

## IMPAIRMENTS, ACTIVITY LIMITATIONS AND PARTICIPATION RESTRICTIONS 6 AND 12 MONTHS AFTER BREAST CANCER OPERATION

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**Objective:** To describe the impairments of upper body and limbs, activity limitations and participation restrictions 6 and 12 months after operation for breast cancer and to examine the impact of impairments on activity limitations.

**Design:** A prospective survey 6 and 12 months after operation.

**Patients:** Ninety-six breast cancer patients.

**Methods:** A questionnaire for assessing the impairments, activity limitations and participation restrictions was developed.

**Results:** The most common impairments 6 months after operation were breast and axilla scar tightness, axilla oedema and neck-shoulder pain. At 12-month follow-up the breast scar tightness ( $p = 0.008$ ) and axilla oedema ( $p = 0.023$ ) decreased, and limb ache ( $p = 0.005$ ) increased significantly. The most limiting impairments were axilla oedema and limb numbness 6 months after operation, and at 12-month follow-up axilla oedema. Lifting, carrying and reaching out caused worsening of impairments to more than half of the respondents at 6-month follow-up. Regression analysis showed that many impairments together were determinants of activity limitations and sleep impairment. Participation restrictions were constant. Respondents had not given up participation in activities in the home, but some had abandoned leisure activities and felt that their work ability had decreased.

**Conclusion:** Impairments and their impact on activities were frequent and constant. There is an urgent need for developing rehabilitation protocols for breast cancer patients.

**Key words:** impairment, body structure and function, activity limitation, participation restriction.

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### INTRODUCTION

Breast cancer is the most common cancer among women. Lately, the number of survivors has increased because of advances in early detection and treatment. Short recovery times and the best possible functioning of patients after breast cancer

operations should be the key interests of rehabilitation. Most studies in the field of breast cancer rehabilitation still have a major concern with impairments, although a shift of interest is gradually taking place towards broader conceptualization of the aspects of health. The International Classification of Functioning, Disability and Health (ICF), published by WHO (1), forms the framework of this report.

Post-treatment impairments in upper limb and upper body structure and function consist, for example, of upper limb oedema, decreased shoulder mobility, neural tissue injuries causing sensory and motor dysfunction and pain. Both radiotherapy and surgery are associated with a range of long-term treatment-related morbidities (2, 3).

One of the most common impairments is lymphoedema of the upper limb, which can develop as a result of the interruption of lymphatic flow from post-surgical, post-radiation and infectious causes (4). Loudon & Petrek (4) reported that the incidence of lymphoedema varied from 6% to 30% after breast cancer treatment. Similarly, the incidence of impaired shoulder movements shows a lot of variability, ranging from 1.5% to as high as 50% (5–11). However, most of the studies concerning post-operative incidence of impaired shoulder movements show an increase in the range of motion during the follow-up (5–7). Both impaired shoulder movements and lymphoedema of the upper limb are more common after mastectomy than after a breast saving operation (3, 6, 8).

Muscle weakness of the upper limb has been found among 18–23% of patients (10–12). Thirteen percent of patients experience weakness 2 years after operation (5). The weakness can also progress and lead to loss of hand function. Post-surgery pain has not, until recently, been a particular concern of rehabilitation. In the studies reviewed by Rietman et al. (13), the prevalence of pain ranged from 12% to 51% 1 year or more after treatment. Up to one-third of patients experienced some pain in the arm even after 5 years (9). Tasmuth et al. (14) found that chronic pain had a significant correlation with other post-treatment symptoms, such as oedema, parasthesia, strange sensations and phantom pain. Pain with values more than 50 mm on the visual analogue scale (VAS) influenced daily activities severely and values between 30 and 50 mm had a moderate effect (9). The incidence of the most common sensory disturbance, numbness, varies from 29% to 81% (5, 15–17) among breast cancer patients after the operation. The incidence of objectively measured numbness decreased very little in 1 year (6).

In contrast to impairments in body functions and structures, little is known about activity limitations and participation restrictions and there is therefore an apparent need for such studies. This has also been shown in the systematic review by Rietman et al. (13). They found only a few studies, published over the last 20 years, investigating late morbidity of the upper limb in relation to daily activities and quality of life. In the more recent cross-sectional study of 55 breast cancer patients, Rietman et al. (2) reported that almost 3 years after treatment pain had a strong relationship to perceived disability and health-related quality of life (RAND-36). While this study lacked baseline assessment and had a relatively small study sample, further studies are required with larger samples and follow-ups. Little is known of how the operation type affects activity limitations and participation restrictions. Gosselink et al. (3) reported that Modified Radical Mastectomy (MRM) patients suffered from greater functional limitations, concerning the ADL of the upper limb, than did Breast Saving Operation (BSO) patients.

Pain-related disability, based on self-evaluation, has been reported in a few studies (14, 18), but the level of functioning has not been assessed systematically. Studies show that patients with arm swelling experienced considerable activity limitations in home and work environments (14, 18–21). Limited shoulder movements and numbness seem to increase self-assessed activity limitation (21). Woods et al. (20) reported self-assessed participation restrictions in breast cancer patients with upper limb oedema and difficulties in functioning in the home and at work.

