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Psychological consequences of lymphoedema associated with breast cancer: A prospective cohort study

Ditte Vassard [a,*], *Maja Halgren Olsen* [a], *Line Zinckernagel* [a], *Jette Vibe-Petersen* [b], *Susanne Oksbjerg Dalton* [a], *Christoffer Johansen* [a]

[a] *Department of Psychosocial Cancer Research, Institute of Cancer Epidemiology, Danish Cancer Society, Strandboulevarden 49, DK-2100 Copenhagen, Denmark*
[b] *Health Care Centre for Cancer Survivors, Ryesgade 27, DK-2200 Copenhagen, Denmark*

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ABSTRACT

Background: The aim of this prospective cohort study of women attending a rehabilitation course at the Dallund Rehabilitation Centre was to explore the emotional and psychological aspects of living with lymphoedema, expressed as psychological distress, poorer quality of life and poorer self-reported health.

Methods: Between November 2002 and January 2007 within the FOCARE study, self-completed questionnaires were collected 3 weeks before and 6 and 12 months after the rehabilitation course to elicit sociodemographic, physical and lifestyle information and responses to three psychometric tests. The population consisted of 633 women, 125 with and 508 without verified lymphoedema (time since surgery, 1 month–5 years). The population was reduced to 553 women at the first follow-up and 494 at the second.

Results: Multivariate analysis showed that, in comparison with women without lymphoedema, those with lymphoedema had a 14% higher risk for scoring one level higher on the POMS-SF test, a 9% higher probability of scoring one point lower on the quality of life scale and a 29% higher likelihood of reporting poorer or bad health than women without lymphoedema. These findings were seen at all three measurement times.

Conclusions: In this cohort of women with breast cancer, women with lymphoedema after surgery for breast cancer had significantly worse overall emotional well-being and adjustment to life compared to women without lymphoedema.

1. Introduction

The main symptoms of breast cancer-related lymphoedema are disrupted sensitivity of the upper limb, with sensations of heaviness and tightness, and visible swelling after strenuous activity.[1] Lymphoedema can occur periodically or may be persistent, and the condition may result in pain, discomfort and reduced functioning. Independent of the stage of breast cancer, the prevalence of lymphoedema is 12–60% in women who have undergone surgery for their cancer. Although lymphoedema usually occurs within 12–14 months of treatment,[2] it can develop several years after diagnosis and initial treatment. In four studies published 2002–2008,[2–5] lymphoedema or 'arm problems' were found in 28–54% of women treated for stages II–V breast cancer. Quality of life was assessed in three of these studies,[2–4] with follow-up periods of up to 5 years, and all found significantly lower scores among women with lymphoedema than among those without. Thus, this condition has a considerable influence on quality of life, even several years after treatment.[6]

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* *Corresponding author*: Tel.: +45 42400533; fax: +45 35257731.
E-mail address: vassard@cancer.dk (D. Vassard).

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The study reported here was based on data obtained from women with breast cancer who were recruited at the Dallund Rehabilitation Centre, which is a combined rehabilitation and research centre for people who have been treated for cancer. During a 6-d retreat, people participate in various activities, including lectures about issues in cancer treatment, psychological reactions, working life, lifestyle and physical activity. The aim of research carried out at the Centre is to gain knowledge about life after cancer and thus identify some of the difficulties experienced after the disease and its treatment.[7,8]

Much of the published research about lymphoedema has addressed its physical and functional dimensions or quality of life. A less extensively studied field is the emotional aspect of living with this condition. The primary aim of the prospective study of women with breast cancer attending a rehabilitation course at the Dallund Rehabilitation Centre reported here was to explore the emotional and psychological aspects of living with lymphoedema, reflected as psychological distress, and the secondary aim to explore the effects on quality of life and self-reported health.

