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# Data in Brief





## Data Article

# Data for the Spanish adaptation of Breast Cancer and Lymphedema Symptom Experience Index (BCLE SEI Esp)



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#### ABSTRACT

Breast cancer is one of the most diagnosed cancer in women worldwide and lymphedema is one of the most common late and chronic adverse effects of breast cancer treatment. Lymphedema symptoms are essential signs of early-stage of lymphedema as they often precede changes in limb size or girth or a lymphedema diagnosis. Therefore, to achieve early detection and prevent lymphedema progression, it is important to promote patient selfcare in terms of the awareness symptoms identification. To this purpose Breast Cancer and Lymphedema Symptom Experience Index (BCLE SEI Esp) scale was used.

Between October 2018 and June 2020, we collected data from 286 lymphedema and non-lymphedema patients post-breast cancer treatment on sociodemographic information, lymphedema symptoms, daily living-function and psychosocial distress, women and the data comparison between lymphedema and non-lymphedema patients were provided in this publication.

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This dataset can be used as a reference in clinical settings or in clinical studies or as an instructional tool to teach breast cancer patients and clinicians to be aware of lymphedema symptoms and to help clinicians and patients to achieve early identification of lymphedema symptoms and the impacts of lymphedema symptoms in womens life and to develop future research, for example, to develop predictive algorithms.

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## **Specifications Table**

Subject	Health and medical sciences
Specific subject area	Lymphedema after breast cancer treatment
Type of data	Table
How the data were acquired:	Data was collected through an online questionnaire. The questionnaire is provided as supplementary material
Data format	Csv
Description of data collection	Data from 286 women, diagnosed with breast cancer were analyzed. Among them, 23.4% ( $n=67$ ) also were diagnosed with lymphedema. Lymphedema symptoms and symptom distress were assessed using Spanish Version of The Breast Cancer and Lymphedema Symptoms Experience Index (BCLE-SEI-Es)
Data source location	Institution: Universidad de Oviedo
	City/Town/Region: Oviedo, Asturias
	Country: Spain
Data accessibility	Repository name: Mendeley Data
	Data identification number: doi: 10.17632/9s9zsb84cb.2
	Direct URL to data: https://data.mendeley.com/datasets/9s9zsb84cb
Related research article	J. Cachero-Rodríguez, A. Menéndez-Aller, M.R. Fu, A. Llaneza-Folgueras, M.M.
	Fernández-Alvarez, R. Martín-Payo, Psychometric Properties of the Spanish
	Version of Breast Cancer and Lymphedema Symptom Experience Index,
	Psicothema 34 (2022) 291–298, doi:10.7334/psicothema2021.388

## Value of the Data

Why are these data useful?

- The data demonstrated the novel and feasible use of the BCLE for Spanish-speaking population.
- The database is useful to know the prevalence of lymphedema symptoms suffered by women after breast cancer diagnosis.
- The information from the data may be useful in implementing strategies to prevent suffering associated with lymphedema symptoms and lymphedema.

## Who can benefit from these data?

- The information from the data will help to improve awareness of the distress from lymphedema symptoms among women diagnoses with breast cancer.
- Researchers can utilize this database, combine it with others' datasets, and analyze them for further insights.

How can these data be used/reused for further insights and/or development of experiments?

The data provided baseline characteristics, different clinical parameters and outcome data of women diagnosed with breast cancer, with or without lymphedema based on which power analysis can be generated for future research.

Our data would allow researchers to conduct further in-depth studies on the impacts of lymphedema symptoms on women's quality of life.

## 1. Data Description

A total of 286 women who were treated for breast cancer participated in the study, 23.4% (n=67) were diagnosed with lymphedema post breast cancer treatment. Mean age was 56.97 (SD = 8.923), most had university studies, married or in a relationship.

Table 1 shows the percentage of each item rating of lymphedema symptoms for women with and without lymphedema and differences between groups. The median punctuation for the scale symptom occurrence, as the summation of each symptom occurrence item score, was

