


# Impact on Health-Related quality of life after wearing compression garment or not for six months in women with mild breast cancer-related arm lymphedema. A cross-sectional study

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## ABSTRACT

**Background:** Women with mild breast cancer-related arm lymphedema (BCRAL) mostly receive treatment with compression garments and instructions in self-care to prevent the progression of lymphedema. However, wearing a compression garment may be experienced as negative and may affect health-related quality of life (HRQOL) more than the lymphedema itself. The aim of this study was to investigate if there is a difference in lymphedema-specific HRQOL, between women with mild BCRAL wearing compression garments or not for 6 months.

**Material and methods:** Participants with mild BCRAL (Lymphedema relative volume <10%) rated their HRQOL by the Lymphedema Quality of Life Inventory (LyQLI), 6 months after diagnosis and being randomized to compression group (CG) or non-compression group (NCG). Both groups received self-care instructions, and the CG was treated with a standard compression garment, compression class 1. Data from 51 women (30 in the CG and 21 in the NCG), were analyzed.

**Results:** Both the CG and the NCG experienced a low negative impact on HRQOL in physical, psychosocial, and practical domains (score <1). However, the CG experienced a higher negative impact on median HRQOL in the practical domain compared to the NCG, 0.23/0.08 respectively, ( $p = 0.026$ ). In the specific items, more participants in the CG reported a negative impact on HRQOL compared to the NCG in *employment activities* 23%/0%, ( $p = 0.032$ ), *embarrassment by lymphedema/compression garments* 33%/5%, ( $p = 0.017$ ), *feeling discomfort/embarrassment while doing sports and hobbies* 30%/5%, ( $p = 0.034$ ) and *having to answer questions about the lymphedema* 27%/0% ( $p = 0.015$ ).

**Conclusion:** Overall, the lymphedema-specific HRQOL was high after 6 months in women with mild lymphedema, with only a minor difference between the groups. Some women may however perceive practical and emotional issues with the compression garment. These aspects should be considered in patient education and when planning/evaluating treatment.

**Trial registration:** ISRCTN51918431

## ARTICLE HISTORY

Received 28 November 2022  
Accepted 9 May 2023

## KEYWORDS



Breast cancer; compression garment; health-related quality of life; lymphedema quality of life inventory; lymphedema

## Background

As treatments for breast cancer have improved and survival rates have increased, more women live for a long time with late effects of cancer treatment, such as decreased strength, fatigue, pain, and lymphedema, which can negatively impact a woman's quality of life (QOL) [1,2]. Therefore, their perceived QOL becomes an increasingly important issue. The term health-related quality of life (HRQOL) refers to the health aspects of QOL, generally considered to reflect the impact of disease and treatment on disability and daily functioning [3]. HRQOL can be described as 'how well a person functions in life and his or her perceived wellbeing in

physical, mental and social domains of health' [4]. Breast cancer-related arm lymphedema (BCRAL) is associated with lower levels of HRQOL and with physical, psychological, and social consequences compared to breast cancer patients without arm lymphedema [5,6].

There are several predictors of low HRQOL in BCRAL. Impaired physical functions in patients with BCRAL have shown to have a higher negative impact on HRQOL than psychological or social function [7], and arm symptoms correlate more with poor HRQOL outcomes than the increase of arm volume characterizing lymphedema [8–10]. Also, an increase in arm lymphedema can make activities of daily

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living difficult, for example carrying or lifting heavy objects and other strenuous tasks [11]. Psychological impacts that have been reported in women with BCRAL in general, are negative emotions such as anxiety, frustration, sadness, anger, fear [1], and decreased self-confidence resulting from a distorted body image [5]. Other important predictors of low HRQOL in women with BCRAL are younger age and high body weight [5], but also a lower education level and family income [12].