Lash & Sillman (22) reported that upper-body dysfunction can affect breast cancer patients sooner or later after operation, and that upper-body function should be followed and appropriate intervention planned for at least 2 years.

The primary aim of this prospective survey was to describe the impairments of upper body and limb functions and structures among breast cancer patients. In addition, the impact of impairments on activity limitations and participation restrictions experienced by breast cancer patients at work, in the home and in leisure activities was examined 6 and 12 months after the operation. Secondary aims were to identify the effects of age, operation type and adjuvant treatments on the impairments, limitations and restrictions.

## MATERIAL AND METHODS

### *Patients*

The cohort study population comprised 110 patients with breast cancer from Satakunta district, Finland. Breast cancer operations were carried out in 3 hospitals. Two of these were district hospitals and 1 was a central hospital. Patients had undergone surgery for breast cancer during the previous year, 1996–97. The criteria for exclusion from the study were subsequent local recurrence of breast cancer, acute psychiatric illness, other severe disease and hospitalization. In addition 1 patient's records contained no contact address and 6 patients had died before the survey was to be carried out. The breast cancer age-adjusted incidence rate in the Satakunta district in 1997 was 78.9 per 100,000 persons and mean annual number of new cases in 1995–99 in this area was 149. The age-adjusted mortality ratio per 100,000 persons in 1997 was 16.3 (23).

### *Data collection*

Data were collected by questionnaire 6 and 12 months after surgery. If no correspondence was received within 2 weeks, a second questionnaire was sent. Patients' medical records were used for more detailed information on surgery, length of hospitalization, drainage time, post-operative treatment (radiotherapy, chemotherapy, hormonal therapy) and post-operative physiotherapy.

*Questionnaires.* The questionnaire included closed- and open-ended questions. Completing the questionnaire took 15–20 minutes.

In the first questionnaire basic data were collected with questions concerning;

- type of surgery
- axillary dissection
- postoperative treatment, duration of hospital stay, drainage duration
- handedness and the side of the operation
- number of aspirations
- social situation (in work, pensioned, on sick leave)
- participation in an adaptation course for cancer patients

Participation in an adaptation course is based on the patient's needs and there are numerous official courses. The main aims of these courses are to enhance the psychosocial rehabilitation of the patients and to facilitate the coping skills of the patient and relatives.

The second questionnaire updated the treatment received, the social situation and participation in the adaptation course during the 6 months following the first survey. Patients were also questioned about weight and height, body mass index (BMI) being calculated based on these. Self-reported weight changes were also surveyed.

### *Impairments of body functions and structures*

Impairments in functions and structures of upper limb, axilla, shoulder joint, breast and neck area were surveyed. In the questionnaire patients were asked to mark the impairment or impairments they experienced from the list. The list included:

- shoulder movement restriction
- upper limb oedema
- axilla oedema
- tightness of scar tissue in axilla
- tightness of scar tissue in breast area
- neck-shoulder pain
- upper limb numbness
- upper limb ache
- upper limb weakness
- pain in the operated breast area
- other; patient could define these

Severity of impairments was surveyed by modified VAS for Breast Cancer Patients (Table I). The scale's alternatives were formed based on the impairment list, and 9 items were formed. On 100-mm VAS, with anchor points 0 (no pain or no difficulty) and 100 (worst possible pain or limitation), the patient marked the level of experience of the item. The reliability of the VAS has been tested and is reported to be high when used repeatedly with the same person (24). McQuay & Moore (25) used individual patient data from 1080 patients to define points for moderate pain and severe pain on a VAS. A VAS score in excess of 30 mm should be considered moderate and in excess of 54 mm severe. VAS scales are considered as tools for assessment of quality of life issues.

In Table I the ICF codes of Body functions domain are included in the items surveyed.

### *Activity limitations and impairments of sleep functions measured by modified Behavioural Rating Scale*

The Scale for Breast Cancer Patients was developed based on the Oswestry Low Back Pain Disability Questionnaire. Its criterion-related validity, discriminant validity, internal consistency and construct validity have been studied (26). The Questionnaire was shown to be an acceptable instrument, with some evidence of criterion-related and factorial validity and moderately high internal consistency ( $\alpha = 0.76$ ) (26).