**Table 1**Percentage of symptoms and differences between women with lymphedema or with non-lymphedema.

	Total $(n = 286)$	Lymphedema $(n = 67)$	Non-lymphedema $(n = 219)$	<b>p</b> *
Pain/aching/soreness				
None	46.9	14.9a	56.6 <sup>b</sup>	<.001
Mild	30.1	31.3 <sup>a</sup>	29.7a	
Moderate	14.0	29.9a	9.1 <sup>b</sup>	
Severe	7.0	16.4a	4.1 <sup>b</sup>	
Very severe	2.1	7.5 <sup>a</sup>	0.5 <sup>b</sup>	
Tenderness				
None	79.0	76.1	79.9	.081
Mild	13.3	9.0	14.6	
Moderate	3.8	7.5	2.7	
Severe	2.8	4.5	2.3	
Very severe	1.0	3.0	0.5	
Arm/hand swelling				
None	66.8	19.4 <sup>a</sup>	81.3 <sup>b</sup>	<.001
Mild	18.5	28.4 <sup>a</sup>	15.5 <sup>b</sup>	
Moderate	11.2	37.3 <sup>a</sup>	3.2 <sup>b</sup>	
Severe	2.1	9.0 <sup>a</sup>	$0_{\rm p}$	
Very severe	1.4	6.0a	$0_{\rm p}$	
Breast swelling				
None	89.2	88.1 <sup>a</sup>	89.5 <sup>a</sup>	.031
Mild	7.0	4.5a	7.8 <sup>a</sup>	
Moderate	2.8	3.0 <sup>a</sup>	2.7 <sup>a</sup>	
Severe	0.7	3.0 <sup>a</sup>	$0_{\rm p}$	
Very severe	0.3	1.5 <sup>a</sup>	O <sup>a</sup>	
Chest wall swelling				
None	90.6	86.6	91.8	.085
Mild	6.3	6.0	6.4	
Moderate	2.4	4.5	1.8	
Severe	0.3	1.5	0	
Very severe	0.3	1.5	0	
Firmness in the affected limb				
None	68.5	49.3a	74.4 <sup>b</sup>	<.001
Mild	21.3	23.9a	20.5a	
Moderate	6.6	16.4 <sup>a</sup>	3.7 <sup>b</sup>	
Severe	1.7	6.0a	0.5 <sup>b</sup>	
Very severe	1.7	4.5 <sup>a</sup>	0.5ª	

Table 1 (continued)

	Total (n = 286)	Lymphedema $(n = 67)$	Non-lymphedema $(n = 219)$	p*
Tightness in the affected limb				
None	72.7	52.2 <sup>a</sup>	79.0 <sup>b</sup>	<.001
Mild	17.5	22.4 <sup>a</sup>	16.0 <sup>a</sup>	
Moderate	7.7	19.4 <sup>a</sup>	4.1 <sup>b</sup>	
Severe	0.7	1.5 <sup>a</sup>	0.5 <sup>a</sup>	
Very severe	1.4	4.5 <sup>a</sup>	0.5 <sup>b</sup>	
Heaviness in the affected limb				
None	59.8	28.4 <sup>a</sup>	69.4 <sup>b</sup>	<.001
Mild	26.6	34.3 <sup>a</sup>	24,2 <sup>a</sup>	
Moderate	9.1	23.9a	4.6 <sup>b</sup>	
Severe	2.4	6.0a	1.4 <sup>b</sup>	
Very severe	2.1	7.5 <sup>a</sup>	0.5 <sup>b</sup>	
Fibrosis (thickness of the skin) in the affected limb				
None	84.6	70.1 <sup>a</sup>	89.0 <sup>b</sup>	<.001
Mild	10.5	11.9 <sup>a</sup>	10.0 <sup>a</sup>	
Moderate	1.4	4.5 <sup>a</sup>	0.5 <sup>b</sup>	
Severe	2.1	7.5 <sup>a</sup>	0.5 <sup>b</sup>	
Very severe	1.4	6.0 <sup>a</sup>	0 <sub>p</sub>	
Stiffness in the affected limb	•			
None	77.3	68.7a	79.9 <sup>a</sup>	.004
Mild	14.3	13.4 <sup>a</sup>	14.6 <sup>a</sup>	
Moderate	4.9	7.5 <sup>a</sup>	4.1 <sup>a</sup>	
Severe	2.8	7.5 <sup>a</sup>	1.4 <sup>b</sup>	
Very severe	0.7	3.0 <sup>a</sup>	0 <sup>b</sup>	
Hotness in the affected limb	0.7	3.0	· ·	
None	76.2	52.2 <sup>a</sup>	83.6 <sup>b</sup>	<.001
Mild	14.3	26.9 <sup>a</sup>	10.5 <sup>b</sup>	<.001
Moderate	6.6	9.0ª	5.9ª	
Severe	1.4	6.0 <sup>a</sup>	0 <sup>b</sup>	
Very severe	1.4	6.0 <sup>a</sup>	0ь	
Redness in the affected limb	1,-1	0.0	U	
None	86.7	74.6a	90.4 <sup>b</sup>	<.001
Mild	7.3	10.4 <sup>a</sup>	6.4 <sup>a</sup>	<.001
Moderate	4.2	7.5 <sup>a</sup>	3.2ª	
Severe	0.3	1.5 <sup>a</sup>	0ª	
Very severe	1.4	6.0 <sup>a</sup>	0ь	
Burning sensation in the affected limb	1,-1	0.0	U	
None	83.2	67.2a	88.1 <sup>b</sup>	<.001
Mild	9.4	11.9 <sup>a</sup>	8.7 <sup>a</sup>	<.001
Moderate	5.2	13.4 <sup>a</sup>	2.7 <sup>b</sup>	
Severe	5.2 1.0	3.0 <sup>a</sup>	0.5 <sup>a</sup>	
Very severe	1.0	4.5 <sup>a</sup>	0.5°	
Numbness in the affected limb	1.0	4.5	J	
None	62.2	47.8ª	66.7 <sup>b</sup>	.002
Mild	18.9	47.8° 16.4°		.002
Moderate			19.6 <sup>a</sup> 7.8 <sup>b</sup>	
	11.2	22.4 <sup>a</sup>		
Severe Vorus covere	3.8	7.5 <sup>a</sup>	2.7ª	
Very severe Stabbing in the affected limb	3.8	6.0 <sup>a</sup>	3.2ª	
	CC 0	EE 24	70 ah	015
None	66.8	55.2ª	70.3 <sup>b</sup>	.015
Mild	22.0	22.4 <sup>a</sup>	21.9 <sup>a</sup>	
Moderate	7.7	14.9 <sup>a</sup>	5.5 <sup>b</sup>	
Severe	2.4	4.5 <sup>a</sup>	1.8 <sup>a</sup>	
Very severe	1.0	$3.0^{a}$	0.5 <sup>a</sup>	
Tingling in the affected limb			aa =h	
None	59.4	46.3 <sup>a</sup>	63.5 <sup>b</sup>	<.001
Mild	25.9	19.4 <sup>a</sup>	27.9 <sup>a</sup>	
Moderate	9.4	$20.9^{a}$	5.9 <sup>b</sup>	
Severe	2.8	4.5 <sup>a</sup>	2.3 <sup>a</sup>	
Very severe	2.4	9.0 <sup>a</sup>	0.5 <sup>b</sup>	

