different in either group.

To examine potential factors that explain PCS and MCS scores in men (N = 101) and women (N = 144), two-step hierarchical regression analyses were performed by entering age and job status as a set in the first step, and support size and social support as a set in the second step for males and females (Table 2). In males, the results confirmed that only social support predicted the PCS and MCS scores, while other variables did not predict either score. As for the coefficient of multiple determinations, a significant value was gained with MCS only in the second step. Further, the R^2 changes identified by the hierarchical regression analysis in the second step were significant in the PCS and MCS scores. On the other hand, in females, it was found from the second step of hierarchical multiple regression analysis that only age explained the PCS score and job status, and support size explained the MCS score. For the coefficient of multiple determinations, a significant value was achieved for PCS and MCS in the first and second steps. The R^2 change was not significant for either analysis of the female data.

One of the important findings that this study identified was a significant difference in HRQOL depending on whether the participants were family caregivers or not. This finding suggests that health care providers should encourage family caregivers to improve their HRQOL more than non-family care givers. Furthermore, there was not a significant difference between family caregivers and non-family caregivers in social network variables.

The second important finding of this study was that the relationship between social networks and HRQOL differed by gender. Specifically, social support explained the PCS and MCS in males, while support size explained the

MCS in females. Likewise, according to the present study, R^2 changes were significant for the MCS in males. From the results of this study, male family caregivers did not necessarily require many supporters to maintain their HRQOL, but rather an attentive listener to their worries or problems. By contrast, the better physical component of female family caregivers was only explained by lower age. Female family caregivers had a preferred mental component if they had a job and many people who support them.

This survey has several limitations. First, because this study was a cross-sectional design, we cannot refer to inferring causal paths. Second, there was a significant difference in HRQOL depending on whether the participants were family caregivers or not, but there were also significant differences in mean age between family caregivers and non-family caregivers. Third, we did not collect data about the degree of care giving for persons with disabilities. Because little research has been directed at evaluating strategies for preserving caregivers physical functioning in addition to their psychological well-being [11], it is very worthwhile to identify social networks as important for the HRQOL of family caregivers. Fourth, in this study, the response rate and R^2 values that were significant were relatively low. It should be noted in the interpretation of the results.

In the future, further studies of family caregivers for persons with disabilities should be conducted in detail. For example, research about the specific disability of the family member (e.g. physical disability, mental disabilities, or intellectual disability) should be done. Additionally, we recommend that future research include an investigation of interventions for family caregivers for persons with disabilities to increase support size and social support.

Table 1: Mean (SD) and results of t-tests for HRQOL and social network by caregiver status

	family caregivers			non-family caregivers			t value
	mean	SD	N	mean	SD	N	
PF	45.31	8.74	291	47.10	7.17	1328	3.70 ***
RP	45.95	7.90	295	47.35	7.74	1340	2.80 **
BP	47.14	8.27	308	48.85	8.09	1369	3.33 ***
GH	46.96	7.28	302	48.33	6.87	1290	3.07 **
VT	49.09	7.24	306	50.24	6.55	1373	2.71 **
SF	45.09	9.04	302	46.75	8.92	1353	2.92 **
RE	47.33	7.91	300	48.85	6.93	1328	3.34 ***
MH	48.49	7.50	307	49.86	6.84	1363	3.11 **
PCS	44.94	7.52	261	46.11	7.20	1172	2.36 *
MCS	48.11	7.59	261	49.29	6.99	1172	2.42 *
support size	3.91	2.75	296	3.96	2.66	1353	0.31 n.s.
social support	3.79	0.74	311	3.80	0.81	1387	0.11 n.s.

*p < .05, **p < .01, ***p < .001

Table 2: Result of hierarchical multiple regression to explain PCS and MCS by sex of the family caregiver

PCS: male			PCS: female		
	step 1	β step 2		step 1	β step 2
age	-.13	-.13	age	-.33***	-.33***
job status	.02	.02	job status	-.03	-.03
support size		.09	support size		-.02
social support		.22*	social support		-.03
R ²	.02	.09	R ²	.09***	.08**
R ² change		.07*	R ² change		.00

MCS: male			MCS: female		
	step 1	β step 2		step 1	β step 2
age	-.07	-.06	age	.18*	.16
job status	-.02	-.02	job status	.20*	.19*
support size		.14	support size		.19*
social support		.25*	social support		.02
R ²	-.02	.07*	R ²	.04*	.06*
R ² change		.11**	R ² change		.04

*p < .05, **p < .01, ***p < .001

List of Abbreviations

HRQOL: health-related quality of life; QOL: quality of life; MOS: Medical Outcomes Study; SF-8: Short Form 8-Item Health Survey; PF: physical functioning; RP: role functioning-physical; BP: bodily pain; GH: general health perception; VT: vitality; SF: social functioning; RE: role functioning-emotional; MH: mental health; PCS: summary scores for the physical components of health; MCS: summary scores for the mental components of health.

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

HA performed the statistical analysis. All authors contributed to the study design, carried out this study, and approved the final version of this paper.