2. Materials and methods

2.1. *Participants and intervention*

The participants of this study are a subsample of patients recruited for a larger study aiming to evaluate the long-term effects of a rehabilitation programme for cancer patients, the FOCARE study[7] (in Danish: Forskning i Cancer Rehabilitering/Research in Cancer Rehabilitation). The present study is a comparison of women with breast cancer who report lymphoedema and those who do not report lymphoedema within this cohort. The participants in the FOCARE study were cancer patients who had been evaluated as in need of rehabilitation and referred by a physician (95%), either on their own initiative or suggested by the physician, or had been invited to participate in a randomized trial by the Department of Psychosocial Cancer Research (5%).[9] The present study population consisted of both self-selected patients and patients randomized to the rehabilitation intervention group, thus all participated in the rehabilitation course. The participants had all completed primary cancer treatment and were physically able to participate in the activities.

The course consists of a combination of lectures and group work on themes such as the treatment of cancer, psychological reactions, spirituality, sexuality, working life and lifestyle. The intervention has been described in detail by Høybye and colleagues.[7]

2.2. *Data collection*

2.2.1. *Questionnaires*

All participants in the rehabilitation course were invited to participate in the FOCARE study.[7] Between 25th November 2002 and 11th January 2007, 3013 cancer survivors filled in a baseline questionnaire 3 weeks prior to and 6 and 12 months after the 6-d course. Of these cancer survivors, 1243 (41%) women had been treated for breast cancer. The questionnaire elicited sociodemographic information, including date of birth, marital status, education (basic, youth, higher) and employment status before cancer diagnosis (working, on sick leave or unemployed, pensioner or other). The physical information included body mass index (computed from height and weight: underweight, <18.5; normal weight, 18.5–24.9; overweight, 25–29.9; obese, 30–34.9; extremely obese, >35), occurrence of symptoms and a number of late effects (including swelling of arms and legs) and current lifestyle, i.e. alcohol consumption (U/week), smoking (smoker, non-smoker, ex-smoker) and physical activity (h/week).

The psychometric Quality of Life Questionnaire (EORTC QLQ-C30) developed by the European Organization for Research and Treatment of Cancer (EORTC) is a multidimensional, cancer-specific 30-item quality-of-life questionnaire covering nine subscales of symptoms and function and a derived estimate of global quality of life. The participants expressed their symptom severity and level of function on four-point Likert scales. The QLQ-C30 is widely used and has been found to be sensitive to differences between patients and to changes over time.[10] The degree of emotional distress was measured on the short form of the original Profile of Mood States questionnaire (POMS-SF).[11] The participants responded by endorsing the degree to which 37 adjectives described them during the past week on four-point Likert scales.[11] Six subscales and a total mood disturbance score were derived. The POMS-SF has been validated and has been used in several studies of psychological distress in breast cancer patients.[11,12]

Self-reported health was measured from a global question about how the participant rated her health in general (excellent, very good, good, less good, bad).[13]

We excluded 295/1243 women (24%) because of missing responses for items in these scales or other parts of the questionnaire.

2.2.2. *Register information*

Since 1st April 1968, the Central Population Registry has assigned all Danish citizens a personal 10-digit identification number, which contains information about the sex and date of birth of every individual, securing accurate linkage of information between this and other registries. Data on vital status was obtained from this registry.

Since 1943, all cases of cancer in Denmark have been registered in the Danish Cancer Register.[14] Information on previously notified cancer cases was obtained from this register, and 149/1243 women (12%) with a previous diagnosis of malignant disease were excluded because of anticipated difficulties in distinguishing the psychological consequences of breast cancer from those of a previous cancer.

Since 1976, the Danish Breast Cancer Cooperative Group has registered the diagnoses, treatment and prognostic characteristics of breast cancer patients in Denmark.[15] Grade of malignancy, chemotherapy, radiotherapy, hormone therapy and type of treatment, including axillary lymph node dissection with or without radiotherapy or sentinel node dissection, were obtained from this register. Eight women (<1%) were excluded from the analysis because of inadequate information about their treatment.