Table 1 (continued)

	Total $(n = 286)$	Lymphedema $(n = 67)$	Non-lymphedema $(n = 219)$	$p^*$
Weakness in the affected limb				
None	62.2	43.3ª	68.0 <sup>b</sup>	<.001
Mild	23.4	23.9ª	23.3ª	<.001
Moderate	23. <del>4</del> 7.7	16.4 <sup>a</sup>	5.0 <sup>b</sup>	
Severe	4.2	9.0 <sup>a</sup>	2.7 <sup>b</sup>	
Very severe	2.4	7.5 <sup>a</sup>	0.9 <sup>b</sup>	
Seroma (pocket of fluid)	2.4	7.5	0.3	
None	76.6	29.9ª	90.9 <sup>b</sup>	<.001
Mild	12.2	29.9ª	6.8 <sup>b</sup>	<.001
Moderate	5.9	19.4ª	1.8 <sup>b</sup>	
Severe	3.5	13.4ª	0.5 <sup>b</sup>	
Very severe	3.5 1.7	7.5 <sup>a</sup>	0.5 0 <sup>b</sup>	
Cording	1.7	1.5	U	
None	83.9	76.1	86.3	.078
Mild	8.0	9.0	7.8	.076
Moderate	4.2	6.0	3.7	
Severe	2.1	6.0	0.9	
Very severe	2.1 1.7	3.0	1.4	
Limited movement in shoulder	1.7	3.0	1.4	
None	61.9	52.2	64.8	.076
Mild	24.5	25.4	24.2	.076
Moderate	24.3 7.7	14.9	5.5	
Severe	3.8	6.0	3.2	
	3.6 2.1	1.5	2.3	
Very severe Limited movement in elbow	2.1	1.5	2.3	
None	88.5	71.6a	93.6 <sup>b</sup>	<.001
Mild	8.4	19.4ª	5.0 <sup>b</sup>	<.001
Moderate	6.4 2.1	6.0 <sup>a</sup>	0.9 <sup>a</sup>	
Severe	0.7	1.5ª	0.5 <sup>a</sup>	
Very severe	0.7	1.5ª 1.5ª	0.5- 0a	
Limited movement in wrist	0.5	1.5"	U"	
None	87.4	70.1 <sup>a</sup>	92.7 <sup>b</sup>	<.001
Mild	6.3	70.1 <sup>a</sup> 10.4 <sup>a</sup>	92.7° 5.0°	<.001
	6.3 3.1	9.0 <sup>a</sup>	1.4 <sup>b</sup>	
Moderate	2.4		0.9 <sup>b</sup>	
Severe	2.4 0.7	7.5 <sup>a</sup>	0.9°	
Very severe	0.7	3.0 <sup>a</sup>	Us	
Limited movement in arm	56.6	27.23	co.ch	0.01
None	56.6	37.3 <sup>a</sup>	62.6 <sup>b</sup>	<.001
Mild	27.3	31.3 <sup>a</sup>	26.0 <sup>a</sup>	
Moderate	8.7	19.4 <sup>a</sup>	5.5 <sup>b</sup>	
Severe	5.2	9.0 <sup>a</sup>	4.1 <sup>a</sup>	
Very severe	2.1	3.0 <sup>a</sup>	1.8 <sup>a</sup>	
Limited movement in fingers	01.5	C2 73	ozah	000
None	81.5	62.7 <sup>a</sup>	87.2 <sup>b</sup>	<.001
Mild	10.8	17.9 <sup>a</sup>	8.7 <sup>b</sup>	
Moderate	3.8	9.0 <sup>a</sup>	2.3 <sup>b</sup>	
Severe	2.4	6.0 <sup>a</sup>	1.4 <sup>b</sup>	
Very severe	1.4	4.5 <sup>a</sup>	0.5 <sup>b</sup>	