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Palliative care needs of cancer outpatients receiving chemotherapy: an audit of a clinical screening project

Tatsuya Morita · Koji Fujimoto · Miki Namba ·
Naoko Sasaki · Tomoko Ito · Chika Yamada ·
Arisa Ohba · Motoki Hiroyoshi · Hiroshi Niwa ·
Takeshi Yamada · Tsuneo Noda

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Abstract

Purpose Although more and more cancer patients are receiving chemotherapy in outpatient settings in their

advanced stage and could have a broad range of palliative care needs, referral to the specialized palliative care service is often delayed. The primary aim of this study is to explore the usefulness of a combined intervention for cancer patients in identifying patients with underrecognized palliative care needs and referring them to the specialized palliative care service. The intervention consisted of (1) introducing the specialized palliative care service when starting chemotherapy, (2) using screening tools, and (3) providing on-demand specialized palliative care service.

Materials and methods All cancer patients newly starting chemotherapy with primary tumor sites of the lung, gastrointestinal, pancreas, bile duct, breast, ovary, and uterus were included. As routine practice, at the first instruction about chemotherapy, pharmacists provided information about the role of the specialized palliative care service using a pamphlet and handed out screening questionnaires. Screening questionnaires were distributed at every hospital visit. Treating physicians and/or nurses checked the questionnaire before examining the patients. The patients were referred to the palliative care team, if (1) the patients voluntarily wished for the specialized palliative care service or (2) the treating physicians clinically determined that, on the basis of the screening results, the patients had physical or psychological needs appropriate for referral to the specialized palliative care service. The screening questionnaire included an open-ended question about their greatest concerns, the severity of 11 physical symptoms, overall quality-of-life, the distress thermometer, help for information about the treatment and decision-making, economic problems, nutri-

T. Morita (✉)

Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, 3453 Mikatabara-cho, Hamamatsu, Shizuoka 433-8558, Japan
e-mail: tmorita@sis.seirei.or.jp

K. Fujimoto · M. Namba

Palliative Care Team, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan

N. Sasaki · T. Ito · C. Yamada · A. Ohba

Pharmacology Department, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan

M. Hiroyoshi

Department of Surgery, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan

H. Niwa · T. Yamada

Department of Thoracic Surgery, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan

T. Noda

Department of Gynecology, Seirei Mikatahara General Hospital, 3453 Mikatahara-cho, Hamamatsu, Shizuoka 433-8558, Japan

tion, daily activities, and wish for help from the specialized palliative care service.

Results Of 211 patients who newly started chemotherapy, 5 patients refused to complete the questionnaire (compliance rate, 98%). We obtained 1,000 questionnaires from 206 patients. The percentages of missing values ranged from 2.7% to 7.0%. Of 206 patients, 38 (18%) were referred to the palliative care team due to newly recognized problems, in addition to 10 patients with problems well-recognized by primary physicians. The total percentage of patients receiving specialized palliative care service was thus 23% of all patients. Frequently identified problems were oral problems (20%), insomnia (20%), help with information and decision-making (16%), psychological distress defined as the distress thermometer (14%), severe fatigue (9.0%), and severe appetite loss (8.8%). As a whole, problems were identified in half of all questionnaires.

Conclusion The combined intervention of introducing the specialized palliative care service, using screening tools and providing on-demand specialized palliative care service, was feasible as part of the routine clinical practice for all cancer patients starting chemotherapy. It might be useful in identifying patients with underrecognized palliative care needs and referring them to the specialized palliative care service at the appropriate time.

Keywords Palliative care team · Neoplasms · Screening · Chemotherapy head · Outpatient

Introduction

The recent literature indicates that more and more cancer patients receive chemotherapy in outpatient settings in their advanced stage [1]. They have a broad range of palliative care needs including physical symptoms, psychological distress, help with decision-making, and economical and practical support [2–7]. Conceptually, palliative care can and should be provided for all patients along with disease-modifying treatment [8]. Referral to the specialized palliative care service is, however, often delayed because patients regard receiving palliative care as an *alternative*, not an additional, resource of anticancer treatment [9–11]. Introducing the specialized palliative care service as an additional resource to improve the quality-of-life of all patients at the earlier stage of cancer treatment, focusing on patient distress not on the stage of the disease, can be a

useful strategy to provide adequate palliative care [12]. Several intervention trials have suggested that the routine use and feedback to the treating physicians of quality-of-life measurements or symptom assessment scales could contribute to improving physician recognition of patient quality-of-life aspects with some beneficial effects on patient psychological well-being [13–17]. On the other hand, some clinical trials including more intensive interventions, such as cognitive behavior intervention with systematic identification of patient needs, have demonstrated positive outcomes in patient physical well-being, not only psychological issues [18–22]. In addition, multidisciplinary intervention by specialized palliative care teams in outpatient settings could contribute to enhancing patient quality-of-life [23–26]. These findings suggest that a combined intervention of (1) introducing the specialized palliative care service at the earlier stage of disease trajectory, (2) using screening tools, and (3) providing on-demand specialized palliative care might contribute to a better quality-of-life for cancer patients receiving active anticancer treatment.

The primary aim of this project is to explore the usefulness of such intervention in identifying patients with underrecognized palliative care needs and referring them to the specialized palliative care service. An additional aim was to clarify the prevalence of physical and psychological symptoms and concerns among a heterogeneous sample of cancer patients receiving outpatient chemotherapy in a regional cancer center.