Previous qualitative research on women with mild to moderate BCRAL has found that wearing a compression garment can be experienced as negative and may therefore affect HRQOL. The negative experience has been related to problems with the compression garments, such as a poor fit [13], or that the compression garment attracted attention and was experienced as warm, ugly, terrible, and un-feminine [14]. In a recent prospective randomized study on women with mild BCRAL (Lymphedema relative volume, LRV,  $\leq 8\%$ ), it was shown that the use of a compression garment, compression class 1 (ccl 1) for 6 months could prevent progression in arm volume. However, 43% of the participants within the non-compression group did not show any progression of arm volume and could manage without compression [15]. Since we do not know which patients who benefit from early compression treatment, all patients with mild BCRAL are recommended to wear compression garments. However, as some women may have negative experiences of wearing compression garments, it is important to investigate its impact on HRQOL.

### **Aim**

The aim of this study was to investigate if there is a difference in lymphedema specific HRQOL, between women with mild BCRAL wearing compression garments or not for 6 months.

## **Material and methods**

### **Design**

This study has a cross-sectional design, where lymphedema-specific HRQOL was assessed in women with mild BCRAL, 6 months after diagnosis and being randomized to treatment with compression garment or not [15]. The STROBE checklist for observational studies was followed, and the study was registered in ISRCTN51918431.

### **Participants and their context from the randomized controlled trial (RCT)**

Fifty-nine participants with mild BCRAL (LRV  $\leq 10\%$ ), included in a previous RCT [15], were invited to a follow-up visit at the Lymphedema Unit, 6 months after diagnosis and randomization to treatment with a compression garment or not at the Lymphedema Unit Skåne University Hospital and at the Physiotherapy Cancer Unit, Karolinska University Hospital. The definition of mild BCRAL, recruitment process, and randomization procedure are described in detail elsewhere [15].

Exclusion criteria for participating in the RCT were recurrent cancer, concurrent diseases, cognitive disability, or inability to understand or speak Swedish. The compression group (CG) received circular knitted compression sleeves (ccl 1) or if needed, individually adjusted compression sleeves (ccl 2) to be worn during the day for six months together with instructions in self-care. The self-care included counseling about exercise, weight control, skin care, instructions on self-massage and the use of compression. The counseling about exercise included general information on the benefit of regular physical activity/exercise of at least 30 min daily during the cancer treatment and included instructions on mobility training of the arm/shoulder according to a specific program. The self-massage comprised instructions on light strokes of shoulder and arm in a proximal direction about 10-15 min a day. If the self-massage was perceived as beneficial, participants were encouraged to continue or if not, they could stop. The non-compression group (NCG) received instructions in self-care only. Of the 59 participants in the RCT, two did not come to the 6 months follow-up visit and one participant did not fill in the HRQOL questionnaire (i.e., Lymphedema Quality of Life Inventory, LyQLI; see below). Thus, in total, 56 participants responded to LyQLI.

### **Ethical approval**

The study was approved by the Regional Ethical Board, Lund University. D nr:2014/399. All participants provided informed consent and data were collected from September 2014 to October 2019.

### **Data collection**

At 6 months after diagnosis and randomization, the participants responded to the questionnaire on lymphedema-specific HRQOL (LyQLI) and various measurements and ratings were performed. Arm volume was measured by the water displacement method (WDM). Body weight (kg) and height (m) were measured to calculate body mass index (BMI). The participants self-rated their experiences of heaviness, tightness, and pain in the affected arm at the time of examination, and without wearing the compression garment, on a 100 mm horizontal Visual Analog Scale (VAS) [16]. They also rated adherence to self-care including physical activity, self-massage, and use of compression garments during the past four weeks. Physical activity level/exercise and housework were rated on a six-point scale (from sedentary to high physical activity) [17]. Frequency of performed self-massage was rated on a four-point scale (no massage, seldom, two-three times a week, every day), as well as the use of compression garment on a three-point scale (not at all, half the day or the whole day). To characterize the participants, background data of surgical methods and adjuvant treatment were retrieved from medical records. Information about age, education and marital status were retrieved from a study-specific questionnaire.