In this study a modified Behavioural Rating Scale was used. In the

Table I. Modified VAS for patients with breast cancer

Items	Scales
How bad is your pain on the operated breast area? b28018	No pain ————— Worst possible pain
How bad is your pain on the axilla area? b28018	No pain ————— Worst possible pain
How bad is your neck-shoulder pain? b28010	No pain ————— Worst possible pain
How bad is your upper limb ache of the operated side? b28014	No ache ————— Worst possible ache
If you have upper limb oedema of the operated side, how limiting is the oedema? b4352	No limitation ————— Worst possible limitation
If you have axillary oedema of the operated side, how limiting is the oedema? b4352	No limitation ————— Worst possible limitation
If you have shoulder movement restriction, how limiting is restriction? b7100	Doesn't limit the use of the upper limb ————— Prevents the normal use of the upper limb
If you have upper limb numbness of the operated side, how limiting is it? b265	No limitation ————— Worst possible limitation
If you have upper limb weakness of the operated side, how limiting is it? b7301	Doesn't limit the use of the upper limb ————— Prevents the normal use of the upper limb

modification only valid and reliable test items found in earlier studies were included in the test (14, 18, 19–22, 27). Personal care has been partially reported in some studies as relating to the patient's ability to use the upper limb, e.g. brushing the hair, closing a back zip, reaching overhead, carrying 5 kg and making a bed (22, 28). In this study, we aimed to find out about the limitations on personal care (washing, dressing), using the items of most common activities in a woman's life. Five items were selected, as shown in Table II. The ranking of each item was 1–6, where 1 meant no limitation in this activity or impairments of sleep functions, and 6 meant that the person was not able to carry out the activity or could not sleep. In the table the ICF codes of Activities domain and Body functions domain are shown along the items surveyed.

#### Test-retest consistency of questionnaire

The consistency of results of the questionnaire (paired measurements) was assessed by a pilot study among breast cancer patients operated 6 months previously. Test-retest consistency of the questions was evaluated. The time between test and retest was 1 week.

Reliability analysis showed that the Coefficient Alpha of questions concerning experienced activity limitations and impairments of sleep functions was in the case of the Behavioural Rating Scale for Breast Cancer Patients (Table II) 0.67 (96% CI = 0.37, 0.82), and in case of VAS for Breast Cancer Patients (Table I) 0.90 (96% CI = 0.83, 0.93). The Kappa value of experienced impairments over 1 week by the same subjects was 0.60. The results of test-retest consistency are acceptable for the further use of the questions (29).

Table II. Behavioural rating scale for patients with breast cancer

Activities and sleep function	Ranking; What is the effect of your impairment/s on the activities and sleep function during the last week?
Personal care (washing, dressing, etc.) ICF coding Chapter 5 Self Care d510–570	I can manage these activities without worsening of the impairments I can manage these activities, but my impairments get a little worse When carrying out these activities it causes considerable worsening of impairments I need help, but I can manage most of the activities independently I need help daily in these activities I don't usually dress or wash my self, I mostly stay in bed
Lifting with the upper limb (operated side) ICF coding Chapter 4 Mobility d4300	I can lift heavy loads without hindrance/inconvenience? I can lift heavy loads, but my impairments get slightly worse I can lift heavy loads, but my impairments get considerably worse I cannot lift heavy loads, but I can manage light weights without worsening of my impairments I can lift light loads, but my impairments get worse I cannot lift anything
Carrying with the upper limb (operated side) ICF coding Chapter 4 Mobility d4302	I can carry heavy loads without worsening of my impairments I can carry heavy loads for awhile, but my impairments get slightly worse I can carry heavy loads just for short time and my impairments get considerably worse I can carry light loads without worsening of my impairments I can carry light loads, but my impairments get worse I cannot carry anything
Reaching out above head level (operated side) ICF coding Chapter 4 Mobility d4452	I can reach out over head level without hindrance I can reach out over head level, but my impairments get slightly worse I can reach out over head level, but my impairments get considerably worse I can only use my upper limb under the horizontal level without hindrance I can use my upper limb under the horizontal level, but my impairments get worse I cannot reach out with my upper limb
Sleeping ICF coding Chapter 1 Mental functions b1342, b1340	My impairments do not affect my sleep Because of my impairments my sleep is discontinuous, but I don't use any medication Because of the impairments I use some medication to sleep I use some medication for my impairments, but still I sleep less than 6 hours. I use some medication for my impairments, but I sleep less than 2 hours I cannot sleep because of my impairments

### Participation restrictions

Closed- and open-ended questions were used to examine whether the respondent experienced restrictions at work, in the home and in leisure activities caused by upper limb impairments. If experiencing restrictions the respondents were asked to define them. They were also asked whether they had had to give up or altered their leisure activities after the operation. The ICF codes of Participation domain surveyed were; at work d8451, in the home d630–d649, and in leisure activities d920.

### Ethics

The Social and Health Ministry of Finland approved the protocol of this survey. Patients were provided with written information about the study and were ensured confidentiality, anonymity and freedom to withdraw from the study without prejudicing any future medical care.

### Statistical analysis

Data were analysed using SPSS version 11.0 for Windows. Descriptive statistics were used to describe the demographic and medical data of the cohort collected by questionnaires and from medical records. Differences between operation types were determined by Spearman with non-parametric variables and Pearson correlation with parametric variables. Correlation between other parametric variables and non-parametric variables were also counted. (Age/VAS, impairments/SF-MPQ, adjuvant treatment /impairments, weight changes/impairments, weight changes/ adjuvant therapies).