<sup>\*</sup> Chi square test; statistically significant test result  $p \le .05$ 

6.0 (IQR=12.25) for both. The score for women with non-lymphedema was 4.0 (IQR=10.00) and for women with lymphedema was 13.0 (IQR=13.00) (p < .001).

Impaired daily living Function median score was 4.0 (IQR=10.250) and for psychosocial distress 8.0 (IQR=15.250). Significant differences (p<.001) were found in both between women with non-lymphedema and with lymphedema (Table 2).

Table 3 shows the percentage of each item of impaired daily living function and psychosocial distress in women with and without lymphedema and differences between groups.

**Table 2**Median (IQR) and differences between groups for impaired daily living function and psychosocial distress.

	Lymphedema ( $n = 67$ )	Non-lymphedema ( $n = 219$ )	p**
Impaired daily living function, median (IQR)	9.0 (16.0)	3.0 (9.0)	<.001
Psychosocial distress	17.0 (22.0)	7.1 (14.0)	<.001

<sup>\*\*</sup> Mann-Whitney U test; statistically significant test result  $p \leq .05$ 

**Table 3**Percentage of physical-functional distress and psychosocial distress items and differences between groups.

72.0	78.1 <sup>a</sup>		<.001
15.7		25.4 <sup>b</sup>	
8.0	6.8 <sup>a</sup>	11.9 <sup>a</sup>	
3.1	1.8 <sup>a</sup>	7.5 <sup>b</sup>	
1.0	0.5 <sup>a</sup>	$3.0^{a}$	
67.8	72.1 <sup>a</sup>	53.7 <sup>b</sup>	<.001
18.2	18.3 <sup>a</sup>	17.9 <sup>a</sup>	
8.7	6.4 <sup>a</sup>	16.4 <sup>b</sup>	
4.2	3.2 <sup>a</sup>	7.5 <sup>a</sup>	
1.0	0 <sup>a</sup>	4.5 <sup>b</sup>	
78.0	82.6a	62.7 <sup>b</sup>	.002
12.9	11.0 <sup>a</sup>	19.4 <sup>a</sup>	
6.3	4.6a	11.9 <sup>b</sup>	
2.1	1.8 <sup>a</sup>	3.0 <sup>a</sup>	
0.7	$0^a$	3.0 <sup>b</sup>	
53.5	58.0a	38.8 <sup>b</sup>	.008
26.9	26.9a	26.9 <sup>a</sup>	
13.6	11.0 <sup>a</sup>	22.4 <sup>b</sup>	
62.9	67.1 <sup>a</sup>	49.3 <sup>b</sup>	<.001
		16.4a	
		16.4 <sup>a</sup>	
	3.2	5.6	
75.2	78 5 <sup>a</sup>	64 2 <sup>b</sup>	.034
			.054
1.7	0.5	4.5	
76.6	78.5	70.1	.067
			.007
1.0	0.3	5.0	
90.2	00.4	95.1	.371
			.3/1
1.0 1.7	0.9 0.9	1.5 4.5	
	15.7 8.0 3.1 1.0 67.8 18.2 8.7 4.2 1.0 78.0 12.9 6.3 2.1 0.7 53.5 26.9 13.6 2.8 3.1 62.9 18.9 10.5 3.1 4.5 75.2 14.0 5.6 3.5 1.7 76.6 15.7 3.8 2.8 1.0 89.2 4.9 3.1 1.0	15.7	15.7

Table 3 (continued)

