BRIEF COMMUNICATION

Patient education, upper-limb symptom perception, and quality of life among Japanese breast cancer survivors

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Abstract

Purpose To examine the effects of perceptions of information received about upper-limb morbidity (ULM) and perceptions of upper-limb symptoms (ULS) on quality of life (QoL) among Japanese breast cancer (BC) survivors.
Methods A total of 166 Japanese BC survivors with postoperative ULS participated in a cross-sectional study. Participants were divided into three groups by time since breast surgery (short-term, middle-term, and long-term). Survivors' perceptions of the information, their perceptions of ULS, and QoL were assessed using questionnaires, including the WHO QoL-BREF Japanese version. Factors associated with QoL were analyzed by multiple regression stepwise analyses.
Results In the short-term group, perceptions of insufficient information about managing ULM were associated with poor physical ($P = 0.002$), psychological ($P = 0.003$), and environmental health ($P = 0.015$). Positive perceptions of ULS were associated with good physical ($P = 0.011$), psychological ($P = 0.024$), and social health ($P = 0.028$). Symptom disclosure was associated with poor physical ($P = 0.036$) and psychological health ($P = 0.041$) in the long-term group. No significant association was found between QoL and perceptions of information or symptoms in the middle-term group.
Conclusions Facilitating positive perceptions of information and ULS may improve QoL, especially in short-term survivors. Healthcare providers should develop patient education programs that take the perceptions of BC survivors into account.

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Introduction

Upper-limb morbidity (ULM) may be experienced following breast cancer (BC) treatment. In Japan, around 32–50 % of BC survivors who undergo axillary lymph node dissection (ALND) and radiotherapy develop ULM within 5 years after surgery [1, 2]. Quality of life (QoL) may be impaired by the number of upper-limb symptoms (ULS) and the restriction of daily activities [3, 4].

To prevent ULM and control symptoms, patient education, such as providing information about self-management, is often emphasized. The rationale behind this is that information provision has patients acquire adequate knowledge to seek medical help without delay and consequently have better health outcomes. However, previous research indicates that cognitions may influence behaviors and outcomes. For example, receiving insufficient information is associated with perceiving symptoms as being less serious, and this leads to delays in medical consultation among mixed cancer samples [5, 6]. Additionally, significant associations of strong symptoms and severity of illness with poor QoL have been found among head and neck cancer survivors [7]. Furthermore, unmet information needs have been found to be associated with poor QoL among BC patients [8].

Little research has examined whether perceptions of the information received about ULM and perceptions of ULS are independently associated with QoL among BC survivors. An advanced search was conducted using MEDLINE, Cochrane Central Register of Controlled Trials, Cumulative Index to Nursing and Allied Health, and PsycINFO
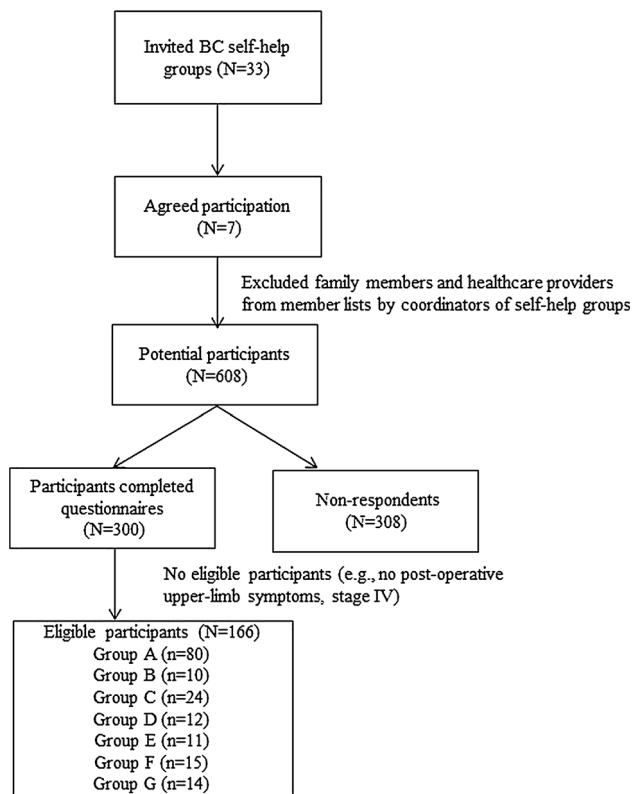
Fig. 1 Sampling and inclusion criteria

(keywords: illness perception, information, QoL, and cancer in English articles). The search failed to retrieve any articles relevant to Japanese BC survivors with ULS. Because perceptions about certain phenomena may vary across cultures [9], understanding the relationship between Japanese BC survivors' perceptions and their health outcomes will help healthcare professionals develop adequate patient education programs for ULM.