## HRQOL questionnaire

### Lymphedema quality of life Inventory (LyQLI)

LyQLI is a questionnaire developed for patients with lymphedema in different parts of the body [18]. It comprises 41 items divided into three domains: physical (12 items), psychosocial (16 items) and practical (13 items). Each item assesses the impact of lymphedema on HRQOL during the last four weeks, on a 4-point Likert scale ranging from 0 = 'None' or 'not relevant' to 3 = 'A lot'. A higher score indicates a more negative impact on HRQOL. The questionnaire also includes four global questions. Item 42 is a question on whether the previous four-week period had been typical regarding the lymphedema and item 43 is a follow-up question if the period was not typical, on how the four-week period had been. Also, item 44 assesses the overall experience of lymphedema and item 45 the overall quality of life, both on a 4-point Likert scale ranging from 'Very bad' to 'Very good'. A higher score indicates a higher overall HRQOL. LyQLI has shown good reliability and validity in patients with upper/lower lymphedema and other lymphedema with a median duration of 7 years [18]. Reliability in terms of ICCs is shown to be 0.88 for the physical domain, 0.87 for the psychosocial domain, and 0.87 for the practical domain [18]. LyQLI assesses all HRQOL domains, including all specific arm symptoms [19].

## Statistical analysis

Descriptive statistics for continuous values are presented as mean  $\pm$  SD and categorical variables are presented as number and proportion (%). Differences between groups regarding participants' characteristics/background data were calculated with a *t*-test for continuous data, Mann-Whitney U-test for ordinal data and Chi square test with Pearson or Fisher's exact test for nominal data. Differences in median HRQOL values between CG and NCG for the physical, psychosocial, and practical domains were calculated with Mann-Whitney U-test. The responses to the 41 specific items of LyQLI were dichotomized into 'none' impact (score 0) or a 'little bit/somewhat/a lot impact' (scores 1,2,3) and item differences between the CG and the NCG were calculated using Pearson Chi square test or Fisher's exact test. Missing items were substituted with the mean of the participant's responses [18]. The analyses were carried out in IBM SPSS Statistics 28 and a significance level of  $p < 0.05$  (two-tailed) was chosen.

## Results

Of the 56 participants who responded to LyQLI, five were excluded due to: (i) recurrence of the cancer disease (three participants in the CG and one in the NCG) and (ii) did not use compression (one participant in the CG depending on

**Table 1.** Characteristics for women with mild breast cancer related arm lymphedema, divided into compression group (CG) and non-compression group (NCG), ( $n = 51$ ).

	CG $n = 30$	NCG $n = 21$	<i>p</i> -value*
Age in years, mean (SD)	58.5 (13.8)	55.5 (12.5)	0.439
BMI kg/m <sup>2</sup> , mean (SD) <sup>a</sup>	25.9 (4.8)	25.7 (4.0)	0.849
Education <sup>a</sup> ,			0.337 <sup>c</sup>
Elementary school, <i>n</i> (%)	2 (6)	2 (10)	
Upper secondary school, <i>n</i> (%)	8 (27)	9 (45)	
University/college, <i>n</i> (%)	20 (67)	9 (45)	
Marital status			0.881
Single, <i>n</i> (%)	8 (27)	6 (29)	
Partner, <i>n</i> (%)	22 (73)	15 (71)	
Surgery			0.148
Surgery, Mastectomy and ALND, <i>n</i> (%)	19 (63)	9 (43)	
Surgery, Lumpectomy and ALND, <i>n</i> (%)	11 (37)	12 (57)	
Reconstruction, <i>n</i> (%)	3 (10)	1 (5)	0.634 <sup>c</sup>
Surgery dominant side, <i>n</i> (%) <sup>a</sup>	17 (57)	7 (35)	0.133
Oncological treatment			
Radiotherapy, <i>n</i> (%)	29 (97)	21 (100)	1.000 <sup>c</sup>
Chemotherapy, <i>n</i> (%)	24 (80)	20 (95)	0.217 <sup>c</sup>
Hormone therapy, <i>n</i> (%)	23 (77)	16 (76)	1.000 <sup>c</sup>
Lymphedema			
Duration, months, mean (SD)	1.0 (1.3)	1.2 (1.8)	0.675
Time from surgery to onset, months, mean (SD)	6.2 (5.5)	7.8 (4.4)	0.264
Affected side, right/left, <i>n</i> (%)	16 (53)/14 (47)	8 (38)/13 (62)	0.283
Hand edema, self-rated, yes/no, <i>n</i> (%) <sup>a</sup>	8 (27)	4 (20)	0.740 <sup>c</sup>
LRV at diagnosis/randomization, %			0.795
Mean (SD)	4.5 (3.1)	4.7 (3.1)	
Median (min-max)	5.6 (-4.8-8.0)	5.8 (-6.6-7.8)	
LRV, 6 months after randomization, %			<0.001
Mean (SD)	0.7 (3.0)	4.5 (4.1)	
Median (min-max)	1.0 (-6.6-6.2)	4.7 (-5.2-10.5)	
Subjective symptoms, 6 months after diagnosis/randomization <sup>b</sup>			
Tension, median (min-max)	0 (0-16)	0 (0-29)	0.729
Heaviness, median (min-max)	0 (0-20)	0 (0-32)	0.721
Pain, median (min-max)	0 (0-61)	0 (0-79)	0.931