	Total $(n = 286)$	Lymphedema ( $n = 67$ )	Non-lymphedema ( $n = 219$ )	p*
Carrying and lifting heavy objects	;			
None	38.5	40.6a	31.3 <sup>a</sup>	.003
Mild	23.4	26.5a	13.4 <sup>b</sup>	
Moderate	19.2	18.3 <sup>a</sup>	22.4 <sup>a</sup>	
Severe	8.7	5.9 <sup>a</sup>	17.9 <sup>b</sup>	
Very severe	10.1	8.7 <sup>a</sup>	14.9 <sup>a</sup>	
Gardening				
None	76.6	79.5 <sup>a</sup>	67.2 <sup>b</sup>	.007
Mild	9.4	9.6 <sup>a</sup>	9.0 <sup>a</sup>	
Moderate	7.3	6.8 <sup>a</sup>	9.0 <sup>a</sup>	
Severe	2.8	0.9 <sup>a</sup>	9.0 <sup>b</sup>	
Very severe	3.8	3.2 <sup>a</sup>	6.0 <sup>a</sup>	
Getting dressed				
None	70.6	72.6	64.2	.387
Mild	19.6	19.2	20.9	
Moderate	4.9	4.1	7.5	
Severe	2.8	2.7	3.0	
Very severe	2.1	1.4	4.5	
Driving				
None	82.2	84.0	76.1	.423
Mild	10.5	10.0	11.9	
Moderate	3.8	2.7	7.5	
Severe	2.1	1.8	3.0	
Very severe	1.4	1.4	1.5	
Making bed				
None	71.0	73.5	62.7	.316
Mild	15.7	15.5	16.4	
Moderate	5.9	5.0	9.0	
Severe	4.5	3.7	7.5	
Very severe	2.8	2.3	4.5	
Leisure activities				
None	64.0	69.9a	44.8 <sup>b</sup>	.003
Mild	21.3	17.4 <sup>a</sup>	34.3 <sup>b</sup>	
Moderate	10.5	9.1 <sup>a</sup>	14.9 <sup>a</sup>	
Severe	2.1	2.3ª	1.5ª	
Very severe	2.1	1.4 <sup>a</sup>	4.5 <sup>a</sup>	
Sleep disturbance				
None	70.3	74.4 <sup>a</sup>	56.7 <sup>b</sup>	.052
Mild	11.2	8.7ª	19.4ª	
Moderate	8.7	7.8 <sup>a</sup>	11.9 <sup>b</sup>	
Severe	5.2	4.6 <sup>a</sup>	7.5 <sup>a</sup>	
Very severe	4.5	4.6 <sup>a</sup>	4.5 <sup>a</sup>	
Psychosocial distress		110		
Family activities				
None	71.7	74.9 <sup>a</sup>	61,2 <sup>b</sup>	.04
Mild	18.9	16.0 <sup>a</sup>	28.4 <sup>b</sup>	
Moderate	6.6	7.3 <sup>a</sup>	4.5 <sup>a</sup>	
Severe	1.7	0.9 <sup>a</sup>	4.5 <sup>a</sup>	
Very severe	1.0	0.9 <sup>a</sup>	1.5 <sup>a</sup>	
Frustration			110	
None	51.4	55.7	37.3	.068
Mild	27.6	26.5	31.3	1000
Moderate	11.2	9.6	16.4	
Severe	5.6	5.0	7.5	
Very severe	4.2	3.2	7.5 7.5	
Sadness	1,2	5.2		
None	40.6	42.9 <sup>a</sup>	32.8 <sup>a</sup>	.003
Mild	29.0	32.4 <sup>a</sup>	17.9 <sup>b</sup>	.003
Moderate	18.9	14.6 <sup>a</sup>	32.8 <sup>b</sup>	
Severe	7.7	6.8 <sup>a</sup>	10.4 <sup>a</sup>	
Very severe	3.8	3.2 <sup>a</sup>	6.0 <sup>a</sup>	

Table 3 (continued)