The Wilcoxon Signed Ranks Test was used for assessment of changes of impairments, and participation restrictions in the home, at work and in leisure activities. Differences between operation types were determined by using one-way ANOVA (oper.type/VAS value, age, hospitalization time, drainage duration). A Paired Samples Test and 95 %CIs were calculated for assessment of changes between VAS-values at 6 and 12 months after operation. The Wilcoxon Signed Ranks Test was used for comparison between different groups. Linear regression analysis was performed by using forward solution and with a ratio of 50 subjects to 1 variable or subsets of variables. Subsets of variables can be used when there is high intercorrelation among variables. By regression analysis the goal was to find out the variable or subsets of variables that will account for the greatest proportion of variance in the dependent variables: activity limitations and sleep disturbances (29–31).

## RESULTS

One hundred and six (96.4%) of the 110 patients returned the first questionnaire. One of them was excluded because of insufficient answers. The second questionnaire was sent out 12 months after the operation to patients who had been included in the first survey ( $n = 105$ ) and 96 (91.4%) patients responded.

Modified radical mastectomy (MRM) was more common with elderly patients ( $r = -0.28$ ,  $p = 0.006$ ). Almost all patients (96.9%) who had undergone a breast saving operation (BSO) had adjuvant therapy and most of them had only radiation therapy. Patients with MRM had more combinations of adjuvant therapy, though again radiation therapy was most commonly used in these combinations. Because the MRM and BSO patients have distinctive disease and recovery profiles, the following results were presented separately for these 2 groups. The demographic and medical data of these 96 respondents in the MRM and BSO patient groups are shown in Table III.

The average length of hospital stay was 4.0 days ( $SD = 1.21$ ). Older patients had significantly ( $r = 0.48$ ,  $p < 0.01$ ) longer hospital stay than younger patients, and the operation type also had an effect on the hospitalization time. Mastectomy patients had a significantly longer hospital stay ( $r = -0.31$ ,  $p = 0.003$ ). Average time for drains was 1.6 days ( $SD = 0.75$ ). The age of the patient ( $r = 0.14$ ,  $p > 0.05$ ) or the type of the operation ( $r = 0.02$ ,  $p > 0.05$ ) did not affect the drainage time.

Six months after operation, 50% ( $n = 16$ ) of BSO patients and 31.3% ( $n = 20$ ) of MRM patients were working (Table III). The number of patients working increased a little in both groups during the follow-up time.

The mean BMI was 27.7 ( $SD = 8.61$ ) at 1-year follow-up.

Table III. Demographic and medical data of study sample ( $n = 96$ ) with modified radical mastectomy (MRM) or breast saving operation (BSO)

	MRM	BSO	Total
Number of patients (%)	64 (66.7)	32 (33.3)	96 (100)
Mean age in years (range)	60.3 (31;86)	53.6 (26;84)	58.1 (26;86)
Work status at 6 months (%)			
Working	20 (31.3)	16 (50)	36 (37.5)
On sick leave	6 (9.4)	2 (6.3)	8 (8.3)
On pension	31 (48.4)	9 (28.1)	40 (41.7)
Students or unemployed	6 (9.4)	4 (15.6)	11 (11.5)
Missing	1 (1.6)		1 (1.0)
Change in work status from 6 months to 12 months (%)			
Working	+3.1	+6.3	+4.2
On sick leave	-7.8	0	-6.2
On pension	+6.3	0	+4.1
Students or unemployed	0	-6.2	-2.1
Number of patients (%) with axillary dissection	60 (93.8)	29 (90.6)	89 (92.7)
Mean number of aspirations (range)	2.2 (0;11)	2.4 (0;10)	2.3 (0;11)
Mean length of hospital stay in days (range)	4.3 (2;7)	3.6 (2;7)	4.0 (2;7)
Number of patients post-operatively instructed by physiotherapist or physiotherapy assistant (%)	52 (81.3)	26 (81.3)	78 (81.3)
Number of patients (%) with adjuvant therapy	45 (70.3)	31 (96.9)	76 (79.2)
Radiation therapy	7 (10.9)	19 (73.1)	26 (27.1)
Chemotherapy	7 (10.9)	0 (0)	7 (7.3)
Hormonal therapy	7 (10.9)	1 (3.1)	8 (8.3)
Radiation therapy + chemotherapy	8 (12.5)	7 (21.9)	15 (15.6)
Radiation + hormonal therapy	13 (20.3)	3 (9.4)	16 (16.7)
Radiation + hormonal therapy + chemotherapy	3 (4.7)	1 (3.1)	4 (4.2)

Table IV. Incidence of impairments of upper body and upper limb and differences between modified radical mastectomy (MRM) (n = 64) and breast saving operation (BSO) (n = 32) groups, 6 and 12 months after breast cancer operation