The maximum time since surgery at baseline was set at 5 years, thereby fixing a range from 1 month to 5 years since surgery. On these grounds, 65/1243 women (5%) were excluded, leaving 726 breast cancer survivors for further investigation.

2.3. *Identification of lymphoedema*

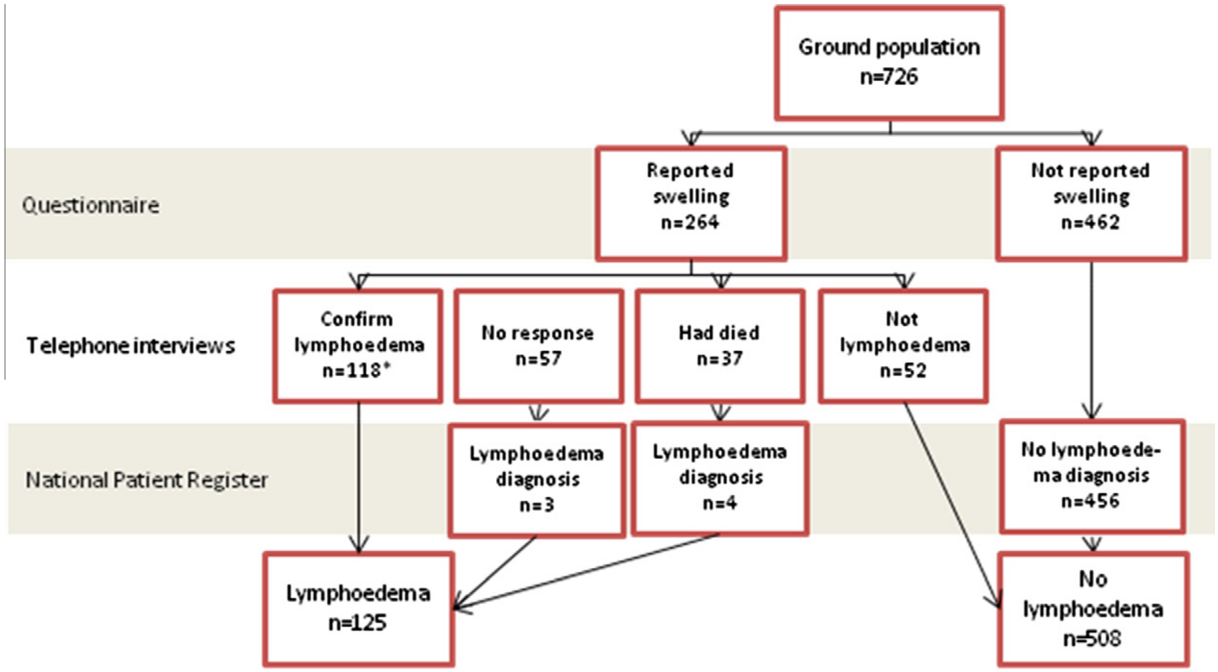
Lymphoedema was identified in two steps. First, positive answers were obtained to the question, 'Do you suffer from swelling of the arms or legs?' from 264/726 women (21% of the total sample). Second, these women were contacted by the first author (D.V.) to determine whether the lymphoedema was ipsilateral to the breast cancer and had been diagnosed after surgery. Of the women who reported swelling 37 had died. For ethical reasons, we did not contact the families of these women. In telephone interviews, 118 women confirmed that they had lymphoedema, 57 did not respond, and 52 reported not having lymphoedema of the ipsilateral arm (Fig. 1).

Since 1977, the National Patient Register (NPR) has obtained information about all hospital admissions for somatic conditions, and, since 1994, has registered all ambulatory contacts with Danish hospitals.[16] Diagnoses of lymphoedema (I97.2 in ICD-10[17]) were obtained from NPR, and seven breast cancer survivors from among the non-responders to the telephone interviews and the women who had died were identified as having had lymphoedema. Women who had died, or who did not respond to the telephone interview and were not identified by diagnosis in NPR (87/264) were excluded because of uncertainty about their status (Fig. 1).