ALND: axillary lymph node dissection. LRV: lymphedema relative volume, The edema volume divided by the total arm volume of the non-affected arm and adjusted with +1.5%, if surgery in non-dominant side, and -1.5% if surgery in dominant side \*Significance level 0.05, bold values are significant, Pearson Chi-square test for nominal data, Mann-Whitney U test for ordinal data, T-test for continuous data, <sup>a</sup>missing value  $n = 1$ , <sup>b</sup>missing value  $n = 2$ , <sup>c</sup>Fisher's exact test.

**Table 2.** Adherence to self-care, 6 months after diagnosis/randomization, divided into compression group (CG) and non-compression group (NCG).

	CG N = 30	NCG <sup>a</sup> N = 20 <sup>a</sup>	p-value*
Physical activity/exercise/housework			0.370
Hardly any to easy physical activity, n (%)	12 (40)	7 (35)	
Moderate to high physical activity/exercise, n (%)	18 (60)	13 (65)	0.327
Self-massage			
No or more seldom, n (%)	21 (70)	9 (45)	
2-3 times/week or every day, n (%)	9 (30)	11 (55)	
Use of compression sleeve			<b>&lt;0.001</b>
No compression, n (%)	0	20 (100)	
Half day, n (%)	2 (7)	0	
Whole day, n (%)	28 (93)	0	

\*Significance level 0.05, bold values are significant, Fisher's exact test, <sup>a</sup>missing value n = 1.

pain during radiotherapy). The remaining 51 participants were eligible for data analysis; 30 in the CG and 21 in the NCG. The women in CG and NCG were comparable regarding characteristics/background data, except for LRV, 6 months after diagnosis/randomization (Table 1). There was no difference in adherence to recommended self-care, except for the use of compression garments (Table 2).

### HRQOL in CG and NCG

Both the CG and the NCG experienced a low negative impact on HRQOL in physical, psychosocial, and practical domains (score <1). However, the CG experienced a higher negative impact on median HRQOL in the practical domain compared to the NCG, 0.23/0.08 respectively, ( $p = 0.026$ ), (Table 3).

In the practical domain (specifically in *employment activities*), more participants in the CG (23%) reported a negative impact on HRQOL compared to the NCG (0%), ( $p = 0.032$ ), (Table 4). In the psychosocial domain, more participants in the CG than the NCG reported a negative impact on HRQOL, in the following items: *embarrassment by lymphedema/compression garments*: CG (33%)/NCG (5%), ( $p = 0.017$ ), *feeling discomfort/embarrassment while doing sports and hobbies*: CG (30%)/NCG (5%), ( $p = 0.034$ ) and *having to answer questions about the lymphedema*: CG (27%)/NCG (0%), ( $p = 0.015$ ), (Table 4).

