

Phantom breast sensations are frequent after mastectomy

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ABSTRACT

INTRODUCTION: Phantom breast sensation (PBS) following mastectomy has been recognized for many years. PBS is a feeling that the removed breast is still there. The reported prevalence and risk factors have not been established in large well-defined patient series. The purpose of this study was to examine the prevalence of PBS following mastectomy and associated risk factors.

MATERIAL AND METHODS: This study was part of a nationwide cross-sectional questionnaire study of women aged 18-70 years treated for primary unilateral breast cancer in Denmark between 1 January 2005 and 31 December 2006. A detailed questionnaire was mailed to respondents between January and April 2008. Only questionnaires from mastectomised women were analyzed. The main outcome measures were prevalence of PBS in mastectomized Danish women and adjusted odds ratio (OR) of PBS with respect to age, pain in the breast area, surgical technique, chemotherapy and radiotherapy.

RESULTS: A total of 1,131 women (84%) answered the questionnaire. A total of 26% experienced PBS, viz. the proportion ranged from 18% to 35% within the six well-defined treatment groups, but only young age was a risk factor for PBS (OR 1.030 per year; 95% CI 1.010-1.050; $p = 0.0026$).

CONCLUSION: The prevalence of PBS during the first 1-3 years after mastectomy is about 25% and it is related to young age.

Every year approx. 4,000 Danish women are diagnosed with breast cancer. This incidence is likely to increase owing to the introduction of a nationwide breast cancer screening programme in 2008 [1]. About 30% of these women still undergo mastectomy [2] although conservative breast cancer surgery has become the standard treatment for certain tumour stages. Previous studies have shown that mastectomised women experience various postoperative sequelae including phantom breast sensation (PBS) in 10-66% of cases [3, 4]. An analysis of 29 studies (25 studies reporting PBS) published in the period from 1950 to 2007 showed that early studies reported a significantly higher PBS prevalence than later studies [5], which indicated a need for more large studies based on well-defined modern principles of treatment.

The purpose of this study was therefore to examine the prevalence and associated factors of PBS among mastectomised Danish women in a nationwide study.

MATERIAL AND METHODS

Definition

The term PBS is defined as a feeling that the removed breast is still present. Thus, PBS covers both phantom breast pain and non-painful phantom breast sensation.

Population

This study was part of a larger nationwide study concerning persistent pain, sensory disturbances, lymphoedema and functional ability among Danish women who received breast cancer surgery [6, 7].

Women aged from 18 to 70 years who received mastectomy for unilateral primary breast cancer in Denmark between 1 January 2005 and 31 December 2006 were included. The exclusion criteria were non-standard treatment, reconstruction or corrective breast surgery, emigration, cancer relapse, new breast cancer, other malignant disease or death. A total of 1,347 women matched the inclusion criteria [8]. A detailed questionnaire was sent to 1,347 eligible women between January and April 2008 with a reminder three weeks later. A total of 1,131 women (84%) answered the questionnaire.

Treatment

All women in the study received treatment according to the 2004 treatment protocol of the Danish Breast Center

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ABBREVIATIONS

ALND = axillary lymph node dissection
ATRT = anterior thoracic radiotherapy, radiotherapy corresponding to the ipsilateral anterior thoracic wall
CI = confidence interval
DBCg = Danish Breast Center Cooperative Group
IQR = interquartile range
LRRT = locoregional radiotherapy, radiotherapy corresponding to periclavicular, axillary level 3 and for right-sided breast cancers, the internal mammary nodes
OR = odds ratio
PBS = phantom breast sensation
SLND = sentinel lymph node dissection

Cooperative Group (DBCG) [8, 9]. They were divided in to six major treatment groups according to type of surgery and adjuvant radiotherapy, and chemotherapy.

Registries

Demographic and treatment data were retrieved from the DBCG [9]. Information on mortality was retrieved from the Danish Civil Registration System and information about reconstruction or corrective breast surgery was retrieved from the Danish National Patient Registry [6].

Ethics

The study was approved by the Danish Data Protection Agency and the Danish National Patient Registry under the Danish National Board of Health. All breast cancer departments in Denmark were informed about the study and gave their approval.

Questionnaire

The questionnaire was based on questions identified in the literature and on open interviews with 20 women who underwent breast cancer surgery [6]. The questions focused on pain in the area of the breast and the severity and frequency of such pain. Furthermore, a number of questions focused on functional impairment, lymph-

oedema, sensory disturbances, discomfort in the breast area and phantom sensation (**Table 1**).

Statistics

Multivariate logistic regression was applied for calculation of an adjusted odds ratio and 95% confidence interval of PBS in relation to age, pain in the breast area (yes versus no), axillary procedure (axillary lymph node dissection (ALND) versus sentinel lymph node dissection (SLND)), chemotherapy (cyclophosphamide, epirubicin and fluorouracil versus none) and radiotherapy (anterior thoracic radiotherapy (ATRT) + locoregional radiotherapy (LRRT) versus none). The wald χ^2 test was applied for calculation of p values and results with a p value ≤ 0.05 were considered significant. PROC LOGISTICS in SAS version 9.1 (SAS Institute, Cary, North Carolina) was applied for these calculations.

Trial registration

This study was not registered in a clinical trial database because it was a questionnaire study based on standard treatment of breast cancer in Denmark.

RESULTS

The overall response rate was 84%. The response rate for each of the six treatment groups was in the range 79-93%. The mean time from the mastectomy to questionnaire response was 26 months (varying from 13 to 41 months).