Among the women who did not report swelling at baseline or who had reported not having lymphoedema in the interviews (514/726), we identified six for whom there was a diagnosis of lymphoedema in the NPR; these were excluded, leaving 633 women in the sample: 125 with and 508 women without verified lymphoedema (Fig. 1). The population under study was reduced to 553 women at the first follow-up (44% of 1243) and 494 at the second follow-up (40%).

2.4. *Statistical methods*

Marginal associations between lymphoedema and the other variables were assessed with chi-square tests.[18] The potential risk factors for lymphoedema were investigated by multivariate logistic regression analysis. All two-way interactions were tested, and the continuous variables were tested as quadratic variables. The results of the regression analyses were presented as odds ratios (ORs) with accompanying 95% confidence intervals (CIs).[18] Statistical analyses of the outcome variables POMS-SF total mood disturbance score, EORTC quality of life score and self-estimated health were carried out separately for each of the three times. Multivariate linear regression analyses were used to identify associations with the POMS-SF score and the QLQ-C30 quality of life score. Multivariate logistic regression analysis was used to identify associations with reporting good, very good or excellent health,[13] with dichotomized self-estimated health (excellent/very good/good, less good/bad). In addition to lymphoedema status, the models included marital status, employment status, education, age at time of surgery, time since surgery and body mass index, because these factors could influence the psychological effect of having lymphoedema. In the analysis of follow-up data we included the baseline score. In all the models, backward elimination was applied in order to limit the number of variables.



* 14/118 women who confirmed lymphedema in the telephone interviews also had lymphedema diagnosis in the National Patient Register

Fig. 1 – The flow chart illustrates the steps in classification of lymphoedema in the study population, as described in Section 2.3.

Table 1 – Baseline medical, demographic, lifestyle and psychological characteristics of the women with (125) and without (508) lymphoedema, and the associations of these characteristics with lymphoedema. FOCARE, Denmark, 2002–2007.

Characteristic	Lymphoedema (%) (*n* = 125)	No lymphoedema (%) (*n* = 508)	OR (95% CI)	Adjusted OR (95% CI)	Chi-square *P*-value
Medical					
Age at time of surgery (years)					0.40
<45	26	22	1.2 (0.6–2.4)		
45–55	44	39	1.2 (0.6–2.3)		
55–65	22	29	0.9 (0.4–1.7)		
>65	9	10	1		
Body mass index (weight status)					<.01
Underweight	2	2	1.4 (0.3–5.7)	1.5 (0.4–6.2)	
Normal weight	39	57	1		
Overweight	29	29	1.4 (0.9–2.1)	1.4 (0.9–2.1)	
Obese	20	8	2.6 (1.6–4.2)	2.3 (1.4–3.8)	
Extremely obese	8	3	2.9 (1.5–5.7)	3.1 (1.6–6.1)	
Menopausal status					0.31
Premenopausal	60	55	1.2 (0.8–1.7)		
Postmenopausal	40	45	1		
Stage of malignancy					0.93
I	19	20	1		
II	38	38	1.1 (0.7–1.7)		
III	25	25	1.1 (0.6–1.8)		
Not ductal	17	14	1.2 (0.7–2.1)		
Tumour size (mm)					0.70
<15	27	31	0.8 (0.5–1.4)		
15–30	50	49	1.0 (0.6–1.5)		
>30	22	20	1		
Type of surgery					0.26
Mastectomy	63	55	1.3 (0.9–1.9)		
Lumpectomy	37	45	1		
Type of treatment					<.01
Sentinel node	7	20	0.4 (0.2–0.7)	0.4 (0.2–0.8)	
Axillary lymph node dissection, no radiotherapy	17	16	0.9 (0.6–1.5)	0.9 (0.6–1.5)	
Axillary lymph node dissection and radiotherapy	70	58	1	1	
Time since surgery (years)					<.01
<1	51	65	0.6 (0.4–0.9)		
⩾1	49	35	1		
Chemotherapy					0.03
Yes	51	40	1.4 (1.0–2.0)		
No	49	60	1		
Hormone therapy					0.06
Yes	59	50	1.4 (1.0–1.9)		
No	41	50	1		
Recurrence of cancer before baseline					0.74
Yes	2	3	0.8 (0.3–2.6)		
No	98	97	1		
Demographic					
Marital status					0.53
Married or cohabiting	72	69	1		
One-person household	28	31	0.9 (0.6–1.3)		
Education					0.84
Basic	10	9	1.2 (0.6–2.1)		
Youth	38	39	1.0 (0.7–1.5)		
Higher	51	52	1		