Impairments of upper body and upper limb	6 months after operation			12 months after operation		
	MRM % (n)	BSO % (n)	Total % (n)	MRM % (n)	BSO % (n)	Total % (n)
<b>Pain</b>						
Breast pain	21.9 (14)	34.4 (11)	26.0 (25)	20.3 (13)	28.1 (9)	22.9 (22)
Neck-shoulder pain	40.6 (26)	34.4 (11)	38.5 (37)	42.2 (27)	37.5 (12)	40.6 (39)
Upper limb ache	12.5 (8)	9.4 (3)	11.5 (11)	26.6 (17)*	15.6 (5)	22.9 (22)**
<b>Tightness</b>						
Breast scar	42.2 (27)	53.1 (17)	45.8 (44)	35.9 (23)	15.6 (5)***	29.2 (28)**
Axillary scar	35.9 (23)	65.6 (21)	45.8 (44)	39.1 (25)	31.3 (10)**	36.5 (35)
<b>Oedema</b>						
Axillary area	45.3 (29)	28.1 (9)	39.6 (38)	28.1 (18)*	25.0 (8)	27.1 (26)*
Upper limb	20.3 (13)	31.3 (10)	24.9 (23)	26.6 (17)	25.0 (8)	26.0 (25)
Shoulder movement restriction	15.6 (10)	18.8 (6)	16.7 (16)	26.6 (17)	15.6 (5)	22.9 (22)
Upper limb weakness	14.1 (9)	15.6 (5)	14.6 (14)	12.5 (8)	28.1 (9)	17.7 (17)
Upper limb numbness	31.3 (20)	43.8 (14)	35.4 (34)	35.9 (23)	25.0 (8)	32.3 (31)
Other; phantom sensation, scar tissue pain, oedema of the operated breast, sensory changes on the operated area etc.	10.9 (7)	18.8 (6)	13.5 (13)	7.8 (5)	37.5 (12)	17.7 (17)

Differences between the incidence at 6-month and 12-month follow-ups.

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

Self-reported increase in weight had taken place in 42.2% of MRM patients and in 28.1% of patients with BSO. Weight had decreased in 15.6% of the MRM patients and in 9.4% of patients with BSO. No significant correlation was found between weight changes and different adjuvant therapies ( $\chi^2 = 9.59$ ,  $p > 0.05$ ).

#### Impairments of upper body and upper limb

The most common impairments that the patients experienced (Table IV) 6 months after operation were breast scar tightness (45.8%), axilla scar tightness (45.8%), axilla oedema (39.6%) and neck-shoulder pain (38.5%). Twelve months after operation the most common impairments were axilla scar tightness (36.5%), limb numbness (32.3%) and neck-shoulder pain (40.6%). In the follow-up, the breast scar tightness ( $p = 0.008$ ) and axilla oedema ( $p = 0.023$ ) had decreased significantly, but limb ache had significantly increased ( $p = 0.005$ ).

MRM patients experienced significantly more breast scar tightness ( $p = 0.039$ ) at 12-month follow-up than BSO patients. Whilst BSO patients experienced other symptoms more ( $p < 0.05$ ) at 12-month follow-up and more axilla scar tightness ( $p = 0.006$ ) at 6-month follow-up than MRM patients.

In the MRM group, axilla oedema decreased ( $p = 0.016$ ) and limb ache increased significantly ( $p = 0.013$ ) during the follow-up time. In the BSO group, patients reported significantly less axilla scar tightness ( $p = 0.002$ ) and breast scar tightness ( $p = 0.001$ ) at 12-month follow-up than at 6-month follow-up.

There were no significant differences between patients with different postoperative adjuvant treatments in the incidence of impairments. Patients with higher BMI experienced upper limb weakness at 12-month follow-up ( $r = 0.22$ ,  $p = 0.033$ ) more often than the thinner subjects.

#### Modified VAS for breast cancer patients

The number of patients filling the Visual Analogue Scale for the worst possible pain or for impairment causing limitation varied from 69 to 79. Based on the VAS (Fig.1), the 2 most limiting impairments at 6-month follow-up were axilla oedema ( $21 \pm 25$  mm) and upper limb numbness ( $22 \pm 25$  mm). The

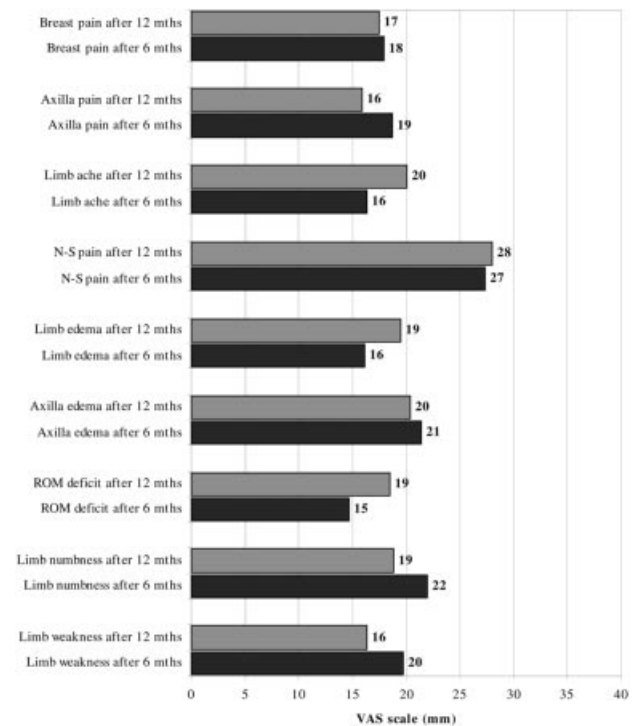


Fig. 1. Modified VAS values breast cancer patients (n = 96) 6 and 12 months after breast cancer operation.

worst pain experienced at 6-month follow-up was neck and shoulder pain, the mean value being 27 mm (SD = 32).