QoL tends to improve with the increasing number of years of survival [10]. This suggests that factors associated with QoL and support needs may vary depending on the time since BC surgery. Therefore, this paper focused on the time-specific QoL. The purpose of the study was to examine whether the perceptions of the information received about ULM and ULS perceptions could be individually associated with QoL among Japanese BC survivors.

Methods

Participants and procedure

Inclusion criteria were Japanese BC survivors (≥20 years old) without metastatic BC, who were reporting postoperative ULS on the operated side, at the time of this study.

Following approval from institutional and medical ethics committees, BC self-help groups were invited, and seven groups in Japan participated in a postal survey (Fig. 1). Participants who completed the questionnaires were provided a 500-yen book token as an incentive.

Measures

QoL was assessed using the 26-item WHO QoL-BREF Japanese version, which includes physical (seven items), psychological (six items), social (three items), and environmental domains (eight items), and overall health (two items), measured on a 5-point scale (1 = "strongly disagree", 5 = "strongly agree"). Alpha values were 0.82, 0.84, 0.66, and 0.78, respectively. High scores indicate good QoL. The psychometric properties of the WHO QoL-BREF have been reported for the Japanese population [11]. Perceptions of information received about ULM were measured by a single item with dichotomous responses (sufficient/insufficient). Three dimensions of ULS perceptions were assessed with six response categories, range from 1 = "strongly agree" to 5 = "strongly disagree" and 0 = "no lymphedema." The three dimensions were assessed using the statements: "I feel that my lymphedema is more serious than BC" (seriousness); "I can still enjoy what I used to do even after the onset of lymphedema" (perceived normality); "I feel afraid to disclose my lymphedema to people other than my family" (symptom disclosure). These dimensions were developed from a previous qualitative study in Japan [12]. High scores indicate positive perceptions (the scores for perceived normality were reversed). Physical discomfort with daily activities was assessed by six items (paid work, housework chores, grooming, hobbies, sleeping, and meeting somebody) using a 5-point face-scale, range from 1 = "a big smiling face" to 5 = "a crying face." This has good factorial validity among BC survivors with ULS (CFI = 0.95, RMSEA = 0.09 (90 % confidence interval 0.04; 0.14), NNFI = 0.91, and SRMR = 0.05) [13]. Alpha value was 0.69. High scores indicate severe discomfort. Age, clinical characteristics, and the presence of ULS (swelling, numbness, loss of strength, poor range of motion, and pain) were assessed using self-report questionnaires.

Statistical analysis

Missing data were found on some measures (ranged 0–12.0 %), and the missing pattern was completely random (Little's MCAR test, $P = 0.111$). Therefore, missing value imputation was applied for continuous variables [14]. The number of responses of "yes" in ULS was counted and dichotomized (1/>1). Participants were divided into three groups by time since breast surgery: ≤2 years (the short-

