

ARM SYMPTOMS AND QoL IN JAPANESE BREAST CANCER PATIENTS

Miyako Tsuchiya, Sandra Horn, Roger Ingham

Abstract

Background: Post-operative arm complications among breast cancer patients are relatively underestimated in clinical settings, but the symptoms may affect quality of life (QoL). **Aims:** To assess the relationships between lymphoedema symptom-related variables and QoL among Japanese women with breast cancer who had undergone surgery. **Methods:** A cross-sectional postal survey investigated the relationships between post-operative arm symptom-related variables (specific arm symptoms, physical discomfort, lymphoedema therapy, self-care and years since the onset of symptoms) and QoL. Self-reported questionnaires, including a standardised QoL measure (WHO QoL-BREF Japanese version), were administered to Japanese women with breast cancer. Of 300 respondents, 138 women who reported arm symptoms on the arm of the operated side were eligible for statistical analysis. **Results:** Pain, arm weakness, poor range of motion and more severe physical discomfort affected physical well-being. Pain and more severe physical discomfort affected psychological well-being, whereas swelling did not affect any domains in the WHO QoL-BREF. Other variables did not affect any domains in this sample. **Conclusions:** Symptoms other than swelling should not be underestimated in clinical settings. **Declaration of interest:** None.

Key words

Post-operative arm complications
Breast cancer (BC)
Quality of life (QoL)
Japan

A cross-sectional postal survey was conducted in Japan to investigate the relationships between arm symptom-related variables and quality of life (QoL) among Japanese women with breast cancer (BC) who had undergone surgery. Symptoms other than swelling (pain, loss of strength and poor range of motion) and discomfort in daily activities affected physical well-being, and pain and discomfort also affected psychological well-being.

Miyako Tsuchiya is Research Student, Sandra Horn is Lecturer, Roger Ingham is Professor in Health and Community Psychology at the School of Psychology, University of Southampton, Southampton

The surgical treatment of breast cancer has improved in sophistication, so most women with early BC no longer undergo radical mastectomies. However, axillary lymph node dissection (ALND), rather than sentinel lymph node biopsy (SLNB), is still widely recommended to check patients' prognosis, especially in Japan. ALND and radiotherapy following breast-conserving surgery have been identified as

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risk factors for secondary lymphoedema (Johansen et al, 2000). In other words, most women with early BC have lower odds of losing an entire breast, but they have an increased probability of acquiring other treatment-related chronic conditions.

BC treatment may affect the lymphatic system because it leaves

scar tissue that can cause blockages, and this may increase the chances of infection and inflammation (Harris et al, 2001); the affected area of swelling is so stretched that it is vulnerable to damage by everyday activities. Several studies have reported that more than half of respondents with BC who have undergone surgery complain of post-operative arm complications (Bosompra et al, 2002; McPhail and Wilson, 2000; Taylor 2004), and that the most commonly reported complication is numbness, with the least common being swelling (McPhail and Wilson, 2000). Pain, including heaviness and tightness, has also been reported (Moffatt et al, 2003).

Some studies have consistently reported that the onset of arm complications after breast surgery may affect QoL. Engel et al (2003), who conducted a prospective study in Germany, found that BC patients with arm complications reported worse QoL scores than those without in all the domains (measured by the European Organization for Research and Treatment QLQ-C30), and that

this pattern was persistent over five years.

Additionally, it has been documented that specific arm symptoms, such as pain, may affect QoL among patients with lymphoedema. Moffatt et al (2003), who conducted a cross-sectional study among lymphoedema patients, reported that respondents with pain had worse physical, emotional, social and physical functioning scores (measured by SF-36) than those from the general UK population. The association between pain and QoL has, for example, been reported among BC patients with lymphoedema (Velanovich and Szymanski, 1999).

In spite of the evidence, complaints that are relatively subjective are often underestimated in clinical settings, and adequate information and care provision tend to be delayed in some countries (Lee et al, 2001; Moffatt et al, 2003, Tsuchiya et al, in press). To improve care, early detection of symptoms is important so that doctors can provide appropriate treatment without delay. If therapies are not available at their own hospitals or clinics, doctors should refer patients to specialists who can provide the necessary care — such as manual lymphatic drainage (MLD), bandaging, and the use of compression sleeves — since it is considered important to contain the condition (Moffatt, 2006). On the other hand, there might be patients with minor conditions for whom intensive therapy is not necessary. These patients, however, need reassurance and empathy (Carter, 1997; Williams et al, 2004) and informational support about self-care management from doctors (Tsuchiya et al, in press). In this study it was hypothesised that symptom management might affect patients' QoL.