Most participants in both the CG and the NCG experienced good/very good overall experience of lymphedema related to HRQOL (item 44), and good/very good overall quality of life (item 45), (Table 4). There were no significant differences between the groups in overall experience of lymphedema related to HRQOL (item 44); mean  $\pm$  SD in CG/NCG, 2.59  $\pm$  0.50/2.55  $\pm$  0.69 or in overall quality of life (item 45), mean  $\pm$  SD in CG/NCG, 2.38  $\pm$  0.56/2.55  $\pm$  0.69.

## Discussion

In the present exploratory study, most participants with mild BCRAL in both the CG and the NCG did not experience that the lymphedema affected their perceived HRQOL to a great extent, only a minor difference in a negative impact on HRQOL between the groups was found in certain aspects. More participants in the CG rated a negative impact on HRQOL than the

**Table 3.** Lymphedema Specific HRQOL, measured with Lymphedema Quality of Life Inventory (LyQLI), divided into the three domains. Six months after diagnosis/randomization to compression group (CG) or non-compression group (NCG).

Domain	CG n = 30	NCG n = 21	Total n = 51	p-value*
<b>Physical domain</b>				0.302
Median (min-max)	0.38 (0-1.42)	0.17 (0-1.91)	0.33 (0-1.91)	
Mean (SD)	0.43 (0.40)	0.36 (0.48)	0.40 (0.43)	
<b>Psychosocial domain</b>				0.210
Median (min-max)	0.25 (0-1.31)	0.13 (0-1.31)	0.19 (0-1.31)	
Mean (SD)	0.32 (0.33)	0.23 (0.30)	0.29 (0.32)	
<b>Practical domain</b>				<b>0.026</b>
Median (min-max)	0.23 (0-0.92)	0.08 (0-0.83)	0.08 (0-0.92)	
Mean (SD)	0.28 (0.27)	0.13 (0.22)	0.22 (0.25)	

Items/ self-rated impact on HRQOL during the last 4 weeks on a four-point scale from none (0), a little bit (1), somewhat (2), a lot (3). A mean score  $\leq 1$  indicates a low impact. \*Significance level 0.05, Mann-Whitney U-test, bold values are significant.

NCG in the practical domain, specifically in *employment activities*. In the psychosocial domain, more participants in the CG than the NCG reported a negative impact on HRQOL regarding *embarrassment by lymphedema/compression garment, feeling discomfort/embarrassment while doing sports and hobbies* and *having to answer questions about the lymphedema*. These findings indicate that wearing a compression garment may have a potential negative impact on HRQOL that needs to be considered.

Most participants in both groups experienced a low lymphedema-related impact on HRQOL in all domains (mean score <1, Table 3). The CG experienced a somewhat higher negative impact on HRQOL in the practical domain compared to the NCG but the difference between the groups was minor and it is uncertain whether the difference is of clinical importance.

In the practical domain, more participants in the CG rated a negative impact on HRQOL regarding *employment activities* compared to the NCG, which indicates that it may be a problem for some patients. In many occupations, of hygienic reasons, it is difficult to wear a compression sleeve and even more difficult to use a glove. Individualized counseling about strategies on how to use the compression garment during work/household activities may be helpful and could probably improve HRQOL. For example, the use of night compression [20] can compensate for part of the day when the patient finds it difficult to use compression. To improve adherence

**Table 4.** Lymphedema Specific HRQOL, measured with Lymphedema Quality of Life Inventory (LyQLI), presented for each item in the domains, six months after diagnosis/randomization to compression group (CG,  $n = 30$ ) or non-compression group (NCG,  $n = 21$ ).