	Total $(n = 286)$	Lymphedema ( $n = 67$ )	Non-lymphedema ( $n = 219$ )	<i>p</i> *
Guilt				
None	87.1	90.4 <sup>a</sup>	76.1 <sup>b</sup>	.009
Mild	6.6	5.9 <sup>a</sup>	9.0ª	
Moderate	4.5	2.7 <sup>a</sup>	10.4 <sup>b</sup>	
Severe	1.4	0.9 <sup>a</sup>	3.0 <sup>a</sup>	
	0.3	0 <sup>a</sup>	1.5 <sup>a</sup>	
Concern				
	27.3	29.7	19.4	.074
Mild	29.4	31.5	22.4	
Moderate	25.5	23.3	32.8	
Severe	11.5	9.6	17.9	
	6.3	5.9	7.5	
Irritability	0.5	3.3	7.5	
-	52.8	56.6a	40.3 <sup>b</sup>	.008
Mild	23.1	24.2 <sup>a</sup>	19.4 <sup>a</sup>	.000
Moderate	13.3	11.4 <sup>a</sup>	19.4 <sup>a</sup>	
Severe	8.0	5.9 <sup>a</sup>	14.9 <sup>b</sup>	
	2.8	1.8 <sup>a</sup>	6.0 <sup>a</sup>	
Fear	۷.0	1.0	0.0	
None	38.5	40.6	31.3	.277
Mild	27.6	27.9	26.9	.211
Moderate				
	19.6	19.2	20.9	
	8.7	6.8	14.9	
	5.6	5.5	6.0	
Anger			h	
None	57.0	60.7 <sup>a</sup>	44.8 <sup>b</sup>	.002
	23.8	25.1 <sup>a</sup>	19.4 <sup>a</sup>	
Moderate	10.5	7.3 <sup>a</sup>	20.9 <sup>b</sup>	
Severe	5.9	5.0 <sup>a</sup>	$9.0^{a}$	
•	2.8	1.8 <sup>a</sup>	6.0 <sup>a</sup>	
Loneliness				
None	68.9	72.1 <sup>a</sup>	58.2 <sup>b</sup>	.004
Mild	17.8	18.7 <sup>a</sup>	14.9 <sup>a</sup>	
Moderate	5.6	3.7 <sup>a</sup>	11.9 <sup>b</sup>	
	4.5	2.7 <sup>a</sup>	10.4 <sup>b</sup>	
Very severe	3.1	2.7 <sup>a</sup>	4.5 <sup>a</sup>	
Dependency				
None	67.5	73.5 <sup>a</sup>	47.8 <sup>b</sup>	.001
Mild	16.4	14.6 <sup>a</sup>	22.4 <sup>a</sup>	
Moderate	9.1	7.3 <sup>a</sup>	14.9 <sup>a</sup>	
Severe	3.8	2.7 <sup>a</sup>	7.5 <sup>a</sup>	
Very severe	3.1	1.8 <sup>a</sup>	7.5 <sup>b</sup>	
Hopelessness				
-	65.4	70.3 <sup>a</sup>	49.3 <sup>b</sup>	.008
Mild	20.3	19.2 <sup>a</sup>	23.9 <sup>a</sup>	
	5.6	4.1 <sup>a</sup>	10.4 <sup>b</sup>	
Severe	5.9	4.1 <sup>a</sup>	11.9 <sup>b</sup>	
	2.8	2.3ª	4.5 <sup>a</sup>	
Anxiety				
	45.5	50.2 <sup>a</sup>	29.9 <sup>b</sup>	.002
Mild	24.1	25.1 <sup>a</sup>	20.9 <sup>a</sup>	<del></del>
Moderate	17.1	15.1 <sup>a</sup>	23.9 <sup>a</sup>	
Severe	8.4	5.9 <sup>a</sup>	16.4 <sup>b</sup>	
	4.9	3.7 <sup>a</sup>	9.0 <sup>a</sup>	
Depression	1,3	5.,	5.0	
None	59.4	65.8 <sup>a</sup>	38.8 <sup>b</sup>	<.001
Mild		19.6 <sup>a</sup>	22.4 <sup>a</sup>	<.001
	20.3		22.4° 20.9 <sup>b</sup>	
Moderate	10.8	7.8 <sup>a</sup>		
Severe	4.9	3.7ª	9.0 <sup>a</sup>	
Very severe	4.5	3.2 <sup>a</sup>	9.0 <sup>b</sup>	

Table 3 (continued)

	Total ( $n = 286$ )	Lymphedema ( $n = 67$ )	Non-lymphedema ( $n = 219$ )	<b>p</b> *
Self-perception				
None	51.7	55.7	38.8	.057
Mild	26.2	26.0	26.9	
Moderate	13.3	11.4	19.4	
Severe	5.9	4.6	10.4	
Very severe	2.8	2.3	4.5	
Sex life with partner				
None	57.0	57.5	55.2	.750
Mild	26.6	26.9	25.4	
Moderate	9.8	9.6	10.4	
Severe	2.1	2.3	1.5	
Very severe	4.5	3.7	7.5	
Emotional relationship with partner				
None	69.2	69.9	67.2	.865
Mild	24.5	24.2	25.4	
Moderate	2.8	2.3	4.5	
Severe	0.3	0.5	0	
Very severe	3.1	3.2	3.0	
Impact on work outside				
None	74.5	77.6 <sup>a</sup>	64.2 <sup>b</sup>	.007
Mild	14.0	14.6 <sup>a</sup>	11.9 <sup>a</sup>	
Moderate	6.3	4.1 <sup>a</sup>	13.4 <sup>b</sup>	
Severe	2.1	1.8 <sup>a</sup>	3.0 <sup>a</sup>	
Very severe	3.1	1.8 <sup>a</sup>	7.5 <sup>b</sup>	

<sup>\*</sup> Chi square test; statistically significant test result  $p \leq .05$ 

Finally, median for total score symptom experience was 23.0 (IQR=33.00), 17.0 (IQR=27.00) and 43.0 (IQR=51.00) for women with non-lymphedema and lymphedema respectively (p < .001).

## 2. Experimental Design, Materials and Methods

The data was collected, using a cross-sectional design, from patients recruited from the Hospital Universitario Central de Asturias (HUCA) in Oviedo, Spain between October 2018 and June 2020 [1]. Is important to highlight that breast cancer-related lymphedema is a chronic complication that occurs in one of five patients who have undergone breast cancer treatment [2]. Lymphedema can cause physical, psychological and social harm [3,4] and negatively affects a patient's quality of life [5]. Therefore, a holistic assessment is essential for clinicians and researchers to understand, diagnose and prevent lymphedema.