Table 1 Participant characteristics

Variables	All participants (N = 166)	Short-term (N = 48)	Middle-term (N = 63)	Long-term (N = 55)	Group differences P value
Age (years)					
Mean (SD)	56.32 (7.99)	52.79 (7.94)	56.90 (8.27)	58.73 (6.66)	0.000***
Types of surgery (N, %)					
Lumpectomy	63 (38.0)	22 (45.8)	27 (42.9)	14 (25.5)	0.050
Mastectomy	88 (53.0)	21 (43.8)	31 (49.2)	36 (65.5)	
Missing	15 (9.0)	5 (10.4)	5 (7.9)	5 (9.0)	
ALND (N, %)					
Yes	154 (92.8)	42 (87.5)	59 (93.6)	53 (96.3)	0.007**
No	4 (2.4)	4 (8.3)	0 (0.0)	0 (0.0)	
Missing	8 (4.8)	2 (4.2)	4 (6.4)	2 (3.7)	
Radiotherapy (N, %)					
Yes	71 (42.8)	30 (62.5)	21 (33.3)	20 (36.4)	0.005**
No	93 (56.0)	18 (37.5)	42 (66.7)	33 (60.0)	
Missing	2 (1.2)	0 (0.0)	0 (0.0)	2 (3.6)	
Chemotherapy (N, %)					
Yes	94 (56.6)	28 (58.3)	37 (58.7)	29 (52.7)	0.731
No	71 (42.8)	20 (41.7)	25 (39.7)	26 (47.3)	
Missing	1 (0.6)	0 (0.0)	1 (1.6)	0 (0.0)	
Stage (N, %)					
Early	133 (80.1)	41 (85.4)	46 (73.0)	46 (83.6)	0.128
Advanced	25 (15.1)	5 (10.4)	14 (22.2)	6 (10.9)	
Missing	8 (4.8)	2 (4.2)	3 (4.8)	3 (5.5)	
Info about manage (N, %)					
Sufficient	81 (48.8)	28 (58.3)	29 (46.0)	24 (43.6)	0.293
Insufficient	81 (48.8)	19 (39.6)	33 (52.4)	29 (52.7)	
Missing	4 (2.4)	1 (2.1)	1 (1.6)	2 (3.7)	
Number of symptoms (N, %)					
1	48 (28.9)	10 (20.8)	19 (30.2)	19 (34.5)	0.289
≥1	118 (71.1)	38 (79.2)	44 (69.8)	36 (65.5)	
Swelling (N, %)					
Symptomatic	80 (48.2)	17 (35.4)	34 (54.0)	29 (52.7)	0.109
Asymptomatic	86 (51.8)	31 (64.6)	29 (46.0)	26 (47.3)	
Physical discomfort					
Mean (SD)	16.11 (6.88)	16.71 (6.15)	17.36 (7.31)	14.14 (6.65)	0.030*
Seriousness					
Mean (SD)	2.17 (1.83)	1.92 (1.90)	2.10 (1.74)	2.49 (1.87)	0.239
Social Disclosure					
Mean (SD)	2.39 (1.97)	2.10 (2.00)	2.44 (1.89)	2.56 (2.03)	0.494
Perceived normality					
Mean (SD)	2.03 (1.89)	1.68 (1.99)	2.17 (1.89)	2.16 (1.81)	0.362

Possible range of physical discomfort scale was 0–30; possible range of seriousness, perceived normality, and symptom disclosure was 0–5

Short-term: up to 2 years since breast surgery; middle-term: 3–5 years since breast surgery; long-term: 6 years and over since breast surgery

SD standard deviations, ALND axillary lymph node dissection

* P < 0.05; ** P < 0.01; *** P < 0.001

term group), 3–5 years (the middle-term group), and ≥6 years (the long-term group). The chi-square test, one-way analysis of variance, or the Kruskal–Wallis test were performed to compare group differences on age, clinical characteristics, perceptions of information received, the ULS variables, and each domain score of the WHO QoL-BREF. One-way analysis for covariance was performed to examine group differences on each domain score of the WHO QoL-BREF, controlling for variables that were found to be significant in the bivariate analyses. Finally, stepwise multiple regression was conducted on the separate groups, with each domain score of the WHO QoL-BREF as an outcome. Age, clinical characteristics, number of ULS, physical discomfort with daily activities, perceptions of

Table 2 Mean scores and SD in scoring of WHO QoL-BREF (Japanese version) across groups stratified by years since breast surgery

Variables	Possible range	All participants (n = 166)	Short-term (n = 48)	Middle-term (n = 63)	Long-term (n = 55)	Group differences	
						F value	P value
Physical	7–35	13.99 (2.61)	13.86 (2.51)	13.88 (2.52)	14.22 (2.81)	0.318	0.728
Psychological	6–30	13.64 (2.63)	13.88 (2.69)	13.42 (2.48)	13.67 (2.76)	0.419	0.658
Social	3–15	14.00 (2.33)	14.36 (2.50)	13.67 (2.22)	14.06 (2.29)	1.129	0.298
Environmental	8–40	13.57 (2.01)	13.65 (1.92)	13.33 (2.07)	13.77 (2.01)	0.758	0.470

Short-term: up to 2 years since breast surgery; middle-term: 3–5 years since breast surgery; long-term: 6 years and over since breast surgery

Physical: the physical domain in the WHO QoL-BREF Japanese version; Psychological: the psychological domain in the WHO QoL-BREF Japanese version; Social: the social domain in the WHO QoL-BREF Japanese version; Environmental: the environmental domain in the WHO QoL-BREF Japanese version. After adjustment for covariates, physical domain scores [$F_{(2,157)}$ = 0.014, P = 0.986], psychological domain scores [$F_{(2,157)}$ = 0.408, P = 0.665], social domain scores [$F_{(2,157)}$ = 1.470, P = 0.233], and environmental scores [$F_{(2,157)}$ = 1.195, P = 0.305]

Table 3 Stepwise multiple regression of factors predicting QoL across groups stratified by years since breast surgery