From a careful review of the literature, it was found that few studies have been conducted in Japan and that lymphoedema-related information was minimal regarding, for example:

- ▶ The types of arm complications most often complained about
- ▶ The amount of discomfort patients experience as a result of complications

- ▶ The lymphoedema therapies patients have actually received
- ▶ The types of self-care management patients have used
- ▶ The length of time that patients have had the complications
- ▶ The effect of these variables on patients' QoL.

The objectives of this study were to gather the descriptive information and to investigate the relationships between post-operative arm symptom-related variables and QoL among female BC patients who had undergone surgery using a standardised QoL questionnaire.

To improve care, early detection of symptoms is important so that doctors can provide appropriate treatment without delay. If therapies are not available at their own hospitals or clinics, doctors should refer patients to specialists who can provide the necessary care.

Method Procedure

The study protocol was approved by the ethics committee of the School of Psychology, University of Southampton and every coordinator of the self-help groups that agreed to participate. These were based in the eastern, western and southern areas in Japan. Thirty-three community-based BC self-help groups across Japan (the northern, eastern, western, southern areas) were selected and invited to participate in this study. Community-based self-help groups are voluntary organisations run by patients. Some groups include patients' families, women with ovarian/uterus cancer and healthy people who wish to support such group's activities, as well as people with BC. Participants were recruited from seven BC self-help groups that agreed to participate. A cross-sectional postal survey study was conducted. The aim was to collect varied information about demographics and medical treatment,

rather than information associated with a specific hospital's practice.

The inclusion criteria were that the women should have undergone breast surgery and be more than 20 years old. Since the group coordinators could not technically select and exclude patients with other than BC from their member lists, a questionnaire package was distributed to all members (n=620), including 12 patients with ovarian and uterus cancer, by the group coordinators. The authors did not have access to member lists. An enclosed letter clearly stated that Japanese women were being recruited who had undergone breast surgery. BC patients were asked to return questionnaires to either their group offices or the first author, using the stamped addressed envelopes provided. Incentives were provided to participants who returned their completed questionnaires (500 yen book tokens, approximately 4.2 US dollars).

Measure

Demographics, breast cancer and lymphoedema treatment-related information

Demographics, including age, marital status, number of children, level of education, employment, and spoken language were assessed by a self-reported single item (i.e. one question, rather than by using scales which are constructed by several items). BC-related information, including the date of breast surgery, side, type of surgery, adjuvant therapy and stage were also assessed by a self-reported single item. Arm therapy by doctors or specialists and self-care management were assessed by a self-reported single item.

Arm lymphoedema symptom check list and arm lymphoedema physical discomfort scales

Following a comprehensive literature review and a preliminary qualitative study (Tsuchiya et al, in press), a self-reported arm lymphoedema symptom checklist and arm lymphoedema physical discomfort scales (ALPDS) were designed for this study. The checklist comprised eight items on dichotomous and polytomous categorical responses, the eight items being:

- ▶ Post-operative arm complications

- ▶ Affected arm side
- ▶ Pain
- ▶ Swelling
- ▶ Numbness
- ▶ Loss of strength
- ▶ Poor range of motion
- ▶ Duration.

Face validity was confirmed among female BC patients with lymphoedema (n=10). Test-retest reliability was investigated after a one-month interval (n=53) using Cohen's Kappa (K)=0.49-0.95 and weighted Kappa quadratic (Kwq)=0.60.

The ALPDS comprises a one-item global scale and six items on a five-point faces scale, the six items being: paid work, household chores, grooming, hobbies, sleeping and meeting somebody. The faces scale ranges from a big smiling face (the lowest discomfort score of 1) to a crying face (the highest discomfort score of 5). Face validity was also confirmed among female BC patients with lymphoedema (n=10). A factor analysis extracted one factor accounting for 56.1% of the variance, and internal consistency (Cronbach's Alpha) was 0.83 (n=100), which was clinically good (Cicchetti and Sparrow, 1990). A confirmatory factor analysis was performed on the present study sample by SAS (version 9.1), and Cronbach's Alpha was 0.79. Test-retest reliability (intra-class correlation) was 0.70, which was clinically good (Cicchetti, 1994). High scores in the ALPDS indicate more severe discomfort.