(*continued on next page*)

Table 1 – (*continued*)

Characteristic	Lymphoedema (%) (*n* = 125)	No lymphoedema (%) (*n* = 508)	OR (95% CI)	Adjusted OR (95% CI)	Chi-square P-value
Employment status before cancer diagnosis					0.72
Working	66	69	1		
On sick leave or unemployed	8	6	1.4 (0.7–2.7)		
Pensioner, other	26	24	1.1 (0.7–1.6)		
Lifestyle					
Alcohol consumption (units/week)					<.01
0	26	17	2.3 (1.3–4.3)		
1–8	62	59	1.7 (1.0–3.0)		
>8	13	24	1		
Smoking status					0.13
Smoker	17	23	0.8 (0.8–1.2)		
Non-smoker	83	77	1		
Physical activity (h/week)					0.16
<15	36	43	1.0 (0.6–1.7)		
15–30	50	40	1.3 (0.8–2.3)		
>30	14	17	1		
Psychological					
Self-estimated health					<.01
Very good or excellent	14	25	0.76 (0.4–1.3)		
Good	38	48	1		
Less good or bad	48	27	1.90 (1.3–2.8)		
EORTC quality of life score[a]	58 (55–62)	65 (63–67)	1.0 (1.0–1.0)		0.08
POMS-SF total mood disturbance score[a]	20 (16–24)	13 (11–15)	1.0 (1.0–1.0)		0.32

[a] Mean value of total score on scale (95% CI).

Table 2 – Baseline linear regression model with adjusted results for POMS-SF total mood disturbance score. FOCARE, Denmark, 2002–2007.

	OR	95% confidence interval	P-value
Lymphedema			<.01
Yes	1	–	
No	0.86	0.8–0.9	
Body mass index			<.01
Underweight	1.20	1.1–1.3	
Normal weight	1	–	
Overweight	1.15	1.1–1.2	
Obese	1.04	1.0–1.1	
Extremely obese	1.19	1.1–1.3	
Employment status			<.01
Working	1	–	
On sick leave or unemployed	1.31	1.2–1.4	
Pensioner, other	1.21	1.2–1.3	
Education			<.01
Basic	1.11	1.1–1.2	
Youth	1.04	1.0–1.1	
Higher	1	–	
Age at time of surgery	0.99	1.0–1.0	<.01
Time since surgery	1.03	1.0–1.0	<.01

3. Results

As shown in Table 1, the presence of lymphoedema was significantly associated with overweight, having undergone axillary lymph node dissection and radiotherapy when compared with sentinel node dissection only. The association between chemotherapy and lymphoedema status is presumably a reflection of the severity of the cancer and its subsequent treatment.

In the multivariate analysis, sentinel node dissection was associated with a significantly decreased risk for lymphoedema (OR, 0.4; 95% CI, 0.2–0.8) when compared with axillary lymph node dissection, particularly in association with radiotherapy. In addition, there was a stepwise increase in risk for lymphoedema with body mass index above normal, with an OR of 3.1 for extremely obese women (95% CI, 1.6–6.1).