Materials and methods

This brief descriptive study included all cancer patients newly starting chemotherapy with primary tumor sites of the lung, gastrointestinal, pancreas, bile duct, breast, ovary, and uterus from April to October 2006. We had decided to include the patients receiving adjuvant chemotherapy because they might receive some benefit from professional emotional support by a member of the palliative care team (the leading department of this project is the Department of Palliative and Supportive Care). As part of the routine practice, at the first instruction about chemotherapy, pharmacists provided information about the role of the specialized palliative care service using a pamphlet and handed out screening questionnaires with coaching on how to complete them. Screening questionnaires were thereafter distributed at every hospital visit. If the patients refused to complete

the questionnaire or recognized no need, they were not obliged to complete the questionnaire.

Treating physicians and/or nurses checked the screening questionnaire before examining the patients. The patients were referred to the palliative care team, if (1) the patients voluntarily wished for the specialized palliative care service or (2) the treating physicians determined that, on the basis of the screening results, the patients had physical or psychological needs appropriate for referral to the specialized palliative care service. Although we instructed the physicians to consider the scores of 5 or more as a threshold for the screening, the decision whether the treating physicians referred patients to the palliative care team was clinically made due to no established cutoff points. In addition, a research nurse provided brief feedback about the screening results via the electronic medical recording system.

Palliative care team activity is widespread throughout our hospital and could respond to all consultations within a few days [27, 28].

Screening questionnaire

The study group constructed the screening questionnaire on the basis of existing validated instruments [29–33]. As the primary intention of this activity was to identify patients with underrecognized needs and facilitate their referral to the specialized palliative care service within the routine clinical practice, not to clarify the exact prevalence of each need, we decided to make the questionnaire as simple and short as possible.

The screening questionnaire included (1) an open-ended question about the greatest concerns of patients; (2) 0–10 numeric rating scales of 8 physical symptoms (pain, dyspnea, nausea, appetite loss, somnolence, fatigue, constipation/diarrhea, numbness) adopted from the Japanese version of the M.D. Anderson Symptom Inventory (MDASI) after modification of the interval (24 h to 1 week) and the timing (worst to average severity) [29]; (3) presence or absence of oral problems, fever, and insomnia; (4) 0–7 numeric rating scale of overall quality-of-life adopted from item 29 of the EORTC-C30 [30]; (5) the distress thermometer [31, 32]; (6) presence or absence of help in 4 areas, i.e., information about the treatment and decision-making, economic problems, nutrition, and daily activities [33]; and (7) wish for help of the specialized palliative care service (see Appendix).

Our hospital required no Institutional Review Board approval for the retrospective analysis of clinical activity,

but admitted patients gave written consent that their clinical information could be used for clinical research.

Analyses

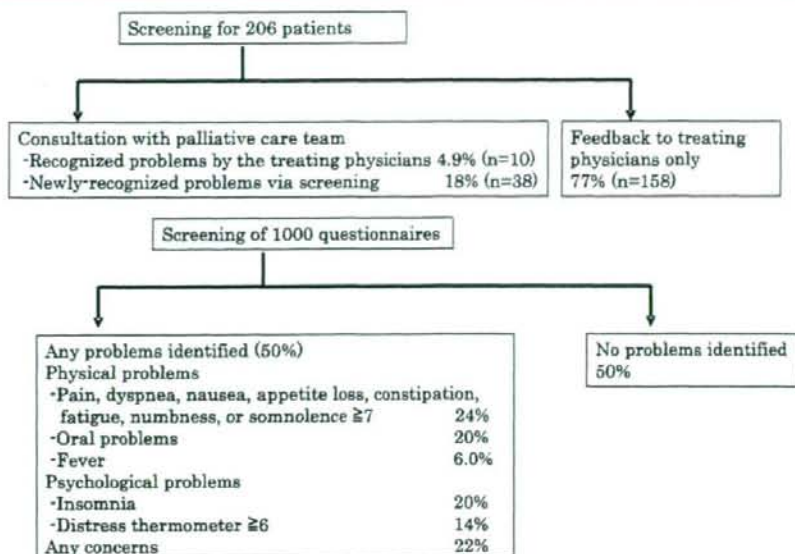
The primary endpoint was the number of patients referred to the palliative care team after treating physicians and/or nurses recognized patient needs via the screening questionnaire.

As additional endpoints, the prevalence of problems was calculated for each visit. For calculations, we adopted ad hoc definition of moderate and severe symptom intensities for the MDASI items as 4–6 and 7–10, respectively. We used cutoff points on the distress thermometer of 6 or more following the previous findings [31, 32]. We determined that a patient had problems if he/she had either MDASI symptoms of 7 or more, oral problem, fever, insomnia, distress thermometer of 6 or more or any help with

Table 1 Patient backgrounds (*n*=206)

