

Original Article

Difference of patient's perceived need in breast cancer patients after diagnosis

Tatsuo Akechi^{1,2,*}, Megumi Uchida^{1,2}, Tomohiro Nakaguchi^{1,2},
Toru Okuyama^{1,2}, Nobuhiro Sakamoto^{2,3}, Tatsuya Toyama⁴,
and Hiroko Yamashita^{4,5}

¹Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, Nagoya, Aichi, ²Division of Palliative Care and Psycho-oncology, Nagoya City University Hospital, Nagoya, Aichi, ³Department of Gastroenterological Surgery, Nagoya City University Graduate School of Medical Sciences, Nagoya, Aichi, ⁴Department of Oncology, Immunology and Surgery, Nagoya City University Graduate School of Medical Sciences, Nagoya, Aichi, and ⁵Breast Surgery, Hokkaido University Hospital, Sapporo, Japan

*For reprints and all correspondence: Tatsuo Akechi, Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University Graduate School of Medical Sciences, Mizuho-cho, Mizuho-ku, Nagoya, Aichi, 467-8601, Japan. E-mail: takechi@med.nagoya-cu.ac.jp

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Abstract

Objective: The purpose of this study was to investigate the difference of patients' perceived needs after cancer diagnosis. Differences in quality of life and psychological distress were also examined.

Methods: Ambulatory breast cancer patients who were randomly selected participated in this study. The patients were asked to complete the Short-form Supportive Care Needs Survey, which covers five domains of need (health system and information, psychological, physical, care and support and sexuality needs), the European Organization for Research and Treatment of Cancer QLQ-C 30 and the Hospital Anxiety and Depression Scale.

Results: A total of 408 patients were enrolled and distributed into four groups [Group 1 ($N=115$)], within 1 year of diagnosis; Group 2 ($N=105$), 1–3 years since diagnosis; Group 3 ($N=94$), >3 years since diagnosis; and Group 4 ($N=94$), recurrence). Significant differences were observed in total, psychological, physical and daily living, and patient care and support needs, as well as in quality of life, whereas there were no significant differences in health system and information, sexuality needs and psychological distress. In general, Groups 1 and 4 had a higher need level and lower quality of life.

Conclusions: Patients' perceived needs and quality of life may vary according to time since cancer diagnosis and the presence of cancer recurrence. The findings suggest that different care for supporting breast cancer survivors after diagnosis should be recommended, and that the time since diagnosis and/or the presence of recurrence may be relevant indicators for providing optimal and individualized care.

Key words: oncology, need, survivorship, supportive care

Introduction

Breast cancer is one of the most common forms of cancer affecting women worldwide. In Japan, it is the most common form of cancer afflicting women, and its prevalence has been increasing yearly

(the latest estimates state that ~60 000 additional women are diagnosed with breast cancer every year). Advances in early detection and individualized medical treatment have improved the survival rate of breast cancer patients, enabling them to live for prolonged

periods of time. The current 5-year survival rate for breast cancer patients is >80% (1), which indicates that the number of breast cancer survivors continues to increase.

Although quality of life (QOL) and patients' satisfaction are common parameters used to measure some of the morbidity outcomes of cancer, these outcomes fail to link practical service outcomes with patient perceptions of morbidity and treatment processes (2). The assessment of patients' needs offers several advantages (3). First, the perceived needs of patients regarding help and patient-important outcomes can be directly assessed; thus, representing a more direct indication of the required resources. The problems and symptoms of patients do not necessarily reflect their actual need for help (4). Second, it allows the identification of the magnitude of the need for help, thereby allowing some prioritization of service needs and the allocation of the available resources where the need is most urgent. Third, an assessment of needs enables the identification of individuals and/or patient subgroups with higher need levels; thus, potentially enabling the prevention or reduction of problems via the adoption of appropriate early interventions (3). Thus, understanding the perceived needs of patients will enable the development by the medical staff of services or interventions designed to meet these specific needs.

Conversely, the patients' perceived needs are possibly different depending on their situation, particularly the time since diagnosis (5). Furthermore, although breast cancer patients have a better prognosis on average than do patients with several other types of cancer in general, it is well known that many breast cancer survivors suffer from long-term psychological distress because recurrence of cancer is mostly incurable. Thus, the elucidation of the differences in patients' perceived needs after a cancer diagnosis is useful for medical staff because it allows them to appropriately support breast cancer survivors. However, to the best of our knowledge, very few studies have addressed the differences in patients' needs focusing on different periods after diagnosis and the presence and/or absence of cancer recurrence.