	None Score 0, n (%)		A little bit/ somewhat/a lot Score 1,2,3, n (%)		p-value*
	CG	NCG	CG	NCG	
<b>Physical domain</b>					
1. Pain/aches due to my lymphedema	18 (60)	17 (81)	12 (40)	4 (19)	0.112
2. Discomfort due to my lymphedema	15 (50)	11 (52)	15 (50)	10 (48)	0.867
3. A feeling of heaviness due to my lymphedema	19 (63)	16 (76)	11 (37)	5 (24)	0.330
4. Pins and needles/numbness due to my lymphedema	16 (53)	13 (62)	14 (47)	8 (38)	0.543
5. Burning sensation/heat due to my lymphedema	26 (87)	21 (100)	4 (13)	0	0.134
6. Swelling/tightness due to my lymphedema	13 (43)	11 (52)	17 (57)	10 (48)	0.524
7. Skin problems due to my lymphedema	24 (80)	20 (95)	6 (20)	1 (5)	0.217
8. Difficulty sleeping due to my lymphedema <sup>a</sup>	23 (77)	19 (95)	7(23)	1 (5)	0.123
9. Movement difficulties due to my lymphedema	21 (70)	15 (71)	9 (30)	6 (29)	0.912
10. Feeling physically aware of my lymphedema all the time	19 (63)	14 (67)	11 (37)	7 (33)	0.806
11. Feeling a loss of strength in the swollen part of my body	18 (60)	14 (67)	12 (40)	7 (33)	0.628
12. Infection	29 (97)	21 (100)	1 (3)	0	1.000
<b>Psychosocial domain</b>					
13. Feelings of frustration/feeling annoyed	17 (57)	16 (76)	13 (43)	5 (24)	0.151
14. Feeling anxious about whether or not the lymphedema will get worse <sup>a</sup>	11 (37)	8 (40)	19(63)	12 (60)	0.812
15. Embarrassed by lymphedema/compression garments	20 (67)	20 (95)	10 (33)	1 (5)	<b>0.017</b>
16. Negative changes in how I see my self	21 (70)	15 (71)	9 (30)	6 (29)	0.912
17. Feeling discouragement	21 (70)	15 (71)	9 (30)	6 (29)	0.912
18. Not being able to do the things I used to enjoy	22 (73)	18 (86)	8 (27)	3 (14)	0.490
19. Concerns about when to seek medical attention	23(77)	18 (86)	7 (23)	3 (14)	0.495
20. Paying constant attention to my condition <sup>a</sup>	15 (52)	10 (48)	14 (48)	11 (52)	0.774
21. Concerns about how lymphedema affects my existing relationship	29 (97)	20 (95)	1 (33)	1 (5)	1.000
22. Concerned about how the lymphedema could affect new relationships	28 (93)	19 (90)	2 (7)	2 (10)	1.000
23. Negative changes in my feelings about intimacy/sexuality	26 (87)	20 (95)	4 (13)	1 (5)	0.391
24. Feeling uncomfortable/ embarrassed while doing sports and hobbies	21(70)	20 (95)	9 (30)	1 (5)	<b>0.034</b>
25. Feeling uncomfortable/ embarrassed when attending social activities with friends and at work	25 (83)	21 (100)	5 (17)	0	0.069
26. Having to ask for help in different situations <sup>a</sup>	24 (83)	17 (81)	5 (17)	4 (19)	1.000
27. Concerns about negative changes in my appearance	20 (67)	19 (90)	10 (33)	2 (10)	0.091
28. Having to answer questions about my lymphedema	22 (73)	21 (100)	8 (27)	0	<b>0.015</b>
<b>Practical domain</b>					
29. Personal activities of daily living (e.g., dressing, combing hair, foot care)	28 (93)	20 (95)	2 (7)	1 (5)	1.000
30. Normal daily activities (e.g., doing housework, sports and hobby activities)	21 (70)	18 (86)	9 (30)	3 (14)	0.315
31. Employment activities <sup>b</sup>	22 (73)	20 (95)	7 (23)	0	<b>0.032</b>
32. Learning to do things differently	21 (70)	18 (86)	9 (30)	3 (14)	0.315
33. Having less energy to do activities (e.g., personal, normal daily or employment)	20 (67)	15 (71)	10 (33)	6 (29)	0.718
34. Financial costs of managing my lymphedema (e.g., clothes, shoes, treatments, garments)	25 (83)	21 (100)	5 (17)	0	0.069
35. Finding well-functioning compression garments (e.g., stockings, sleeves, gloves)	24 (80)	21 (100)	6 (20)	0	
36. Traveling long distances by car, train, plane, etc.	27 (90)	17 (81)	3 (10)	4 (19)	0.427
37. Finding clothes and shoes that are comfortable and attractive, the right size and type of material <sup>a</sup>	24 (83)	19 (90)	5 (17)	2 (10)	0.684
38. Limitations in hot weather/sun	16 (53)	16 (76)	14 (47)	5 (24)	0.097
39. The constant self-care I need to do to stop my lymphedema from getting worse	19 (63)	18 (86)	11 (37)	3 (14)	0.078
40. Obtaining information about how to manage my lymphedema	26 (87)	20 (95)	4 (13)	1 (5)	0.391
41. Being prepared for emergencies (e.g., always having a script for antibiotics)	29 (97)	19 (90)	1 (3)	2 (10)	0.561
	<b>Very bad/ bad (0-1)</b>		<b>Good/ very good (2-3)</b>		
	CG	NCG	CG	NCG	
44. Overall experience of lymphedema <sup>b</sup>	0	2 (10)	29 (100)	18 (90)	0.162
45. Overall quality of life <sup>b</sup>	1 (3)	2 (10)	28 (97)	18 (90)	0.559