At 12-month follow-up, the most limiting impairment was axillary oedema ( $20 \pm 26$  mm) and the worst pain experienced was still neck and shoulder pain ( $28 \pm 31$  mm).

Even though 5 of 9 items of VAS decreased during the follow-up, only limitation caused by upper limb numbness decreased significantly ( $p = 0.04$ ). The mean relative difference was  $-5.64$  (95% CI =  $-11.03, -0.24$ ). Four items of VAS increased, however, the increases were not significant.

BSO patients experienced at 6-month follow-up significantly more severe axilla pain (95% CI 18.7–39.6) than MRM patients (95% CI 7.6–18.3), ( $p = 0.003$ ). BSO patients also experienced more breast pain (95% CI 15.1–37.6) than MRM patients (95% CI 8.2–19.0) at 6-month follow-up ( $p = 0.022$ ). Lower BMI was associated with more axilla pain ( $r = -0.277$ ,  $p = 0.015$ ) and higher BMI with increased neck-shoulder pain ( $r = 0.263$ ,  $p = 0.024$ ) and more limiting shoulder movement restriction ( $r = 0.238$ ,  $p = 0.049$ ).

#### *Behavioural Rating Scale for breast cancer patients: activity limitations and impairments of sleep functions*

Lifting with the upper limb was limited and caused worsening of the impairments to 59 (61.5%) patients at 6-month follow-up and to 54 patients (56.3%) at 12-month follow-up. Carrying with the upper limb caused worsening of the impairments to 51 (53.1%) at 6-month follow-up and to 47 (49%) patients at 12-month follow-up. Reaching out above head level caused worsening of the impairments to 51 (53.1%) patients at 6-month follow-up and to 41 (42.7%) at 12-month follow-up.

Postoperative impairments were interfering with the sleep of 37 (38.5%) patients at 6-month follow-up and 34 (35.4%) at 12-month follow-up. In personal care, patients experienced fewer problems, only 10 (10.4%) patients had complaints or could not manage themselves at 6-month follow-up. Eight (8.3%) still experienced limitations in personal care at 12-month follow-up.

Although the number of patients complaining about the limitations in daily activities or sleep disturbance decreased during follow-up, the changes were not statistically significant. Age had an effect, younger patients complained of more difficulties in sleeping ( $r = -0.246$ ,  $p = 0.027$ ) because of the impairments and older patients complained of worsening of the impairments when lifting ( $r = 0.235$ ,  $p = 0.032$ ). The operation type had no significant effect on the limitations in daily activities or on difficulties in sleeping.

#### *Participation restrictions*

At 6-month follow-up, 16 (16.7%) patients experienced restrictions at work and at 12-month follow-up 15 (15.6%). Restrictions at home were experienced by 31 (32.3%) patients at 6-month and 12-month follow-ups. Restrictions during leisure activity were experienced by 24 (25%) patients at 6-month follow-up and 16 (16.7%) patients at 12-month follow-up. This change was statistically significant ( $p = 0.02$ ).

At 12-month follow-up, only one respondent stated that she could not carry out all tasks involved in her work, and a few stated ( $n = 3$ ) that they could not carry out the tasks at full capacity. Most of the respondents defining the arm problems at work ( $n = 11$ ) described their experienced impairments in their work, such as weakness, pain, oedema and restriction of movements. None of the respondents ( $n = 31$ ) had given up any home activities totally. Some stated that the arm became tired more easily ( $n = 3$ ), that they could carry out tasks fully ( $n = 3$ ), tasks felt more difficult ( $n = 4$ ) and the tasks increased experienced impairments ( $n = 12$ ). Four respondents had given up all their leisure activities after breast cancer operation and a few stated specific activities that had been given up, e.g. swimming ( $n = 2$ ), cross-country and downhill skiing ( $n = 1$ ). Four respondents also stated that they had reduced their leisure activities, e.g. baking, skiing. Some subjects ( $n = 5$ ) stated that they had continued some activities even though these activities had worsened their experienced impairments, such as upper limb ache, upper limb oedema and axilla oedema.

At 6-month follow-up, 5 patients had participated in an adaptation course and at 12-month follow-up an additional 16 patients had had this possibility. In total, 22.9% of the breast cancer patients participating in this survey had completed an adaptation course during the year after operation. At 12-month follow-up, there were no statistically significant differences in any of the examined factors between the group that had participated in the adaptation course and the one that had not.

Linear regression analysis of factors explaining the activity limitations and impairments in sleep functions examined by Behavioural Rating Scale for Breast Cancer Patients at 6- and 12-month follow-ups are shown in Table V.