Summary of patient backgrounds	
Age	62±11 years
Sex	
Male	41% (<i>n</i> =84)
Female	59% (<i>n</i> =122)
Primary sites	
Lung	30% (<i>n</i> =62)
Breast	27% (<i>n</i> =56)
Colon, rectum	15% (<i>n</i> =31)
Stomach	13% (<i>n</i> =26)
Uterus, ovary	10% (<i>n</i> =21)
Pancreas, bile duct	2.9% (<i>n</i> =6)
Others	3.9% (<i>n</i> =8)
Chemotherapy regimens	
Taxanes	27% (<i>n</i> =55)
Carboplatin and taxanes	19% (<i>n</i> =39)
Doxorubicin and cyclophosphamide	12% (<i>n</i> =25)
Oral tegafur gimeracil oteracil	11% (<i>n</i> =22)
Fluorouracil	10% (<i>n</i> =21)
Gemcitabine	3.4% (<i>n</i> =7)
Irinotecan with/without taxanes	2.9% (<i>n</i> =6)
Transtumab with/without taxanes	2.9% (<i>n</i> =6)
Cyclophosphamide, methotrexate, and fluorouracil	2.4% (<i>n</i> =5)
Gefitinib	1.5% (<i>n</i> =3)
Low-dose cisplatin and 5-fluorouracil	1.5% (<i>n</i> =3)
Vinorelbine	1.0% (<i>n</i> =2)
Oxaliplatin and 5-fluorouracil/leucovorin	1.0% (<i>n</i> =2)
Oral capecitabine	1.0% (<i>n</i> =2)
Others	3.4% (<i>n</i> =7)

Fig. 1 Results



information and decision-making, nutrition, economic problems or daily activities.

Results

During this study interval, of 211 patients who newly started chemotherapy, 5 patients refused to complete the screening questionnaire (compliance rate, 98%). Each patient completed a median of 3.0 screening questionnaires during this study period (range 0–15) and we obtained 1,000 questionnaires from 206 patients. The percentages of missing values ranged from 2.7% (appetite loss) to 7.0% (distress thermometer). Table 1 summarizes the patient backgrounds.

Of 206 patients who completed the initial questionnaire, 38 (18%) were referred to the palliative care team due to newly recognized problems via the screening tool, in addition to 10 patients who consulted the palliative care team due to well-recognized problems (Fig. 1). The percentage of patients receiving the specialized palliative care service was thus 23% of all patients by treating physicians (48/206).

The main reasons for the referral via the screening tool were: psychological distress (58% of 38 patients, $n=22$), appetite loss/nausea/constipation (26%, $n=10$), pain (24%,

$n=9$), numbness (13%, $n=5$), fatigue (13%, $n=5$), and dyspnea/cough (5.3%, $n=2$). On the other hand, the main symptoms of the patients who consulted the palliative care team due to well-recognized problems were: pain (40% of 10 patients, $n=4$), dyspnea (30%, $n=3$), delirium (20%, $n=2$), and psychological distress (10%, $n=1$).

For the questionnaire level (Table 2), frequently identified problems were oral problems (20%), insomnia (20%), help with information and decision-making (16%), psychological distress (defined as the distress thermometer ≥ 6 ; 14%), severe fatigue (9.0%), and severe appetite loss (8.8%). As a whole, problems were identified in half of all questionnaires (Fig. 1).

Discussion

The first important finding of this study was the feasibility of our clinical intervention. The percentage of patients who completed the screening questionnaire at instruction was over 90%. The percentages of missing values in each screening item were below 7.0%. These findings demonstrated that this intervention was feasible for the majority of cancer patients receiving chemotherapy as part of the routine clinical practice.

The second important finding was the potential usefulness of our intervention in identifying patients with under-

Table 2 Problems identified in 1,000 questionnaires

	Prevalence (%) ^a			Mean±SD (median) ^b
	Severe	Moderate	Total	
Physical problems				
MDASI items				
Fatigue	9.0	16	25	2.4±2.5 (2.0)
Appetite loss	8.8	11	20	1.9±2.6 (0.0)
Constipation	5.6	13	19	1.7±2.3 (1.0)
Somnolence	4.9	14	19	1.8±2.2 (1.0)
Pain	4.9	9.9	15	1.6±2.1 (1.0)
Numbness	6.0	7.5	14	1.4±2.3 (0.0)
Dyspnea	2.9	7.5	11	1.2±1.9 (0.0)
Nausea	3.4	6.9	10	1.1±2.0 (0.0)
Oral problems			20	
Fever			6.0	
Psychological problems			20	
Insomnia			14	
Distress thermometer				
Concern			16	
Information and help with decision-making			6.8	
Nutrition			5.6	
Daily activities			2.9	
Economic problems				

^a The percentages of responses with moderate (4–6) and severe (7–10) symptom intensity for the MDASI items. The percentages of the score ≥ 6 for the distress thermometer. The percentages of problem presence for the other items.

^b Mean values calculated for the MDASI items only.

recognized palliative care needs and referring them to the specialized palliative care service when patients wished for. Among the half of the patients who received chemotherapy and reported physical or psychological problems or concerns at the questionnaire level, 23% of all cancer patients were newly referred to the palliative care team with the primary aim of improving their quality-of-life. Despite clear limitation of the lack of control group, this finding strongly indicates that our intervention could provide specialized care for patients with profound symptoms irrespective of the disease extent.

The additional but third important finding was the clarification of the types of symptoms and concerns observed

in heterogeneous cancer outpatients receiving chemotherapy. In this study, psychological issues (insomnia, distress), concern about information and decision-making, nutrition-related issues (oral problems and appetite loss), and fatigue were major concerns for patients. Consistent with the previous findings from Western countries, this finding indicates that developing systematic intervention strategies targeting psychosocial distress, decision-making, nutrition, and fatigue is of great importance and an emerging task for Japanese palliative care specialists [34–39].