Items 1–41: self-rated impact on HRQOL dichotomized to none (score 0) or a little bit/somewhat/lot impact (scores 1,2,3). Items 44–45: self-rated impact on HRQOL dichotomized to very bad/bad (score 0–1) and good/very good (score 2–3). \*Significance level 0.05, Pearson Chi-Square test or Fisher's exact test. Bold values are significant. <sup>a</sup>Missing value,  $n = 1$  <sup>b</sup>Missing value,  $n = 2$ .

and optimize compression treatment it is important to apply a person-centered approach and ask about the patient's own experience and consider the possible negative impact on HRQOL in relation to the preventive effect. The compression treatment should also be evaluated regularly to ensure that the lymphedema is not over- or under-treated.

In the psychosocial domain, more participants in the CG than the NCG rated a negative impact on HRQOL in the items *feelings of embarrassment by lymphedema/compression garments*, *feeling discomfort/embarrassment while doing sports and hobbies* and *having to answer questions about the lymphedema* compared to the NCG. Even though the difference

between the groups was minor, clinical experience and some previous qualitative research indicate that these feelings may be of importance for some of the patients. In an interview study of 16 women with mild to moderate BCRAL, it was described that some women stopped using the compression garment by their own initiative, related to problems with the arm sleeve. Appearance and comments from others reduced the motivation to use compression garments, and some women felt that the compression garment became a constant reminder of the cancer [13]. It can be helpful for the patients to discuss potential negative feelings with the healthcare staff or other patients with lymphedema. Also,

information about that exercise without compression do not worsen the lymphedema may be important to know for the patients [21]. Continuous information/education about self-care strategies and listening to the patient's experience both in terms of comfort and appearance, may further improve perceived lymphedema-specific HRQOL.

The CG decreased in LRV during the 6 months intervention (4.5% to 0.7%) and rated a low lymphedema-related impact on HRQOL at 6 months. However, because we did not have any baseline measurements of HRQOL we cannot draw any conclusions about a possible change in HRQOL during the intervention. Bundred et al. [22] investigated HRQOL in a prospective cohort study including women with moderate/severe BCRAL (LRV >10%), with the Functional Assessment of Cancer Therapy-Lymphedema (FACT-B + 4) and found that HRQOL following a sleeve application increased for those with an increase of LRV >5% ( $n = 116$ ), but did not change for those with an increase of LRV <5% ( $n = 86$ ).