The baseline results from the multivariate analysis of the POMS-SF test showed that women who were ill or unemployed were at a 31% increased risk for scoring one level higher on total mood disturbance (POMS scale) than employed women (Table 2). Women with lymphoedema had a 14% higher risk for scoring one level higher on this scale, as also apparent at the 6- and 12-month follow-ups (data not shown).

Women with lymphoedema had a 9% increased probability of scoring one point lower on the quality of life scale, as measured by the QLQ-C30, than women without lymphoedema (Table 3), as also seen at the 6- and 12-month follow-ups (data

Table 3 – Baseline linear regression model with adjusted results for EORTC QLQ-C30 quality of life score. FOCARE, Denmark, 2002–2007.

	OR	95% confidence interval	P-value
Lymphedema			<.01
Yes	1	–	
No	1.09	1.1–1.1	
Body mass index			<.01
Underweight	0.95	0.9–1.0	
Normal weight	1	–	
Overweight	0.89	0.9–0.9	
Obese	0.94	0.9–1.0	
Extremely obese	0.83	0.8–0.9	
Employment status			<.01
Working	1	–	
On sick leave or unemployed	0.90	0.9–0.9	
Pensioner, other	0.93	0.9–1.0	
Education			<.01
Basic	1.03	1.0–1.1	
Youth	1.01	1.0–1.0	
Higher	1	–	
Marital status			<.01
Married or cohabiting	1	–	
One-person household	0.96	0.9–1.0	
Age at time of surgery	1.00	1.0–1.0	<.01
Time since surgery	1.00	1.0–1.0	0.09

Table 4 – Baseline logistic regression model with adjusted results for self-rated health. FOCARE, Denmark, 2002–2007.

	OR	95% confidence interval	P-value
Lymphedema			<.01
Yes	1	–	
No	1.29	1.2–1.4	
Body mass index			<.01
Underweight	0.92	0.7–1.2	
Normal weight	1	–	
Overweight	0.82	0.8–0.9	
Obese	0.97	0.9–1.1	
Extremely obese	0.59	0.5–0.7	
Education			<.01
Basic	0.94	0.8–1.1	
Youth	1.12	1.1–1.2	
Higher	1	–	
Time since surgery	0.99	1.0–1.0	0.50

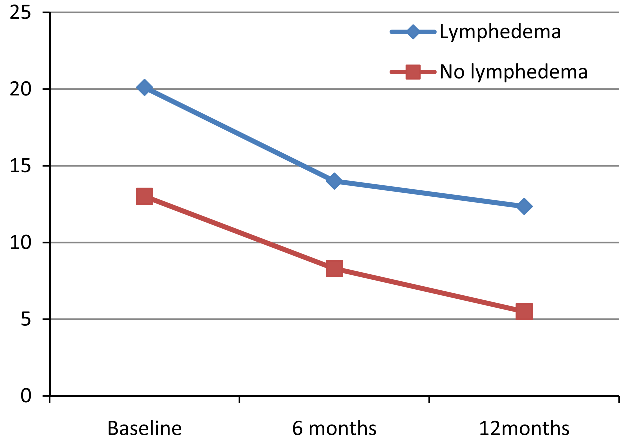


Fig. 2 – The figure shows the mean scores on the POMS-SF total mood disturbance at three measuring points. The lines indicate, that the differences between women with and without lymphoedema are persistent during the year of follow-up.