In addition, this study revealed a considerable difference between the symptom patterns of the patients referred via the screening system and those from the treating physicians. While pain, dyspnea, and delirium were major reasons for the referral from the treating physicians, the screening system identified a broader range of patient distress, such as psychological distress, appetite loss, numbness, and fatigue. The result indicates that the screening system could be useful in identifying the patients with serious psychological distress, appetite loss, numbness, and fatigue, which are often overlooked by physicians.

This was a descriptive study of routine clinical experience and thus had considerable limitations. First, we did not formally measure the changes in the symptoms and concerns after consulting the palliative care team and we cannot conclude whether referral to the specialized palliative care service actually provided a benefit for the patients. Second, as the patients were a heterogeneous sample of their primary tumor sites, stages, and chemotherapy regimens, the results might not be automatically generalized to specific target populations. We believe this is not a fatal flaw of this study because we need to develop a useful system for heterogeneous outpatients receiving chemotherapy. Third, as this was a single institution study where the palliative care unit and palliative care team have been regarded as an essential function of the hospital [27, 28], the results could not be generalized to other institutions. Finally, because we had not decided to explore solid cutoff points, the most appropriate cutoff points for the screening and the definition of moderate and severe symptom intensities should be further studied.

In conclusion, the combined intervention of introducing the specialized palliative care service, using screening tools, and providing on-demand specialized palliative care service when starting chemotherapy as a part of routine clinical practice was feasible and could be useful in identifying patients with underrecognized palliative care needs and referring them to specialized palliative care service. To evaluate the accurate effects of this intervention, controlled trial is promising.

Appendix

Screening questionnaire

A. What is your greatest concern?

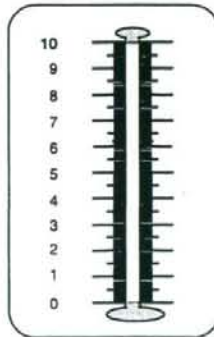
B. Physical symptoms. During the last week, how severe were your symptoms on the average?

	Not present	←————→										As bad as you can imagine
	0	1	2	3	4	5	6	7	8	9	10	
Pain	0	1	2	3	4	5	6	7	8	9	10	
Shortness of breath	0	1	2	3	4	5	6	7	8	9	10	
Nausea	0	1	2	3	4	5	6	7	8	9	10	
Lack of appetite	0	1	2	3	4	5	6	7	8	9	10	
Drowsy (sleepy)	0	1	2	3	4	5	6	7	8	9	10	
Fatigue (tiredness)	0	1	2	3	4	5	6	7	8	9	10	
Constipation/Diarrhea	0	1	2	3	4	5	6	7	8	9	10	
Numbness or tingling	0	1	2	3	4	5	6	7	8	9	10	
Oral problems	YES	NO	Fever	YES	NO	Sleep Difficulty	YES	NO				

C. In the past week...

- | | Very poor | ←————→ | | | | | | Excellent | |
|----------------------------|-----------|--------|----|---|---|---|---|-----------|--|
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| 1) Overall quality of life | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | |
| 2) Body Weight | (|) | kg | | | | | | |
| 3) How distressed are you? | | | | | | | | | |

Extreme distress



No distress

D. Do you need some help with...

- Information about the treatment and help with decision making
- Economic problems
- Nutrition
- Daily activities (house work, work, toilet...)

E. Do you wish for specialized palliative care (see the reverse side for detailed information)

→ WISH NOT wish

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Original Article

Screening for Discomfort as the Fifth Vital Sign Using an Electronic Medical Recording System: A Feasibility Study

Tatsuya Morita, MD, Koji Fujimoto, RN, Miki Namba, RN, Emi Kiyohara, RN, Satoshi Takada, BBA, Ritsuko Yamazaki, RN, and Kimiyo Taguchi, RN
Department of Palliative and Supportive Care (T.M.), Palliative Care Team (T.M., K.F., M.N.), and Seirei Hospice (T.M., E.K.), Department of Medical Informatics (S.T.), and Nursing Department (R.Y., K.T.), Seirei Mikatahara Hospital, Shizuoka, Japan

Abstract

Late referral to a specialized palliative care service hinders quality symptomatic management. The aim of this article is to describe the feasibility and clinical usefulness of screening for patient discomfort as the fifth vital sign using an electronic medical recording system to identify patients with undertreated physical symptoms. For the electronic medical recording system, all admitted patients received routine nurse assessment of discomfort (defined as any physical symptom) at every vital signs check using Item 2 of the Support Team Assessment Schedule Japanese version (STAS). All medically treated cancer patients admitted to seven oncology units were automatically screened at one-week intervals. Positive screening was defined as a STAS score of 2 or more at least two times during the previous week. For each patient identified by screening, a palliative care team reviewed the medical record and provided written recommendations when other treatments might improve the patient's physical symptoms. Of 629 patients screened, 87 (14%) initially met the positive screening criteria. Fifteen (17%) were false positive due to psychiatric symptoms without physical symptoms or due to misrecording. Of 72 cases with actual discomfort, 33 had already been referred to the palliative care team, 14 had received adequate palliative care as determined by the palliative care team, 14 had self-limiting transient discomfort, and one patient died before the screening day. In the remaining 10 cases (11% of symptomatic patients, 1.7% of all screened patients), the palliative care team recommended potentially useful interventions for symptom control; seven patients were referred to the palliative care team within one week. The time required for all screening processes was about 30 minutes per week. This experience demonstrates that screening for patient discomfort as the fifth vital sign using an electronic medical recording system can be successfully implemented and may be useful in facilitating early referral of distressing patients to the specialized