Based on current evidence, early diagnosis, and intervention, including compression treatment is important to prevent progression [23]. However, few studies have examined the effect of compression garments. In our previous randomized study, we found that treatment with compression garments prevented the progression of mild BCRAL [15]. Also, Paramanandam et al. found that prophylactic use of a compression garment could decrease the incidence of arm lymphedema by 10% [24]. Moreover, some patients with early symptoms of lymphedema, in particular a feeling of tension in the tissue, experience reduced tension after the application of a compression garment [15]. The results in the present study showed that there was only a minor difference in perceived impact on HRQOL between the groups and that the compression garment was well tolerated. Therefore, treatment with compression garments should be recommended in mild BCRAL. However, patients with mild BCRAL have few subjective symptoms and it was previously shown that 43% of the women not treated with compression garments did not progress in arm volume [15]. Also, the potential negative impact on HRQOL, when using a compression garment may have consequences for adherence potentially affecting the progression of lymphedema. Therefore, the possible negative impact should be considered and discussed with the patients when planning and evaluating treatment to improve adherence. LyQLI could be a useful screening instrument to detect and meet individual needs.

We found that most participants in both CG and NCG experienced a very good overall experience of lymphedema related to HRQOL and overall HRQOL, indicating that mild BCRAL only has a minor impact on HRQOL. Our results differ from previous research on patients with moderate/severe BCRL, who experienced a low HRQOL [5]. Possible reasons might be the difference in severity of the lymphedema, and compression class of the compression garment used. Also, there may be a difference in the availability of treatment, and education, or that different HRQOL questionnaires were used. The finding in our study shows that it is important to early intervention in mild BCRAL, preventing further progression and negative impact on HRQOL.

## Strengths and limitations

In the present exploratory study, data from 51 participants could be analyzed. This resulted in a comparison between two relatively small groups, which may have affected the power and ability to detect significant differences between the groups. The cross-sectional design without any baseline measurements of HRQOL, means that we cannot draw any conclusions regarding changes in HRQOL over time, but only describe differences in perceived HRQOL between the groups 6 months after diagnosis/randomization. The participants were monitored slightly more frequently than patients who got usual care, which may have influenced the experience of care, perceived HRQOL, and the results in a positive direction. Strengths of the study are few missing data, comparable groups regarding participants' characteristics, and adherence to self-care. There is no consensus on the best questionnaire to measure HRQOL in patients with BCRAL. Most studies have used generic or cancer-specific instruments, which may not capture the specific symptoms suffered by BCRAL patients [5]. LyQLI is a lymphedema-specific instrument, shown to be sensitive to change and suitable to evaluate treatment [25]. However, the instrument is not validated in patients with early mild BCRAL. Also, no minimal important difference in the instrument is reported and therefore we do not know if the significant difference between the CG and NCG is of clinical importance. Some of the items concerning the use of compression may not be relevant for the participants in the NCG, and they had to answer 0 for both 'Not relevant' and 'None', which may have affected the results. On the other hand, if the items regarding compression had been excluded, we would not have been able to find out how the use of compression affects HRQOL. Furthermore, only participants that could read and speak Swedish were included in our study, which means that the results cannot be generalized to the entire population of patients with mild BCRAL.

## Conclusions

Conclusion: Overall, the lymphedema-specific HRQOL was high after 6 months in women with mild lymphedema, with only a minor difference between the groups. Some women may however perceive practical and emotional issues with the compression garment. These aspects should be considered in patient education and when planning/evaluating treatment.

## Acknowledgements

The authors would like to thank the participants in this study, RPT Christina Snöbohm and Polymnia Nikolaidis who have assisted in the examinations and PhD, RPT Michael Miller for language editing.

## Author contribution

Katarina Blom and Karin Johansson were responsible for the study's design, and data collection. All authors were responsible for analysis, critical revisions, and the drafting of the manuscript.

## Disclosure statement

All authors declare no competing financial interests.

## Funding

This research was supported by the Swedish Cancer Foundation CAN 2013/610 and the Swedish Breast Cancer Association (BRO) 2014-12-05.

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## Data availability statement

The data that supports the findings of this study are available on request from the corresponding author, (KB)

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