Analysis revealed that breast pain, neck-shoulder pain, shoulder movement restriction and younger age were together the best determinants of the sleeping disturbances at 6-month follow-up, accounting for 56% ( $R^2$ ) of the variance of sleeping disturbances. At 12-month follow-up upper limb weakness and shoulder movement restriction together explained 46% of the variance. For limitations in lifting at 6-month follow-up axilla pain, upper limb weakness and oedema were together the best determinant, accounting for 47% of the variance. At 12-month follow-up, the best determinants for lifting limitation were upper limb weakness and ache, explaining 38% of the variance. For limitations of carrying at 6-month follow-up, the best determinants were breast pain and shoulder movement restriction, accounting for 32% of the variance. At 12-month follow-up, upper limb ache and oedema together with older age explained 46% of the variance of limitations in carrying.

## DISCUSSION

In this study, we found that the amount of impairments at 6- and 12-month follow-ups were quite constant. About one-third of the patients still experienced neck-shoulder pain, breast and axillary scar tightness and upper limb numbness 1 year after the operation. Even though in this study the axilla oedema decreased

Table V. Results of linear regression analysis of subsets of variables explaining the activity limitations and sleep impairment at 6- and 12-month follow-ups

Dependent variables	Independent variables impairments, other factors	$\beta$	$R$	$R^2$	$F$
<i>At 6-month follow-up</i>					
Personal care	Breast pain	0.393**	0.393	0.155	10.602**
Lifting with the upper limb	Axilla pain	0.353**			
	Upper limb weakness	0.334**			
	Upper limb oedema	0.254*			
	Axilla pain, upper limb weakness and oedema		0.689	0.465	17.184***
Carrying with the upper limb	Breast pain	0.461***			
	Shoulder movement restriction	0.273*			
	Breast pain and shoulder movement restriction		0.561	0.315	13.103***
Reaching out above the head level	Upper limb weakness	0.387**			
	Upper limb ache	0.288*			
	Upper limb ache and weakness		0.538	0.289	11.789***
Sleeping	Breast pain	0.374**			
	Neck-shoulder pain	0.312**			
	Shoulder movement restriction	0.275**			
	Age	-0.274**			
	Breast and neck-shoulder pain, shoulder movement restriction, age		0.746	0.556	16.919***
<i>At 12-month follow-up</i>					
Personal care	Neck-shoulder pain	0.372**			
	Age	0.331**			
	Neck-shoulder pain and age		0.499	0.249	8.278**
Lifting	Upper limb weakness	0.371*			
	Upper limb ache	0.319*			
	Upper limb weakness and ache		0.621	0.383	15.667***
Carrying with the upper limb	Upper limb ache	0.301*			
	Upper limb oedema	0.393**			
	Age	0.249*			
	Upper limb ache and oedema, age		0.675	0.455	13.364***
Reaching out above the head level	Shoulder movement restriction	0.592***	0.592	0.350	27.506***
Sleeping	Upper limb weakness	0.485***			
	Shoulder movement restriction	0.339**			
	Upper limb weakness and shoulder movement restriction		0.677	0.459	21.200***

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

significantly during the follow-up time (from 40% to 27%), the incidence of upper limb oedema was fairly constant during the 1-year period (25–26%). These findings were somewhat similar to a population-based Australian study (32) where the incidence of upper limb oedema at 1-year follow-up was 20%, but at 4-year follow-up 29%. Compared with the earlier study carried out in Finland by Tasmuth et al. (14), the incidence of oedema in this study was much lower. While the time after operation was the same in both studies and the type of questioning similar, one of the differences seen in the demographic data was that in this study the number of patients receiving radiotherapy was less than in the study of Tasmuth et al. (14). In addition, in this study radiotherapy was not associated with the incidence of oedema, as seen in other studies (5, 12). Neither was the operation type, obesity or older age associated with experienced upper limb oedema in this study.

In line with other studies (6, 13), the incidence of shoulder movement restriction in this study was 23% at 1-year follow-up. Upper limb weakness in this study was reported less frequently than the other common impairments. The incidence of upper

limb weakness seems to vary in the previous studies, and is dependent on the assessment methods as well as on treatment methods of breast cancer (5, 6, 10–12). The most common sensory disturbance, numbness, was also a common impairment in this study. Almost one-third of patients experienced numbness at 1-year follow-up, which was, however, low compared with most other studies (5, 15, 16).

The worst pain experienced 6 months after operation was neck-shoulder pain, with a VAS value of 27 mm. Based on the study of Tengrup et al. (9), pain values less than 30 mm should not affect daily activities significantly. As seen in this study (Table V), most of the activities, except 2 (reaching out above head level and sleeping at 12 months follow-up), were affected by pain symptoms. The pain intensity, of 17 mm, reported by Hack et al. (33) was similar to the axilla and breast pain intensity reported in this study.