Address correspondence to: Tatsuya Morita, MD, Department of Palliative and Supportive Care, Palliative Care Team and Seirei Hospice, Seirei Mikatahara Hospital, 3453 Mikatahara-cho, Hamamatsu,

Shizuoka 433-8558, Japan. E-mail: tmorita@sis.seirei.or.jp

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Key Words

Palliative care team, neoplasms, screening, fifth vital sign, pain

Introduction

Multiple empirical studies suggest that health care professionals often underestimate the symptom distress of advanced cancer patients,¹⁻⁴ and the timing of referral to specialized palliative care services might be late.⁵⁻⁷ Screening methods to identify patients with considerable distress could be beneficial, encouraging earlier and more appropriate referral to specialized care from additional resources, such as specialized palliative care services. Several empirical studies have suggested the clinical efficacy of such a screening system,⁸⁻¹³ but these studies focus on psychological distress rather than physical discomfort and use patient-reported assessment scales. Using patient-rated assessment scales is essential to receive accurate information about patient distress, but in busy clinical practice, the screening procedure itself may be a burden to both patients and medical professionals.

The American Pain Society describes pain as the fifth vital sign and recommends that clinicians assess patients for pain every time they check the pulse, blood pressure, temperature, and respiration.¹⁴ If all patients receive such "screening" at every vital signs check, this would contribute to better symptom control by identifying patients with undertreated pain, with minimum burden to patients and clinicians. To our knowledge, however, empirical studies have not confirmed the clinical usefulness of such a screening system.^{15,16}

The aim of this report is to describe the feasibility and potential clinical usefulness of screening for patient discomfort as the fifth vital sign using an electronic medical recording system to identify patients with undertreated physical symptoms.

Patients and Methods

Selecting the Screening Tool

The primary aim of this study was to identify patients with considerable physical discomfort.

Patient discomfort was conceptualized as any physical symptom, such as pain, dyspnea, nausea, fatigue, and constipation. The rationale to target multiple symptoms, in addition to pain, was their high prevalence and considerable impact on patients' quality of life.¹⁷⁻²⁰ We decided not to include psychological symptoms, despite their well-acknowledged importance in patients' quality of life, because (1) routine assessment of multiple items would be a significant burden to nurses as the first step of our project, and (2) medical professionals cannot always provide proxy assessment of patients' psychological distress.¹⁻⁴

We developed the following screening methodology: Nurses recorded the intensity of discomfort of all patients at every vital signs check (routinely three times per day) using Item 2 of the Support Team Assessment Schedule Japanese version (STAS).²¹⁻²⁴ The STAS is a well-established comprehensive outcome measurement tool rated by medical professionals, and Item 2 rates the intensity of patients' physical symptoms as 0 (none), 1 (mild), 2 (moderate), 3 (severe), or 4 (extreme). The rationale for selecting the STAS was as follows: (1) the STAS has established reliability and validity for the Japanese population;²⁴ (2) the STAS requires no active participation from and causes no additional burden to patients; (3) the STAS is applicable for all patients including the physically very ill and cognitively impaired who could not complete self-reported questionnaires; (4) rating using Item 2 requires only several seconds and would cause minimum burden to nurses; and (5) the STAS was adopted as a standardized assessment scale for clinical use throughout the hospital, not only for the present study.

We applied the electronic medical recording system so that all admitted patients received routine nurse assessment of patient discomfort. Figure 1 demonstrates that the levels of patient discomfort are visualized on the electronic medical recording system along with the vital sign data. Furthermore, we developed

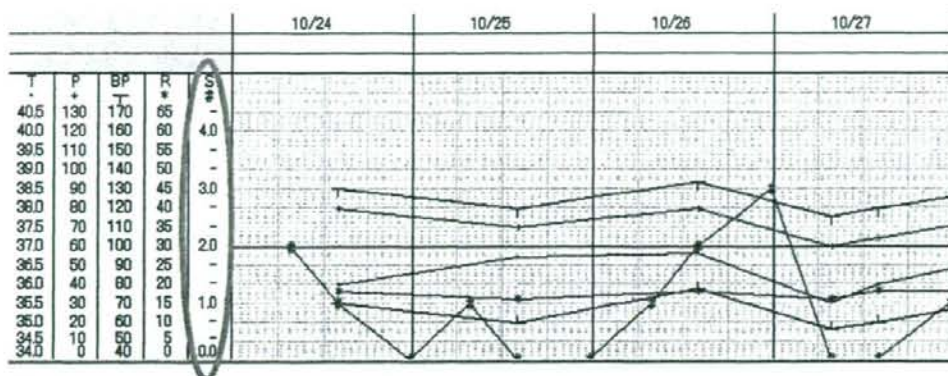


Fig. 1. Patient discomfort visualized as the fifth vital sign.

a computer-based program to automatically screen the scores of the STAS of all admitted patients and list the patients censored (Fig. 2). This procedure required only a few minutes. This system development required only minimum in-house modifications, and no additional costs were incurred.