The primary purpose of this study was to investigate the differences in patients' needs after cancer diagnosis including those with recurrence. In addition, differences in QOL and psychological distress after diagnosis were investigated.

Patients and methods

Subjects

This study was conducted using data from previous studies published in 2011 (6). The study subjects were ambulatory female patients with breast cancer who attended the outpatient clinic for Oncology, Immunology and Surgery at the Nagoya City University Hospital between February 2006 and 2007. Potential participants were randomly sampled using a visiting list and a random number table.

The eligibility criteria for inclusion in the study were as follows: (i) diagnosis of breast cancer (all stages and at any time point after diagnosis), (ii) an age of ≥ 20 , (iii) an awareness of cancer diagnosis and (iv) a general condition that was sufficient to enable the completion of the survey questionnaire [a score of 0–3 on the Eastern Cooperative Oncology Group (ECOG) Performance Status scale]. The exclusion criteria were: (i) the presence of severe mental or cognitive disorders or (ii) an inability to understand the Japanese language.

This study was approved by the Institutional Review Board and Ethics Committee of the Nagoya City University Graduate School of Medical Sciences, Japan, and was conducted in accordance with the principles laid down in the Helsinki Declaration. Written consent was obtained from each patient after a thorough explanation of the purpose and methods of the study was provided.

Procedure

After informed consent was obtained, the patients were asked to complete the self-administered questionnaires (described below) at home and return them the following day. When questions were inadequately answered, clarifications were sought over the telephone.

Patients' perceived needs: the short-form supportive care needs survey questionnaire (SCNS-SF34)

SCNS-SF34 is a self-administered instrument for assessing the perceived needs of patients with cancer (7). SCNS-SF34 consists of 34 items that cover five domains of need: psychological (10 items), health system and information (11 items), physical and daily living (five items), patient care and support (five items) and sexuality (three items). The respondents were asked to indicate the level of their need for help over the last month in relation to their having cancer using the five response options: 1 [No Need (Not applicable)], 2 [No Need (Satisfied)], 3 [Low Need], 4 [Moderate Need] and 5 [High Need]. Subscale scores were obtained by summing the individual items. In addition, a total score was obtained by summing all the subscales (range, 34–170). A higher score indicated a higher perceived need. Alternatively, the scale can be used to obtain information on the presence/absence and number of perceived unmet needs (a rating of three or higher was regarded as an unmet need), depending on the researcher's clinical question. The validity and reliability of the Japanese version of the SCNS-SF34 have been established (8).

Quality of life: EORTC QLQ-C 30

Patient QOL was assessed using the European Organization for the Research and Treatment of Cancer (EORTC) QLQ-C30 (9). QLQ-C30 is a 30-item, self-reported questionnaire that covers functional and symptom-related aspects of QOL in cancer patients. The validity and reliability of the Japanese version of EORTC QLQ-C30 has been confirmed (10). In this study, the Global Health Status score was used. A high Global Health Status score represents a high QOL.

Psychological distress: hospital anxiety and depression scale

Hospital Anxiety and Depression Scale (HADS) was for use in medically ill patients and does not include any questions regarding physical symptoms. HADS is a self-reported questionnaire consisting of 14 items. The subjects were asked to rate how they felt during the previous week using a four-point Likert scale. HADS consists of an anxiety and a depression subscale (0–21 points each), and the total score can range from 0 to 42. A higher score indicates more severe depression and anxiety (11). The Japanese version of HADS has been validated for cancer populations (12). The optimal cutoff point for screening for adjustment disorders and/or major depressive disorders (indicating psychological distress) is 10/11.

Sociodemographic and biomedical factors

An *ad hoc* self-administered questionnaire was used to obtain information on the patients' sociodemographic status, including their marital status, level of education and employment status. The performance status, as defined by ECOG, was evaluated by the attending physicians. All other medical information (time since diagnosis and anticancer treatment) was obtained from the patients' medical records.