Quality of Life measure

QoL was measured by the World Health Organization (WHO) QoL-BREF Japanese version, a standardised generic measure (Nakane et al, 1999). One of the merits of using a generic measure is that researchers can compare the QoL scores among patients with other chronic illnesses or a healthy population. WHO QoL-BREF contains the global score (two items) and four domains (physical, seven items; psychological, six items; social, three items; environmental, eight items), and they are assessed by five-point scales. High scores indicate good QoL. A report (Skevington et

al, 2004) has shown that the internal consistency among the Japanese population was good (Alpha=0.71, 0.75, 0.66 and 0.75).

Data analysis

Inclusion criteria for statistical analysis were pre-determined:

- ▶ Female Japanese women who were aged twenty years and over and had undergone breast surgery
- ▶ Those who had reported arm symptoms on the arm of the operated side
- ▶ Those with stage I, II and III BC.

After exclusion of missing values (<5%), descriptive statistics were performed to assess sample characteristics. Next, normality and homogeneity of variance were assessed, and bivariate analyses (one-way analysis of variance [ANOVA] and the Mann-Whitney U test when the assumption of homogeneity of variance was violated) were performed to investigate the relationships between QoL scores and pre-determined independent variables, namely: the specific arm symptoms; physical discomfort in daily activities (ALPDS); doctors' arm therapy; self-care performance; and years since the onset of the symptoms. Since the authors were interested in how the independent variables affected each domain in the WHO QoL-BREF, several mean tests were performed. Scores in the ALPDS were dichotomised by the median. Finally, interaction effects were examined using a two-way ANOVA between the independent variables that yielded significant results in the bivariate analyses and years since breast surgery. All the statistical analyses were performed using the Statistical Package for Social Science version 11.5 (SPSS Inc, Chicago IL, USA). The statistical significance level adopted was 0.05.

Results

Participants

A total of 300 BC patients returned questionnaires (response rate of 49.3%) to either their group offices or the first author. Of the sample of 300, 186 participants (62%) reported the

presence of arm symptoms on the arm of the operated side. After exclusion, 138 participants' data were eligible for analysis.

The mean age was 56.1 years (age ranged from 31 to 84 years, SD=8.3). Most were married (rounded to 79%) with children (77%), and 42% had completed high school education. Sixty-four per cent of participants did not have a paid job. Most participants (81%) were at an early stage of BC (stages I and II). More than half of the participants (57%) had undergone mastectomies, and most participants (93%) had undergone ALND. Thirty-nine per cent had received radiotherapy, 57% had received chemotherapy, and 74% had received hormonal therapy after breast surgery. The mean number of years since surgery was 5.4 (years ranged from 0.6 to 43, to SD=5.5).

Post-operative arm symptoms

The most frequently reported arm symptom was numbness (21%) and the least reported was pain (1%) (Figure 1). Other symptoms included loss of strength (20%) and swelling (20%). Sixty-one per cent had had the arm symptoms for less than three years (Figure 2). The variable (time since the onset of arm symptoms) is categorical, a range and SD is not included here. Thirty-one women (23%) were diagnosed with lymphoedema, mostly by inspection and palpation. Sixty women (44%) had undertaken arm therapy from doctors (exercise, 27%; MLD, 22%; skin care, 15%; compression sleeves, 15%) (Figure 3). More than half the participants (67%) had performed self-care management (massage, 47%; exercise, 36%) (Figure 4).