The Spanish Version of The Breast Cancer and Lymphedema Symptoms Experience Index (BCLE-SEI-Es), adapted from the English version [6], were used to assessment lymphedema symptoms and impacts of lymphedema symptoms. BCLE-SEI-Es Spanish version is a two-part, 5-point, Likert-type self-report instrument. Part I, symptom occurrence, include 24 items (symptoms) related to lymphedema described in Table 2. Part II assesses the symptom distress, that is, the negative impact and suffering evoked by an individual's experience of lymphedema symptoms. It has two subscales impaired daily living function (15 items) and psychosocial distress (17 items) described in Table 4. Each item is rated on a Likert-type scale from 0 (no presence of a given symptom/ no distress) to 4 (greatest severity of a given symptom/ higher distress). Total symptom occurrence, impaired daily living function and psychosocial distress score is the summation of the items included on each subscale. In all subscales higher scores reflects more severe symptom distress. Finally, symptom occurrence score and distress score were added together to result the total score symptom experience.

#### Table 4

## BCLE-SEI-Es Spanish version data description

# Sociodemographic and clinical characteristics

- (A) Age: age of women
- (B) Study level: knowledges of years of study
- (C) Marital Status: civil status of each woman
- (D) Type of job: a full or part-time position of paid employment, homemaker, unemployment or retired
- (E) Laboral Status: currently working or not
- (F) Year of diagnosis: year of the diagnosis of the breast cancer
- (G) Time since diagnosis: years between the diagnosis of breast cancer and the questionnaire made
- (H) Tumor side: place where the tumor developed (right or left breast)
- (I) Lymphedema diagnosis: diagnosis or not of lymphedema
- (J) Months since Lymphedema diagnosis: months between the diagnosis of breast cancer and the develop of lymphedema
- (K) Surgery: mastectomy or tumourectomy
- (L) Radiotherapy: received or not this type of treatment
- (M) Chemotherapy: received or not this type of treatment

#### Symptoms

- (N) Pain/aching/soreness: assessment of pain as a symptom of lymphedema in the affected limb
- (O) Tenderness: assessment of tenderness as a symptom of lymphedema in the affected limb
- (P) Arm/hand swelling: assessment of inflammation arm/hand as a symptom of lymphedema in the affected limb
- (Q) Breast swelling: assessment of breast inflammation in the tumor side as a symptom of lymphedema
- (R) Chest wall swelling: assessment of chest wall inflammation in the tumor side as a symptom of lymphedema
- (S) Firmness in the affected limb: assessment of firmness as a symptom of lymphedema in the affected limb
- (T) Tightness in the affected limb: assessment of tightness as a symptom of lymphedema in the affected limb
- (U) Heaviness in the affected limb: assessment of heaviness as a symptom of lymphedema in the affected limb
- (V) Fibrosis in the affected limb: assessment of fibrosis (thickness of the skin) as a symptom of lymphedema in the affected limb
- (W) Stiffness in the affected limb: assessment of stiffness as a symptom of lymphedema in the affected limb
- (X) Hotness in the affected limb: assessment of hotness as a symptom of lymphedema in the affected limb
- (Y) Redness in the affected limb: assessment of redness as a symptom of lymphedema in the affected limb
- (Z) Burning sensation in the affected limb: assessment of burning sensation as a symptom of lymphedema in the affected limb
- (AA)Numbness in the affected limb: assessment of numbness as a symptom of lymphedema in the affected limb
- (AB) Stabbing in the affected limb: assessment of stabbing as a symptom of lymphedema in the affected limb
- (AC) Tingling in the affected limb: assessment of tingling as a symptom of lymphedema in the affected limb.
- (AD) Weakness in the affected limb: assessment of weakness as a symptom of lymphedema in the affected limb
- (AE) Seroma: assessment of pocket of fluid as a symptom of lymphedema in the affected limb
- (AF) Cording: assessment of tissue cords, palpable and even observable, that go from the armpit to the inner side of the arm, accompanied by axillary pain and limited movement of the shoulder, as a symptom of lymphedema in the affected limb
- (AG) Limited movement in shoulder: assessment of movement limitation in the shoulder as a symptom of lymphedema in the affected limb
- (AH) Limited movement in elbow: assessment of movement limitation in the elbow as a symptom of lymphedema in the affected limb
- (Al) Limited movement in wrist: assessment of movement limitation in the wrist as a symptom of lymphedema in the affected limb
- (AJ) Limited movement in arm: assessment of movement limitation in the arm as a symptom of lymphedema in the affected limb
- (AK) Limited movement in fingers: assessment of movement limitation in the fingers as a symptom of lymphedema in the affected limb

#### Physical-functional distress

- (AL) Cooking: assessment of negative impact to cook by the experience of lymphedema symptoms in the daily living function
- (AM) Cutting food with a knife: assessment of negative impact to cut food with a knife by the experience of lymphedema symptoms in the daily living function