Outcomes	Short-term (n = 48)		Middle-term (n = 63)		Long-term (n = 55)	
	Predictors	β (95 % CI)	Predictors	β (95 % CI)	Predictors	β (95 % CI)
Physical	Info (manage)	−0.410** (−3.325;−0.839)	Physical discomfort	−0.327* (−0.202;−0.024)	Physical discomfort	−0.284* (−0.238;−0.003)
	No. of symptoms	−0.313* (−1.204;−0.145)			Disclosure	−0.297* (−0.795;−0.027)
	Perceived normality	0.332* (0.104;0.736)				
	Age	−0.275* (−0.166;−0.008)				
Psychological	Info (manage)	−0.419** (−3.753;−0.807)	None		Physical discomfort	−0.308* (−0.242;−0.014)
	Perceived normality	0.316* (0.061;0.795)			Disclosure	−0.288* (−0.765;−0.017)
Social	Perceived normality	0.338* (0.047;−0.805)	None		None	
Environmental	Info (manage)	−0.372* (−2.598;−0.293)	None		Age	0.348* (−0.025;−0.185)
					Stage	−0.308* (−3.582;−0.259)

Short-term: up to 2 years since breast surgery; middle-term: 3–5 years since breast surgery; long-term: 6 years and over since breast surgery

β Standardized beta coefficients; CI confidence interval. Physical: the physical domain in the WHO QoL-BREF Japanese version; Psychological: the psychological domain in the WHO QoL-BREF Japanese version; Social: the social domain in the WHO QoL-BREF Japanese version; Environmental: the environmental domain in the WHO QoL-BREF Japanese version; Info (manage): perceptions of information patients received about management of ULS; No. of symptoms: the number of subjective ULS

* $P < 0.05$; ** $P < 0.01$

information received, and ULS perceptions were the independent variables. All statistical analyses were performed by SPSS (version 20).

Results

Three hundred BC survivors returned their questionnaires, for a response rate of 49 %. A total of 166 respondents met all the inclusion criteria. Table 1 presents the characteristics of the participants. Table 2 shows that the domain scores of the WHO QoL-BREF did not significantly differ across the groups. After adjusting for age, ALND, radiotherapy, and physical discomfort scores, the domain scores still were not significantly different across the groups. Table 3 shows the results of multiple regression analyses. The main findings in the short-term group were that perceiving the received information was insufficient and was significantly associated with poor physical (P = 0.002), psychological (P = 0.003), and environmental

health ($P = 0.015$). Perceived normality ("still enjoy what I used to do") was significantly associated with good physical ($P = 0.011$), psychological ($P = 0.024$), and social health ($P = 0.028$). Feeling comfortable about discussing ULS was significantly associated with poor physical ($P = 0.036$) and psychological health ($P = 0.041$) in the long-term group. No significant association was found between perceptions about the information or ULS with any domain of the WHO QoL-BREF in the middle-term group.

Discussion

This study found that time since breast surgery was not significantly related to QoL among Japanese BC survivors with ULS, which is inconsistent with the findings of a previous study [10]. ULS may persistently affect the health of BC survivors regardless of survival time, which may account for the lack of differences observed among the groups.

This study revealed that factors associated with QoL varied by time since breast surgery. Perceived insufficient information and perceived normality were significantly related to health outcomes in the short-term group, which accords with previous studies [5, 8, 15, 16]. Because short-term group members are often the most concerned about recurrence [17], they might not expect the onset of ULS and may feel that they were under informed about managing these symptoms, which could lead to difficulties in adjusting to ULM. Perceived normality after the onset of ULS may require treating the symptoms as minor and paying more attention to more life-threatening aspects of cancer [18], which may help adjustment to ULM. Among the long-term group, disclosure of ULS to others was significantly related to physical and psychological health. Many survivors are aware that 5-year survival is a critical clinical benchmark, indicating a decreased chance of recurrence. Although many Japanese BC survivors feel inhibited by social stigma to disclose their status [19], participants in the groups may literally feel themselves to be "survivors" and be less reserved about discussing BC-related ULS when they have severe discomfort.

The present study has several limitations. The data were collected from self-help groups, so the participants may have had more social support than other survivors, which could have affected QoL. Generalization of the findings is limited because the study used a cross-sectional design; hence, causality cannot be inferred. Additionally, because missing value imputation was applied to the data, the findings need to be interpreted with caution. Moreover, retrospectively collected data, especially responses to clinical characteristics in a self-administered questionnaire,

may be biased by human memory. The present study did not assess knowledge of ULM and various aspects of patient education. Further studies should include these important factors for the management of ULM.