Similar to earlier studies (14, 19–21), upper limb oedema was experienced as one of the most limiting impairments at 12-month follow-up. In this study, upper limb numbness was at 6-month follow-up one of the most limiting impairments, as

seen in some other studies (18, 21). However, patients seemed to be able to adjust to the numbness, because self-assessed activity limitation caused by numbness decreased significantly during 1-year follow-up. This result is in line with the study by McCredie et al. (32) where arm numbness of all other symptoms, interfered least in the activities of daily living. Our finding suggests that patients with higher BMI have more neck-shoulder pain and that shoulder movement restrictions are limiting their activities more.

Activity limitations in lifting, carrying and reaching out were experienced by many of the subjects in this study. Although the limitations decreased during the follow-up, the changes were not statistically significant. Similar to the study by Lash & Sillman (22), this study clarifies the activities that are most limited after breast cancer operation. The regression analysis highlights the possible factors that mostly explained activity limitations (Table V). This analysis suggests that most of the impairments experienced by patients also limit activities. At 6-month follow-up and 12-month follow-up, there is an alteration of subsets that mostly explain the activity limitations in the regression analysis. Breast pain, for example, was one of the factors explaining the activity limitations at 6-month follow-up, but not at 12-month follow-up. One explanation could be that the incidence of some impairments increased, for example, limb ache. In addition, there could also have been some adaptation to the impairments.

Less reported in the earlier studies is the sleep function. In this study, impairments were interfering with maintenance of sleep and the amount of sleep among one-third of the patients during the follow-up time. Less affected was personal care (washing, dressing); results showed that most patients were able to carry out personal care, with only a few having limitations.

The information arising from the answers concerning participation at work, in the home and in leisure activities is a little conflicting. Even though the restrictions in the home were constant and greater than at work and in leisure activities, patients had not given up any tasks at home. In leisure activities respondents had given up activities, which could mean narrowing the social participation of respondents. The restrictions at work were constant at 6- and 12-month follow-ups. Some respondents described reduced work ability, which can also lead to earlier retirement and increased sick leave.

It is important to emphasize that many of the impairments considered in this study were still present at the end of this follow-up. In order to assess the consistency of experienced impairments, activity limitations and participation restrictions, longer follow-up should be carried out. In some other studies (11, 12, 16), with longer follow-up time, it has been shown that some impairments persist whilst some new impairments may occur. In addition, the sizes of the adjuvant treatment subgroups were too small for further analysis in this study. For better analysis of the effects of post-operative treatments on functioning of breast cancer patients a larger cohort study should be carried out.

This study used a survey method for collecting data of the

experienced impairments, activity limitations and participation restrictions. Even though those self-reports have good correlation to the measured ones (34), one can argue that more exact data could have been achieved by other, more time-consuming, measurements. However, objective measurements alone would not reflect patients' perceptions of their functioning. Therefore, a combination of reliable objective measurements and patient self-assessment has been suggested (11, 35).

The questionnaire used in this study seemed to be easy to complete, because only 1 of the returned questionnaires had to be excluded. More information concerning the factors affecting the functioning could have been achieved by interviewing those patients with limiting and restricting impairments. Such a questionnaire could be useful for screening breast cancer patients who need rehabilitation.

In this study, the ICF framework was a useful tool for understanding the functioning of breast cancer patients. Activity and participation domains were in this study separated, but more research into the differentiation should be carried out to determine the criteria for the classification as already stated by Jette et al. (36). When comparing this study with previous studies we can assume that with the use of ICF we have managed to achieve enhanced understanding of the process of disablement of breast cancer patients. With ICF we have been able to conclude that without severe impairment there were activity limitations and, on the contrary, having impairments necessarily entail activity limitations or participation restrictions. Experienced impairments did not either lead to similar participation restrictions at work, in the home and in leisure activities. The results of this study suggest that the participation domain should be assessed by using various measures of both performance and capacity: here we narrowed this perspective to the physical dimension of functioning and the questionnaire used can be seen as a performance qualifier.

This study showed that breast cancer patients still had several impairments of upper body and upper limb 1 year after the operation. Many of the patients experienced limitations in activities of daily living and some had disturbances in sleep. These factors might also have a major impact on the quality of life, though the studies concerning the relationship between late morbidity and QOL are few (13) and the QOL was in this study assessed only with VAS and with open-ended questions concerning participation restrictions. A negative association between experienced pain and quality of life has been reported earlier (33).

Inevitably, there is an urgent need for developing systematic rehabilitation protocols for breast cancer patients to support their functioning and to prevent permanent, limiting disabilities that would affect the health condition. Furthermore, these protocols should be specific for breast cancer patients with different operations and postoperative treatment, because the recovery pattern and postoperative impairments are discrete. An effective, individually tailored, evidence-based education and therapy for supporting functioning will enhance working ability and overall wellbeing among breast cancer patients.



The main aim of this study was to examine the consistency of impairments, activity limitations and some participation restriction, concentrating upon the physical functioning of the patient, and to discover the possible critical issues for the follow-up protocol for the assessment of upper limb functioning. The wider rehabilitation concept and plan for each breast cancer patient should also include more information about social and environmental aspects.

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