For the clinical implementation of this system, we conducted multiple educational sessions for all nurses over six months, and distributed the rating instructions via the Web and written portable materials for each nurse.

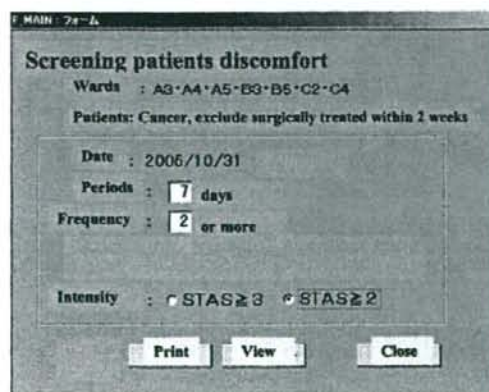
Screening and Palliative Care Team Intervention

Just after ending the educational sessions, during August to October 2006, all cancer

patients admitted to seven oncology units were automatically screened with the electronic medical recording system at one-week intervals. Each automatic screening required only a few minutes. Patients who had undergone surgery during the previous two weeks were excluded.

We defined positive screening as patients with a STAS score of 2 or more at least two times in the previous one week. We determined this ad hoc cutoff point after several explorative testing phases whereby stricter criteria (i.e., STAS score of 3 or more) detected only a small number of patients.

For all patients identified by automatic screening, the palliative care team reviewed each patient's medical records, with help



Screening window

STAS スクリーニング結果 (STAS ≥ 2)

A4 病室	コンピュータ入力検査 (NO) : 80% (136 / 170)
対象患者数: 14	コンピュータ入力検査 (NO) : 80% (8 / 14)
STAS ≥ 2 回数	患者数: 0 / 0
STAS ≥ 3 回数	患者数: 0 / 0
A5 病室	コンピュータ入力検査 (NO) : 80% (45 / 56)
対象患者数: 5	コンピュータ入力検査 (NO) : 80% (5 / 5)
STAS ≥ 2 回数	患者数: 0 / 0
STAS ≥ 3 回数	患者数: 0 / 0
B3 病室	コンピュータ入力検査 (NO) : 80% (276 / 345)
対象患者数: 17	コンピュータ入力検査 (NO) : 71% (12 / 17)
STAS ≥ 2 回数	患者数: 0 / 0
STAS ≥ 3 回数	患者数: 0 / 0
B5 病室	コンピュータ入力検査 (NO) : 80% (113 / 141)
対象患者数: 14	コンピュータ入力検査 (NO) : 80% (5 / 14)
STAS ≥ 2 回数	患者数: 0 / 0
STAS ≥ 3 回数	患者数: 0 / 0

Patient list

Fig. 2. Computer-based screening system.

from ward nurses, to determine (1) whether the patient actually suffered physical discomfort and (2) whether the patient had already received maximum palliative care medical intervention. If the palliative care team determined that additional treatments might improve the patient's physical symptoms, written recommendations were made in the medical record. This process required about 3 minutes for each patient.

For patients whose palliative care physicians provided written recommendations, primary physicians' adherence to recommendations was followed up one week later.

Palliative Care System in the Seirei Mikatahara General Hospital

The palliative care team that provided specialist input for this study is well established. The Seirei Mikatahara General Hospital is a local cancer center with about 700 beds. The resources of the palliative care division include an inpatient hospice (palliative care unit, 27 beds; four attending physicians and 27 nurses) and a specialized palliative care consultation service (150–200 consultation activities per year; one attending physician and two certified nurses) and receives regular support from liaison psychiatry, a pain service, rehabilitation, oral care, nutrition, social work division, and home-care groups. Symptom control manuals are available via the hospital home page. The clinical activity of the palliative care team has been generally recognized, and thus the

existing human network could have played a screening role before the beginning of this study (e.g., if a pharmacist notices a patient with unrelieved pain, he/she could freely call the palliative care specialist by phone and receive advice within 24 hours).

Results

In this nine-week study period, nurses completed 8,713 assessments of the 11,697 opportunities to apply the STAS (overall compliance rate, 74%). Of the 629 case records screened, 87 cases (14%) initially met the positive screening criteria, that is, a STAS score of 2 or more at least two times during the previous week (Fig. 3). The time required for screening was estimated to be about 30 minutes per week (87 cases/9 sessions, 3 minutes/patient).

Of 87 cases initially screened as positive, 15 (17%) were false positive due to psychiatric symptoms without physical symptoms ($n=13$) and misrecording ($n=2$). Thus, 72 of the 87 cases (83% of positive-screened patients, 11% of all screened patients) had actual physical symptoms.