In summary, favorable perceptions of patient education and ULS were associated with better QoL among short-term survivor groups. Stronger positive feelings about disclosing ULS and greater physical discomfort were related to poor QoL in long-term survivor groups. Healthcare providers should carefully develop education programs, considering the content and amount of information necessary to meet survivors' needs, help for survivors to decrease stigma, and encourage help-seeking behaviors to reduce their physical discomfort.

References

1. Kitamura, K., & Akazawa, H. (2010). Nyugan jyutugo no rinpafush kansuru tashisetsu jittai chousa (multi-centered survey in lymphedema following breast surgery). *Rinsho Kango, 36*, 889–893.
2. Kagawa, N., Fukuda, Y., Shimomura, M., Matsugu, Y., & Urushibara, T. (2007). Predictive factor of lymphedema of arm in breast cancer patients. *Nihon Rinsho Geka Gakkaishi, 68*, 1082–1087.
3. Hormes, J. M., Bryan, C., Lytle, L. A., Gross, C. R., Ahmed, R. L., Troxel, A. B., et al. (2010). Impact of lymphedema and arm symptoms on quality of life in breast cancer survivors. *Lymphology, 43*, 1–13.
4. Collins, L. G., Nash, R., Round, T., & Newman, B. (2004). Perceptions of upper-body problems during recovery from breast cancer treatment. *Supportive Care in Cancer, 12*, 106–113.
5. Husson, O., Thong, M. S. Y., Mols, F., Oerlemans, S., Kaptein, A. A., & Lonneke, V. P. F. (2013). Illness perceptions in cancer survivors: What is the role of information provision? *Psychooncology, 22*, 490–498.
6. de Nooijer, J., Lechner, L., & de Vries, H. (2001). Help-seeking behavior for cancer symptoms: Perceptions of patients and general practitioners. *Psychooncology, 10*, 469–478.
7. Scharloo, M., de Jong, R. J. B., Langeveld, T. P. M., van Velzen-Verkaik, E., Doorn-Op den Akker, M. M., & Kaptein, A. A. (2010). Illness cognitions in head and neck squamous cell carcinoma: Predicting quality of life outcome. *Supportive Care in Cancer, 18*, 1137–1145.
8. Akechi, T., Okumura, T., Endo, C., Sagawa, R., Uchida, M., Nakaguchi, T., et al. (2011). Patient's perceived need and psychological distress and/or quality of life in ambulatory breast cancer patients in Japan. *Psychooncology, 20*, 497–505.
9. Applegate, J. L., & Sypher, H. E. (1988). A constructivist theory of communication and culture. In Y. Y. Kim & W. B. Gudykunst (Eds.), *Theories in intercultural communication* (pp. 41–65). Beverley Hills, CA: Sage.
10. Cimprich, B., Ronis, D. L., & Martinez-Ramos, G. (2002). Age at diagnosis and quality of life in breast cancer survivors. *Cancer Practice, 10*, 85–93.

11. Tazaki, M., & Nakane, Y. (1997). WHO QoL-26 Reyou no tebiki [WHO QoL-BREF Manual]. Tokyo: Kanekoshobo.

12. Tsuchiya, M. (2007). *Development of a new quality of life measure for Japanese breast cancer patients with lymphedema*. Southampton: University of Southampton.

13. Tsuchiya, M. (2012). Development of the arm lymphedema physical discomfort scale: Validity and reliability testing with Japanese breast cancer survivors. *The Japanese Journal of Health Psychology, 25*, 74–82.

14. Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics*. Boston: Pearson Education Inc.

15. Engel, J., Kerr, J., Schlesinger-Raab, A., Eckel, R., Sauer, H., & Hölzel, D. (2003). Predictors of quality of life of breast cancer patients. *Acta Oncologica, 42*, 710–718.

16. Kerr, J., Engel, J., Schlesinger-Raab, A., Sauer, H., & Hölzel, D. (2003). Communication, quality of life and age: Results of a 5-year prospective study in breast cancer patients. *Annals of Oncology, 14*, 421–427.

17. Thewes, B., Butow, P., Zachariae, R., Christensen, S., Simard, S., & Gotay, C. (2012). Fear of cancer recurrence: A systematic literature review of self-report measures. *Psychooncology, 21*, 571–587.

18. Williams, A. F., Moffatt, C. J., & Franks, P. J. (2004). A phenomenological study of the lived experiences of people with lymphedema. *International Journal of Palliative Nursing, 10*, 279–286.

19. Tsuchiya, M., Horn, S., & Ingham, R. (2012). Development of the psycho-social discomfort scale (PsDS): Investigation of psychometric properties among Japanese breast cancer survivors. *Psychooncology, 21*, 161–167.