Statistical analysis

To compare the differences in perceived needs in breast cancer patients after diagnosis, we defined four different groups: Group 1 (within 1 year of cancer diagnosis), Group 2 (1–3 years since cancer diagnosis), Group 3 (>3 years since cancer diagnosis) and Group 4 (cancer recurrence, irrespective of time since cancer diagnosis). Since it is suggested

that the time of first year since diagnosis and the time after recurrence is critical period for cancer patients and that patients' psychological distress seems to continue at least 2 years after breast surgery, we decided these four groups for the comparison (13). First, an analysis of variance (ANOVA) was performed to assess differences in patients' perceived needs, as measured using SCNS-SF34. Furthermore, ANOVA was performed to investigate differences in QOL and psychological distress, as measured using the Global Health Status score of EORTC QLQ-C30 and the total score of HADS, respectively. If significant differences were observed in ANOVA, multiple comparison analyses were performed using Tukey's method to check differences between the groups.

A P value < 0.05 was adopted as the significance level in all statistical analyses, and all P values reported were two tailed. All statistical analyses were conducted using IBM SPSS Statistics version 19 software for Windows (SPSS Inc., 2010).

Results

Patient characteristics

A total of 408 patients among 420 potential participants were enrolled in this study and distributed among four groups: Group 1 ($N = 115$), within 1 year of diagnosis; Group 2 ($N = 105$), 1–3 years since diagnosis; Group 3 ($N = 94$), > 3 years since diagnosis; and Group 4 ($N = 94$), recurrence. In contrast, 12 patients were excluded: seven refused to participate, two were excluded because of cognitive disturbances, one was excluded because of physical illness, and two were excluded for not providing responses, despite their consent to participate in the study. The characteristics of these 408 patients are summarized in

Table 1. Approximately half of the subjects had full-/part-time jobs in Groups 1, 2 and 3, whereas only 36% of the patients with recurrence (Group 4) had a job. More than 90% of the participants included in Groups 1, 2 and 3 had no physical impairment (ECOG PS = 0), whereas $> 30\%$ of the patients with recurrence (Group 4) had impairment of any degree. Regarding cancer treatment, the participants from all groups received hormone therapy. However, 24% of the patients in Group 1 and 43% of the patients in Group 4 had been receiving chemotherapy, whereas almost no subjects in Groups 2 and 3 received chemotherapy. All of the subjects who received radiotherapy belonged to Group 1. More than one-fourth of patients in each group suffered from clinical psychological distress ($HADS \geq 11$).

Differences in patients' perceived needs

ANOVA revealed the presence of statistically significant differences in total needs, psychological needs, physical and daily living needs and patient care and support needs, whereas there were no significant differences with regard to health system and information needs or sexuality needs (Fig. 1). The subjects included in Group 1 had a higher level of total needs compared with those in Groups 2 and 3, and similar findings were obtained for psychological needs and physical and daily living needs. With regard to patient care and support needs, Group 4 exhibited a higher level of need compared with Group 1.

Differences in QOL and psychological distress

ANOVA revealed the presence of statistically significant differences in the Global Health Status score of EORTC QLQ-C30, whereas there was no significant difference in the total score of HADS.

Table 1. Characteristics of the study participants

Characteristic	N (%)				
	All ($N = 408$)	–1 year ($N = 115$)	1–3 years ($N = 105$)	3 years ($N = 94$)	Rec. ($N = 94$)
Age [mean (SD) in years]	56 (12)	53 (12)	56 (13)	58 (10)	58 (12)
Marital status					
Married	311 (76)	83 (72)	80 (76)	71 (76)	77 (82)
Education					
> 12 years	153 (38)	51 (44)	40 (38)	36 (38)	26 (28)
Employment status					
Full time/part time	182 (45)	52 (45)	50 (48)	46 (49)	34 (36)
Duration since diagnosis (days)					
Mean (SD)	1040 (1353)	148 (91)	707 (210)	1920 (776)	1621 (2261)
Median	701	119	702	1679	974
Performance status ^a					
0	369 (90)	109 (95)	103 (98)	92 (98)	65 (69)
1	33 (8)	6 (5)	2 (2)	2 (6)	23 (25)
2	4 (1)	0 (0)	0 (0)	0 (0)	4 (4)
3	2 (1)	0 (0)	0 (0)	0 (0)	2 (2)
Current anticancer treatment ^b					
Surgery ^c	34 (8)	25 (22)	0 (0)	1 (1)	8 (9)
Chemotherapy	68 (17)	28 (24)	1 (1)	0 (0)	40 (43)
Trastuzumab	18 (4)	6 (5)	0 (0)	0 (0)	12 (13)
Hormonal therapy	195 (48)	39 (34)	72 (69)	46 (49)	38 (40)
Radiation therapy	9 (2)	9 (8)	0 (0)	0 (0)	0 (0)
Clinical psychological distress					
HADS ^d ≥ 11	142 (35)	48 (42)	29 (28)	27 (29)	38 (40)

^aEastern Cooperative Oncology Group criteria.