Of 72 cases with actual discomfort, 33 had already been referred to the palliative care team, 14 had self-limiting transient discomfort, 14 received adequate palliative care as determined by the palliative care team, and one patient died before the screening day. Transient discomfort was related to (1) invasive procedures

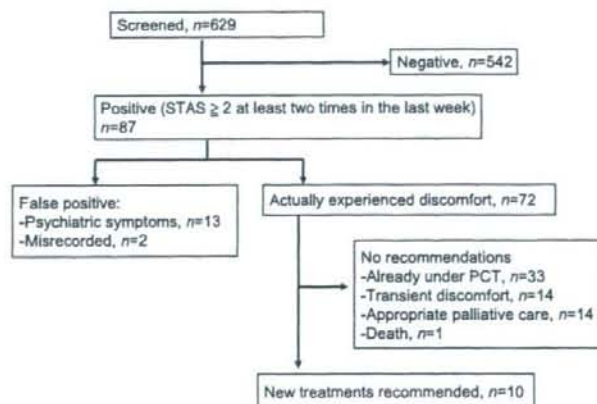


Fig. 3. Results.

(e.g., chest tube, percutaneous biliary drainage, and intubation), (2) radiation or chemotherapy-induced nausea, diarrhea, and fatigue, or (3) benign complications (e.g., pneumonia, gastric ulcer, and cholangitis).

In the remaining 10 cases (11% of symptomatic patients, 1.7% of all screened patients), the palliative care team recommended potentially useful interventions for symptom control, and seven patients were ultimately referred to the palliative care team within one week (Table 1). The majority of cases had complicated and/or multiple physical symptoms, such as neuropathic pain, a combination of pain and delirium, and pain and nausea. All three patients for whom the palliative care team recommended potentially useful interventions but did not refer them to the palliative care team received the recommended treatments by primary physicians.

Discussion

This study suggests that a screening system for patient discomfort as the fifth vital sign using an electronic medical recording system is feasible and may be useful to identify patients with undertreated physical symptoms. The greatest advantage of such a system is its high feasibility. The system development required no additional cost, and this method caused no patient burden and only a minimal burden to nurses. It is, therefore, applicable in busy

clinical practice settings. Thanks to advanced technology, the computer-based program screened the discomfort levels of all admitted patients within a few minutes. In addition, palliative care specialists could review each patient's records with positive screening results on an average of three minutes (30 minutes per week), as they could see all patient records via a single computer terminal in the office.

The assessment completion ratio was not high (i.e., 74%). We believe this figure is reasonable, however, because this observation was performed just after completing the six-month educational sessions. We have now achieved a greater than 85% completion ratio four months after this initial study period (unpublished data).

Overall, 11% of all screened patients actually experienced physical symptoms, and 11% of them, that is, 1.7% of all screened patients, received potentially useful treatments following written recommendations from palliative care specialists. Ultimately, 70% of the identified patients were referred to the palliative care team within one week. The relatively low percentages of patients with physical symptoms (11% of all patients: 72/629) and the patients with physical symptoms who were not referred to the specialized palliative care service (18% of patients with not-transient physical symptoms: 10/57) are unexpected but welcome findings in this study. The possible interpretations are (1) nurses underestimated patient symptoms and/or (2) the specialized palliative care system had been fully established in our hospital and patients with complicated symptomatology had already been referred to our team. We believe the latter is the most likely because previous studies suggested the increased awareness of the role of the palliative care team in our hospital.^{25,26}

Although we cannot demonstrate empirical data beyond the study aim, potential advantages of this system include (1) checking patient discomfort along with vital signs for all patients in *itself* could increase clinician attention to patient discomfort and contribute to improving patients' quality of life, (2) using the standardized tool STAS throughout the hospital could contribute to improving patient assessment, (3) informing doctors of the activity of the specialized palliative care team via the screening could promote physicians

Table 1
Recommended Interventions by Palliative Care Specialists

Case	Symptoms	Interventions
1	Hiccups	Clonazepam, herbal medicine
2	Neuropathic pain	Oxycodone
3	Neuropathic pain	Neck MRI, radiation, baclofen, oxycodone
4	Nausea, bone pain	Serum calcium, brain MRI, bone CT, epidural block, OR
5	Nausea, delirium	Hydration reduction, antihistamine, somatostatin
6	Abdominal pain	Epidural block, fentanyl
7	Nausea, headache	Brain CT, steroids, OR, antihistamine
8	Nausea, bone pain	Serum calcium, brain CT, antihistamine
9	Bone pain, delirium	Bisphosphonate
10	Abdominal swelling	Steroids, OR

OR = Opioid rotation.

unfamiliar with palliative care to consult our team, and (4) patients very reluctant to disclose their physical discomfort to their physicians may receive some benefits.

A major limitation of this study was the lack of a direct assessment of patient symptoms after screening, and this study, therefore, cannot conclude whether this screening system changed the patient outcome. Second, we excluded psychological and psychiatric symptoms in our initial project, and so the next step is to identify overlooked patient psychological modalities. Also, we did not measure formal psychometric properties as a screening instrument (sensitivity, specificity) due to the study design.

In conclusion, screening for patient discomfort as the fifth vital sign using an electronic medical recording system is feasible and may be useful for facilitating earlier and more appropriate referral of distressed patients to the specialized palliative care service. We believe that the low percentage of identified patients is mainly due to the widespread use of the specialized palliative care service in our hospital, and thus, we strongly encourage further studies to clarify the clinical effectiveness of this system in hospitals in which palliative care team activity has not been sufficiently introduced.

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