Quality of life

Table 1 shows the results of the bivariate analysis. Women who had had pain on the arm reported significantly worse physical domain scores (M=23.21) than those who had not (M=26.08), and worse psychological domain scores (M=20.19) than those who had not (M=21.68). Women who had felt the arm weaken reported significantly worse physical domain

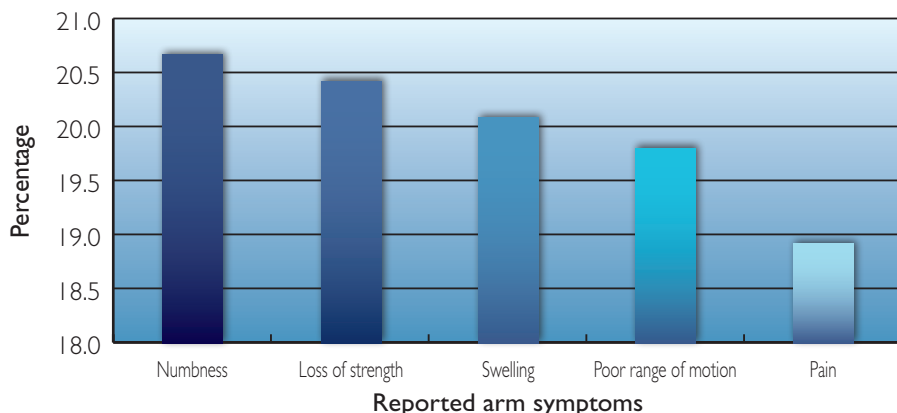


Figure 1. The percentage of reported post-operative arm symptoms.

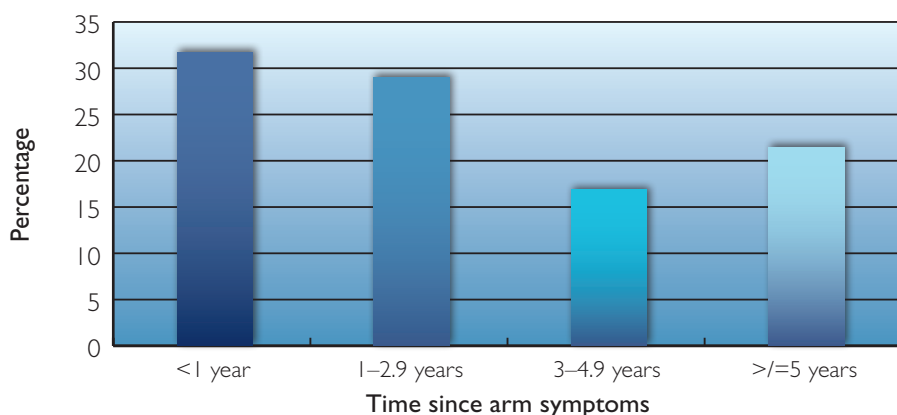


Figure 2. The percentage of years since the onset of post-operative arm symptoms.

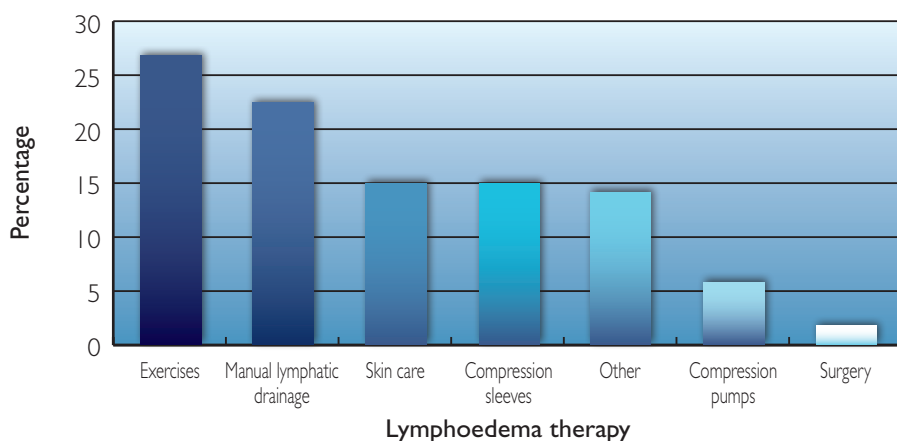


Figure 3. The percentage of types of arm therapy provided by doctors or specialists.