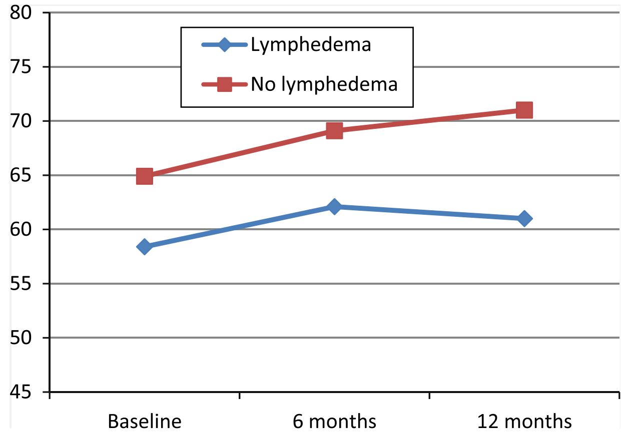


Fig. 3 – The figure shows the mean scores on the EORTC-C30 Quality of Life scale at three measuring points. The lines indicate, that the differences between women with and without lymphoedema are persistent during the year of follow-up, with an increase in the difference between groups at the 12 month follow-up.

not shown). Further, women who were underweight or overweight were more likely to score a lower level than women of normal weight, extremely obese women having a 17% increased probability.

At baseline, women with lymphoedema were 29% more likely to report less good or bad health than women without lymphoedema (Table 4). A similar effect was seen at the two follow-up times; the difference between the two groups was much lower at the 6-month follow-up (OR, 1.1; 95% CI, 1.0–1.2) but increased again at the last follow-up (OR, 1.2; 95% CI, 1.1–1.3) (data not shown).

Figs. 2–4 illustrate how, at all times, women with lymphoedema scored lower on the psychometric scales than women without lymphoedema.

4. Discussion

In this cohort of women with breast cancer who participated in a rehabilitation course, we found that the occurrence of lymphoedema after surgery for breast cancer significantly affected overall emotional well-being and adjustment to life, with persistently worse outcomes for women with lymphoedema in the year of follow-up compared to women without

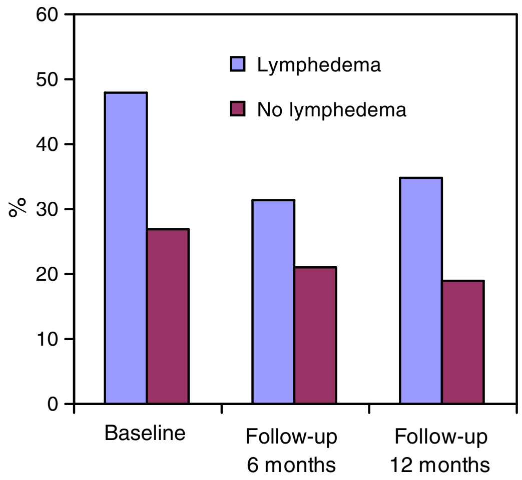


Fig. 4 – The figure shows the proportion of women with and without lymphoedema reporting less good or bad health at three measuring points. It shows that women with lymphoedema report worse health than women without lymphoedema during the year of follow-up.

lymphoedema. A difference in 10 points on the EORTC QOL-C30, as found at 12 months follow-up, corresponds to a minor to moderate, but clinically significant difference in physical, emotional and social function.[19] Several studies have shown that lymphoedema has negative effects on quality of life.[2–4,20–27] In a United States (US) cohort study of 151 early-stage breast cancer patients, 28% of the women with lymphoedema had lower scores for four of five measures of quality of life than women without lymphoedema.[3] A German cohort study among 990 patients with all stages of breast cancer found that women with 'arm problems' scored considerably worse on all measures of quality of life over the 5 years of follow-up.[4] Likewise, in a US cohort study of 622 patients with stage I, II or III invasive breast cancer, the prevalence of lymphoedema was 54% at 3 years' follow-up and women with lymphoedema reported significantly lower scores for quality of life.[2] Thus, existing evidence suggest negative effects on quality of life, regardless of country, clinic or method used.[28] In addition, several studies have reported serious declines in physical functional ability among women with lymphoedema.[3,24,29–32]