^bMultiple choice.

^cThe patient had received surgery within the previous month.

^dHospital Anxiety and Depression scale.

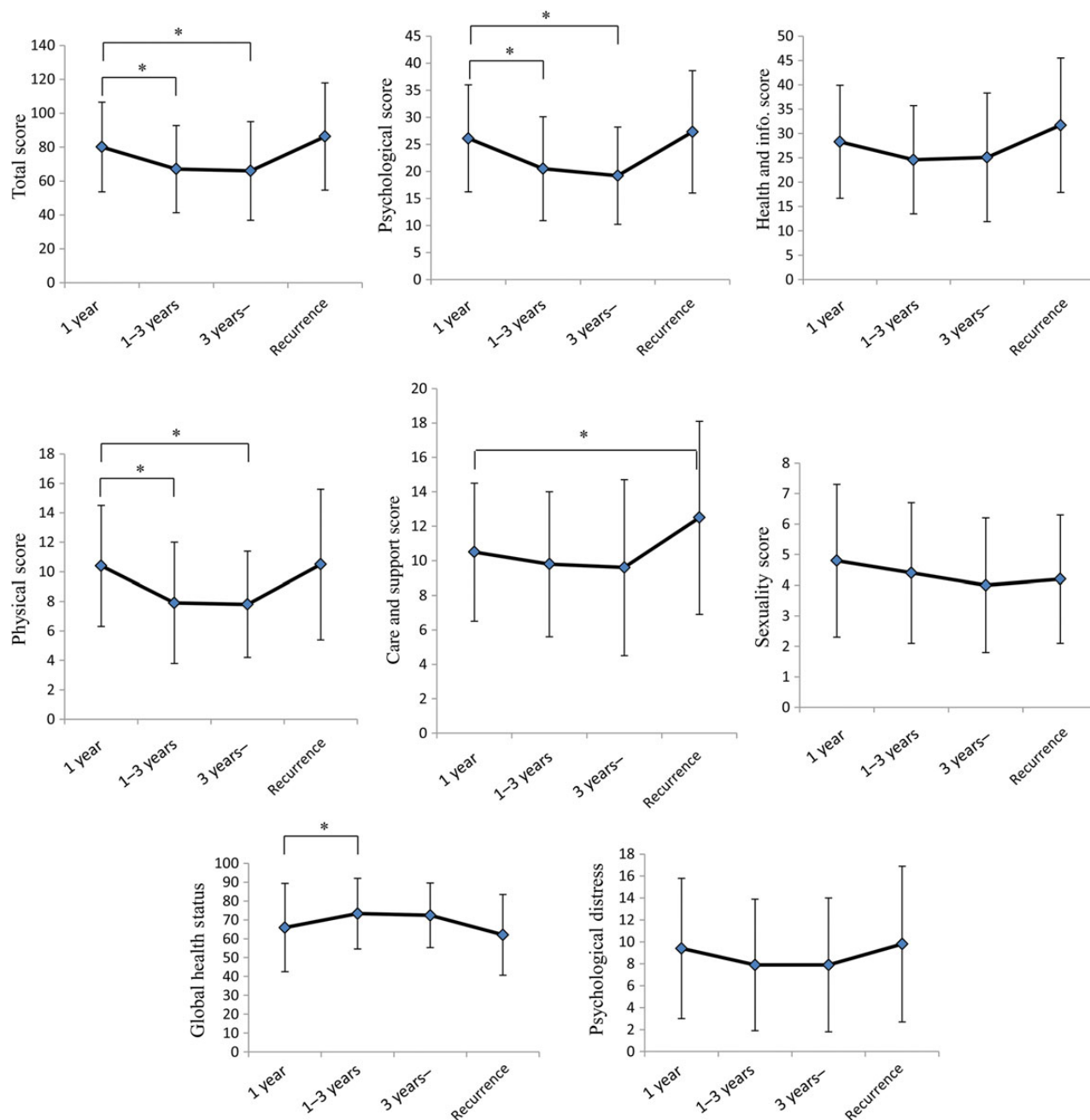


Figure 1. Differences in patients' perceived needs, quality of life and psychological distress. * $P < 0.05$; vertical bars indicate standard deviations.