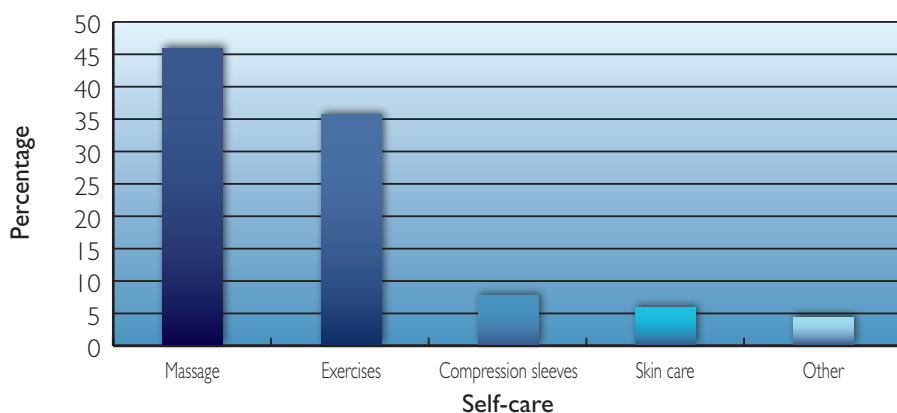


Figure 4. The percentage of types of self-care management.

scores (M=23.99) than those who had not (M=25.55). Women who had poor range of motion reported significantly worse physical scores (M= 23.94) than those who had not (M=25.55). Women who experienced more severe physical discomfort in daily activities reported significantly worse physical domain scores (M=23.84) than those who had not (M=25.89), and worse psychological domain scores (M=20.34) than those who had not (M=21.80). Neither the symptom management nor time since the onset of arm complications affected any domains in this sample.

Two-way ANOVA revealed that there were no interaction effects between the significant variables, the variable years since surgery and the QoL scores in this sample.

Discussion

In this study, about 60% of respondents reported post-operative arm complications, and the most frequently reported problem was numbness (McPhail and Wilson, 2000; Taylor, 2004), although the percentages of reported loss of strength and swelling were quite similar to that of numbness. The least frequently reported problem was pain. However, the mean difference in QoL scores showed that reported pain significantly affected both physical and psychological well-being, a finding that is consistent with previous studies (Moffatt et al, 2003). Additionally, physical discomfort in daily activities, loss of strength and poor range of motion affected physical well-being, whereas neither reported numbness nor swelling affected any WHO QoL domains. It was assumed that some differences would be found between women who had taken up arm therapy by doctors and those who had not, and women who had performed self-care management and those who had not. However, these variables did not affect any QoL domains in this sample. It was also assumed that some symptoms, for example, the sensation of pain and numbness would gradually diminish as time since breast surgery passed. However, the effects of the symptoms and discomfort on the QoL scores did not significantly differ between less

Table 1

Bivariate analysis: the arm symptom-related variables and QoL (WHO QoL-BREF)

	WHO-phy		WHO-psy		WHO-soc		WHO-env	
	F	M (SD)	F	M (SD)	F	M (SD)	F	M (SD)
Pain	15.08***		5.36*		3.29		3.39	
Presence		23.21 (4.15)		20.19 (3.78)		10.35 (1.75)		26.66 (3.76)
Absence		26.08 (4.45)		21.68 (3.75)		10.86 (1.49)		27.93 (4.26)
Swelling	0.17		0.57		0.63		0.51	
Presence		24.62 (4.53)		20.76 (3.98)		10.52 (1.51)		27.62 (3.98)
Absence		24.94 (4.57)		21.25 (3.68)		10.74 (1.73)		27.13 (4.18)
Numbness	0.30		-1.96 ^a		1.36		-0.20 ^a	
Presence		24.57 (4.13)		21.65 (3.26)		10.79 (1.64)		27.31 (3.37)
Absence		25.00 (4.91)		20.40 (4.23)		10.47 (1.60)		27.41 (4.69)
Loss of strength	4.20*		2.75		-1.59 ^a		1.12	
Presence		23.99 (4.90)		20.46 (3.92)		10.22 (1.72)		26.99 (4.04)
Absence		25.55 (4.05)		21.54 (3.68)		11.01 (1.44)		27.72 (4.11)
Poor range of motion	4.44*		1.92		0.10		0.08	
Presence		23.94 (4.53)		20.54 (4.06)		10.58 (1.78)		27.26 (3.86)
Absence		25.55 (4.43)		21.44 (3.57)		10.67 (1.48)		27.45 (4.29)
ALPDS	7.36**		5.15*		2.74		0.62	
<13		25.89 (4.27)		21.80 (3.54)		10.88 (1.46)		27.66 (3.92)
>/=13		23.84 (4.57)		20.34 (3.95)		10.42 (1.74)		27.011 (4.22)
The duration	0.06		0.00		-1.59 ^a		0.13	
<3 years		24.71 (4.33)		21.00 (3.70)		10.58 (1.76)		27.26 (3.90)
>/=3 years		24.91 (4.88)		21.04 (4.04)		10.70 (1.40)		27.52 (4.37)
Doctor's therapy	-0.06 ^a		0.17		0.42		0.00	
Yes		24.73 (4.98)		21.17 (3.71)		10.73 (1.53)		27.37 (4.05)
No		24.83 (4.19)		20.90 (3.93)		10.55 (1.70)		27.36 (4.12)
Self-care	1.92		0.60		0.07		0.00	
Yes		24.42 (4.62)		20.84 (3.96)		10.66 (1.56)		27.35 (4.43)
No		25.56 (4.30)		21.38 (3.54)		10.58 (1.76)		27.38 (3.27)