Our results point to a negative effect on the psychological functioning of these women, in line with the results of a cross-sectional study of 283 breast cancer survivors, which found significantly more psychological distress among women with than among those without lymphoedema, measured in the GHQ-30 survey.[21] In a case–control study of 128 women, the authors found reduced body confidence and more emotional distress (measured in the POMS-SF) among women with than among those without lymphoedema.[22] The mechanisms of the emotional distress associated with lymphoedema have been linked to the degree of functional impairment and feelings of numbness[30] and also to correlate with the number of symptoms experienced.[33] Furthermore, anxiety, depression, sexual dysfunction, disturbed body image and social avoidance have been reported to be associated with a diagnosis of lymphoedema.[33]

Although the results of these studies point in the same direction, they are difficult to compare, as the cross-sectional method limits the interpretation of cause and effect, and case–control studies may be prone to recall bias. In addition, the definition and measurement of 'lymphoedema' varies widely, being self-reported in some studies and measured objectively in others. As swelling can have other physical causes than lymphoedema related to breast cancer, we further investigated the symptoms in numerous ways. We assumed that the women who did not report swelling did not have lymphoedema; as subjective definition of lymphoedema results in fewer cases than definition by measure of volume or circumference,[34] our estimate of the frequency of lymphoedema might be low. This is illustrated by the findings of a study in the USA of 936 women, which showed significant discordance between the presence of measured and patient-perceived lymphoedema. The authors noted that an objective measure, such as a 2-cm difference in arm circumference, can be arbitrary, as it does not include patient perceptions.[34]

Our study has several advantages, including the homogeneous population: all had finished primary cancer treatment and were participating in activities at the Dallund Rehabilitation Centre. Several restrictions in the definition of participants minimized the risk that selection bias was an explanation for the findings of the analysis. The Danish public health system and free access to medical treatment at all levels, from the general practitioner to highly specialized clinics, minimize the risk for selection bias in the diagnosis of lymphoedema. The data obtained for the women in this study are extensive, stemming from the FOCARE questionnaire and several valid and complete registries established for administrative purposes.[14–16] This ensured the availability of detailed information on clinical, sociodemographic and lifestyle factors.

Our study also had limitations, mainly due to the fact that it relied primarily on subjective sources of information on lymphoedema, and thus we might have underestimated the true number of women with lymphoedema after surgery for breast cancer. This bias could affect the results, due to the fact that women who report swelling are more likely affected by it. Also, most of the women in the FOCARE project applied for their stay at Dallund Rehabilitation Centre themselves, introducing a risk for selection bias in the study population. We acknowledge that we were unable to exclude this bias completely as a potential explanation for our findings. The distribution of stages of breast cancer in the sample population was not the same as that among all breast cancer survivors in Denmark, so that the prevalence of lymphoedema in this study is not representative of that in the general population but only for a population of survivors with an estimated need for rehabilitation. Furthermore, the women were not included in the study at the same time in their disease, but from 1 month to 5 years after diagnosis of the breast cancer. This gives a cross-sectional estimate of the presence of lymphoedema; therefore, the psychological consequences over time should be interpreted in the context of different times in the course of breast cancer survival. Finally, when interpreting the longitudinal findings of this study we do not know how the intervention has affected the lymphoedema in itself, quality of life nor psychological distress, but a positive effect is most likely. However the differences between the women with and without lymphoedema persisted over time, even though all participated in the intervention.

This study is among the first to illustrate that lymphoedema in women treated for breast cancer has an important emotional effect and that the emotional disturbances are associated with poorer quality of life. We were able to obtain detailed information about lifestyle factors and a number of potentially important clinical and sociodemographic variables and followed-up the women for 12 months. Our findings point to the need for further long-term follow-up studies but also for clinical interventions to ensure the best information and treatment of lymphoedema, which may severely affect both the psychological and the physical function of women treated for breast cancer.

Conflict of interest statement

None declared.

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