#### Table 4 (continued)

- (AN) Writing/typing: assessment of negative impact to write or type by the experience of lymphedema symptoms in the daily living function
- (AO) Cleaning the house: assessment of negative impact to clean the house by the experience of lymphedema symptoms in the daily living function
- (AP) Vacuuming: assessment of negative impact to vacuum the house by the experience of lymphedema symptoms in the daily living function
- (AQ) Doing the laundry: assessment of negative impact to do the laundry by the experience of lymphedema symptoms in the daily living function
- (AR) Bathing or showering: assessment of negative impact to take a bath or shower by the experience of lymphedema symptoms in the daily living function
- (AS) Taking care of children: assessment of negative impact to take care of children by the experience of lymphedema symptoms in the daily living function
- (AT) Carrying and lifting heavy objects: assessment of negative impact to carry heavy objects by the experience of lymphedema symptoms in the daily living function
- (AU) Gardening: assessment of negative impact to garden by the experience of lymphedema symptoms in the daily living function
- (AV) Getting dressed: assessment of negative impact to garden by the experience of lymphedema symptoms in the daily living function
- (AW) Driving: assessment of negative impact to drive by the experience of lymphedema symptoms in the daily living function
- (AX) Making bed: assessment of negative impact to make the bed by the experience of lymphedema symptoms in the daily living function
- (AZ) Leisure activities: assessment of negative impact to the leisure activities by the experience of lymphedema symptoms
- (BN) Sleep disturbance: assessment of negative impact on the sleep (wake up at night) by the experience of lymphedema symptoms in the daily living function

#### Psychosocial distress

- (AY) Family activities: assessment of psychosocial distress on the family, friends, neighbors or groups activities by the experience of lymphedema symptoms
- (BA) Frustration: assessment of the frustration as psychosocial distress by the experience of lymphedema symptoms
- (BB) Sadness: assessment of the sadness as psychosocial distress by the experience of lymphedema symptoms
- (BC) Guilt: assessment of the guilt as psychosocial distress by the experience of lymphedema symptoms
- (BD) Concern: assessment of the concern as psychosocial distress by the experience of lymphedema symptoms
- (BE) Irritability: assessment of the irritability as psychosocial distress by the experience of lymphedema symptoms
- (BF) Fear: assessment of the fear as psychosocial distress by the experience of lymphedema symptoms
- (BG) Anger: assessment of the anger as psychosocial distress by the experience of lymphedema symptoms
- (BH) Loneliness: assessment of the loneliness as psychosocial distress by the experience of lymphedema symptoms
- (BI) Dependency: assessment of the dependency as psychosocial distress by the experience of lymphedema symptoms
- (BJ) Hopelessness: assessment of the hopelessness as psychosocial distress by the experience of lymphedema symptoms
- (BK) Anxiety: assessment of the anxiety as psychosocial distress by the experience of lymphedema symptoms
- (BL) Depression: assessment of the depression as psychosocial distress by the experience of lymphedema symptoms
- (BM) Self-perception: assessment of psychosocial distress on the self-perception by the experience of lymphedema symptoms
- (BO) Sex life with partner: assessment of psychosocial distress on the sexual relationships by the experience of lymphedema symptoms
- (BP) Emotional relationship with partner: assessment of psychosocial distress on the emotional relationship with partner by the experience of lymphedema symptoms
- (BQ) Impact on work outside: assessment of psychosocial distress on the work by the experience of lymphedema symptoms
- (BR) Symptom\_OC\_total: summatory of the total symptom occurrence score
- (BS) Physical\_Functional\_distress: summatory of the total physical-functional distress
- (BY) Phychosocial\_distress: summatory of the total psychosocial distress
- (BU) Total\_Score: result of the total score BCLE-SEI-Es

For the description of the demographic characteristics of the sample and subscale items, means and standard deviations (SD) and absolute and relative values were calculated depending on the nature of the variables. The assumption of non-normality of the distribution of the quantitative variables was verified using the Kolmogorov-Smirnov test and the corresponding non-parametric tests were performed. Total scores, median, and IQR for each subscale and for total score symptom experience was calculated. To compare these scores between groups (non-lymphedema and lymphedema diagnosed) the Mann-Whitney test was used.

#### **Ethics Statements**

The study was performed in accordance with the Helsinki Declaration and local law and was approved by the Principado de Asturias Research Ethics Committee (ref. 190/18). All patients were informed about the objective of the study and presented data are anonymized.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

# **Data Availability**

Data for BCLE SEI Esp (Original data) (Mendeley Data).

#### **CRediT Author Statement**

**R Martin-Payo:** Conceptualization, Methodology, Formal analysis, Writing – original draft; **J Cachero-Rodriguez:** Investigation; **E Alvarez-Gomez:** Formal analysis, Writing – review & editing; **MR Fu:** Conceptualization, Methodology, Writing – original draft; **A Llaneza-Folgueras:** Investigation; **MdM Fernandez-Alvarez:** Methodology, Investigation, Formal analysis, Writing – review & editing.

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# **Supplementary Materials**

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.dib.2022.108699.

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