Discussion

To the best of our knowledge, this is the first study to suggest that patients' perceived needs may be different and vary among breast cancer patients depending on the time since cancer diagnosis and the presence of cancer recurrence. In contrast, some previous studies reported that the differences in perceived needs in breast cancer patients are associated with patients' demographic characteristics including age, marital status and living status (e.g. urban versus rural) (14–16).

The present findings suggest that although the patients' perceived needs are high within the first year since diagnosis, they gradually decrease in the absence of cancer recurrence. These findings can be partly explained by the higher psychological and physical needs that were

observed within 1 year of the cancer diagnosis. Within this period, breast cancer patients have to cope with the psychological impact of the disclosure of the cancer diagnosis, and have to confront and manage various difficult and complicated experiences including treatment choice, body image changes, loss of femininity and replanning of daily life. As summarized in Table 1, considering that within 1 year of the cancer diagnosis the patients are more likely to receive multimodal anticancer treatment, various adverse events of cancer therapy may influence the patients' needs because a recently published systematic review suggests that greater symptom burden is associated with a higher level of needs (5). However, the current study did not evaluate the specific impact of the various events that occur after cancer diagnosis, or the

adverse effects of anticancer treatments; thus, further studies are required to clarify the potential sources of patients' perceived needs within the first year after diagnosis. Moreover, comprehensive support aimed at satisfying patients' perceived unmet needs should be essential for breast cancer patients because the illness trajectory of breast cancer is generally long lasting, regardless of the occurrence of cancer recurrence.

Our findings demonstrated that the needs of breast cancer patients who experience cancer recurrence appear to be higher. This finding was consistent with those of previous studies (5,17). This was not unexpected because the psychological impact of experiencing cancer recurrence is markedly strong (18,19), and patients with recurrent breast cancer are likely to receive long-lasting anticancer treatments including aggressive regimens (20). Considering that our previous study also reported a very high prevalence of unmet needs (e.g. 17 of the most-frequent unmet needs measured using SCNS-SF34 were >50%) (21), novel intervention programs focusing on reducing the needs of patients with recurrent breast cancer are warranted. As our previous study showed that a multifaceted psychosocial intervention program that involved screening for psychological distress and comprehensive support, including individually tailored psychotherapy and pharmacotherapy provided by mental health professionals, is feasible (22), a multidisciplinary supportive intervention program may be promising for patients with recurrent breast cancer.

Because patients' QOL is also worse within the first year since diagnosis, early supportive and palliative care is essential to maintain QOL. Some previous studies have suggested that early multidisciplinary care provided since soon after cancer diagnosis is useful for maintaining QOL for cancer patients (23,24), optimal treatment including both appropriate comprehensive care as well as anticancer treatment is also promising for breast cancer patients. There were no significant differences in terms of time since cancer diagnosis with regard to psychological distress. However, the fact that the psychological distress score measured by HADS was considerably high, and that the prevalence of clinical distress has always been more than one-fourth of the subjects, regardless of the period since diagnosis, may suggest the long-lasting profound psychological impact of breast cancer and its treatment. A previous study that investigated suicide among breast cancer patients demonstrated that the risk of suicide was significantly elevated >25 years of follow-up after a cancer diagnosis. These findings suggest the eminent and long-lasting psychological impact of the breast cancer experience (25). Considering the current increase in breast cancer incidence, maintaining the mental health of patients with this disease should not be neglected from the viewpoints of public health and of inhibiting suicide.

In conclusion, patients' perceived needs and QOL vary according to time since cancer diagnosis and the presence or absence of cancer recurrence. The present findings suggest that different types of care for supporting breast cancer survivors after diagnosis should be recommended, and that the duration of diagnosis and/or the presence of recurrence may be relevant indicators for providing optimal and individualized care.

The present study had several limitations. First, the investigation was cross-sectional in design, precluding any conclusions from actual longitudinal changes in patients' needs, QOL and psychological distress. Further prospective studies are needed to address each patient's specific changes regarding these factors because a previous review emphasized the necessity of longitudinal studies (5). Second, because supportive care needs can be influenced by the patients' cultural background and each country's medical system, these findings may not be applicable to other patient populations. Third, because the

present study was conducted at one single institution, an institutional bias may exist. Finally, because this study focused on ambulatory breast cancer patients, relatively few patients with low physical functioning or advanced cancer were enrolled and a previous study showed that needs can longitudinally differ over illness trajectory among patients with advanced breast cancer, our results may not be applicable to patients with other types and/or a long duration of advanced stages of cancer.

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Conflict of interest statement

None declared.

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