Note: WHO-py = the physical domain; WHO-soc = the social domain; WHO-env = the environmental domain

^a = z score (the Mann-Whitney U test); * = <0.05; ** = <0.01; *** = <0.001

than and more than three years since surgery.

It was not clear why the symptoms did not affect the social and environmental domains in this study, however, the median score of ALPDS, physical discomfort of arm complications were mild, and participants may have perceived that physical symptoms and

discomfort were not severe enough to seek help. This perception may be related to the QoL scores. Additionally, since respondents were members of self-help groups where MLD workshops were sometimes held and additional information was provided, they may have obtained social support relatively easily. This circumstance may affect the QoL scores.

Care provision

In this sample, 23% of participants were diagnosed with lymphoedema by doctors. This percentage almost matched that of self-reported swelling (20%). The dominant diagnosis procedure was both inspection and palpation, which meant that when BC patients sought help, doctors tended to focus on one symptom, i.e. swelling,

and so lymphoedema was the clinical diagnosis.

The percentage of participants who had taken up arm therapy by doctors or specialists was nearly twice that of those who were diagnosed with lymphoedema, which meant that some care was provided for patients without lymphoedema. However, it was unclear whether the patients had received adequate social support from a breast cancer specialist doctor, from whom they needed expert help (Tsuchiya et al, in press; Williams et al, 2004). Again, because of the nature of the self-help groups, it was unclear whether doctors referred the patients to a rehabilitation unit, or the patients found a clinic where appropriate care was provided through self-help groups. Experiences since the onset of arm symptoms, including help-seeking behaviours, should be explored fully to improve patient care.

Methodology

There was a relatively low response rate (49.3%) in the studies (although in the authors' experience not low in comparison to many other postal surveys). It might be helpful to follow up non-respondents and to examine any differences of characteristics between respondents and non-respondents. However, it was not feasible in this study. Additionally, the entire sample was drawn from self-help groups, and they might differ from patients who had not joined such groups (Grande et al, 2006). Further, a random sampling method was not applied. Due to these factors, the results cannot be generalised and applied to all BC patients in Japan.

Furthermore, the study investigating QoL was cross-sectional so that the direction of causality could not be confirmed, and the study focused only on the relationships between the reported specific arm symptoms, arm complication-related variables and QoL. Objective lymphoedema diagnosis or objective measurement should be included in future studies. Other factors, such as demographics and BC treatment, that might be important predictive factors of QoL

in the patients, were not included. A prospective study and multivariate analysis including all potential predictors needs to be carried out.

Conclusions

Several types of arm symptoms — pain, loss of strength and poor range of motion — and discomfort in daily activities affected physical well-being, and pain and discomfort affected psychological well-being in this sample of Japanese women. Arm symptoms other than swelling should be considered when BC patients seek help. **JL**

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Key points

- ▶▶ A cross-sectional postal survey was conducted in Japan.
- ▶▶ Around 60% of respondents with breast cancer reported post-operative arm symptoms.
- ▶▶ Reported pain and discomfort in daily activities significantly affect both physical and psychological quality of life scores
- ▶▶ Effects of symptoms other than swelling should be considered in clinical settings.