The prevalence of PBS was 26% (**Table 2**). Ninety-six percent of the women who responded to the questionnaire answered the question concerning PBS. Logistic regression analysis was applied for calculation of the association between the prevalence of PBS and age, pain in the breast area, chemotherapy, radiotherapy and ALND. Data on pain in the breast area were missing in the answers from 3% of the women. All other data were retrieved from registries and were therefore complete for all 1,131 women.

A significant association was found between PBS and age, PBS being highest among young women (OR 1.030 per year; 95% confidence interval (CI) 1.010-1.050; $p = 0.0026$). Pain in the breast area was associated with an increased prevalence of PBS (OR 2.999; 95% CI 2.251-3.997; $p < 0.0001$). The women who received ALND had a significantly lower prevalence of PBS than those receiving SLND (OR 0.645; 95% CI 0.420-0.991; $p = 0.0456$). Neither chemotherapy (OR 0.909; 95% CI 0.638-1.295; $p = 0.5970$) nor radiotherapy (OR 0.907; 95% CI 0.630-1.307; $p = 0.6013$) was associated with PBS (**Table 3**).

DISCUSSION

This study showed that 26% of mastectomised women experienced PBS 1-3 years after their surgery, and PBS



TABLE 1

The questions from the questionnaire analyzed in the present study^a.

Questions	Possible answers
Do you feel pain in the area of the breast, the axilla, the side of the thorax or the arm on the side where you received surgery?	Yes No
If "Yes", where do you feel pain? (Tick <i>all</i> the areas where you feel pain)	The area of the breast The side of the thorax The axilla The arm
If you feel pain in the area of the breast, how intense is the pain on average? (0 indicates no pain and 10 indicates the worst possible pain)	<input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10
If you feel pain in the area of the breast, how frequent is the pain?	Every day or almost every day 1-3 times a week Less frequently
Do you experience sensory disturbances or discomfort in the area of the breast, the axilla, the side of the thorax or the arm on the side where you received surgery?	Yes No
If "Yes", where do you experience sensory disturbances or discomfort? (Tick <i>all</i> the areas where you experience sensory disturbances or discomfort)	The area of the breast The side of the thorax The axilla The arm
Do you experience phantom sensation after your surgery? (phantom sensation is a feeling that the removed breast is still there)	Yes No

a) The questionnaire was originally in Danish language. The questions have not been validated in English language.



TABLE 2

Phantom breast sensation, pain and sensory disturbances in the breast area among 1,131 mastectomised Danish women categorized into six treatment groups according to type of surgery, radiotherapy and chemotherapy.

Adjuvant therapy	Treatment modality						Total
	mastectomy and SLND		mastectomy and ALND		ATRT+LRRT ^b without chemo- therapy	ATRT+LRRT ^b and chemo- therapy ^a	
	none	chemo- therapy ^a	none	chemo- therapy ^a			
Nonresponders, n (%)	40 (21)	15 (15)	36 (20)	7 (7)	62 (15)	56 (16)	216 (16)
Age, years, median (IQR)	62 (58-66)	54 (41-62)	59.5 (55-64)	48 (46-51)	62 (59-66)	48 (41-52)	
Responders, n (%)	153 (79)	86 (85)	147 (80)	96 (93)	352 (85)	297 (84)	1,131 (84)
Age, years, median (IQR)	62 (58-66)	53 (48-61)	60 (56-65)	48.5 (43-56)	61 (57-65)	48 (44-55)	
PBS, n (%)	41 (27)	29 (34)	26 (18)	34 (35)	87 (25)	75 (25)	292 (26)
Pain in the breast area, n (%)	37 (24)	28 (33)	49 (33)	39 (41)	153 (43)	138 (46)	444 (39)
Sensory disturbances in the breast area, n (%)	44 (29)	31 (36)	36 (24)	38 (40)	115 (33)	129 (43)	393 (35)

ALND = axillary lymph node dissection; ATRT = anterior thoracic radiotherapy, radiotherapy corresponding to the ipsilateral anterior thoracic wall; IQR = interquartile range; LRRT = locoregional radiotherapy, radiotherapy corresponding to periclavicular, axillary level 3 and for right-sided breast cancers, the internal mammary nodes; PBS = phantom breast sensation; SLND = sentinel lymph node dissection.

a) Chemotherapy: cyclophosphamide, epirubicin and fluorouracil.

b) Radiotherapy with 48Gy over 24 fractions.

was associated with low age as it was 34% higher for e.g. women aged 30 years than for women aged 40 years (OR 1.030 pr. year^{-10 years} = 1.344).

Compared with previous literature [3, 10-18], the strength of our study lies in its nationwide setup, its large number of participants and its high response rate.

All participants were treated in accordance with the DBCG's guidelines [8, 9] and categorization of the participants by treatment group was therefore made possible with no loss of data. Demographic data and information on treatment, mortality, reconstructive and corrective breast surgery was retrieved from registries which ensured complete data coverage for all participants in conformity with well-defined inclusion criteria.

The cross-sectional design of this study only permits study of associations, but not causality. Women receiving non-standardized treatment, breast reconstruction or corrective breast surgery and women with cancer relapse or other malignant disease were excluded from the study. It is possible that this heterogeneous group has another PBS profile than the group of women comprised by this study.

The comparability of this study with other studies must be assessed in light of the structure of the Danish society. The Danish population is mostly ethnically homogeneous (Caucasian) and well-educated and all citizens have equal access to a uniform public health system. These factors may limit the generalizability of the results from this study to other populations.

The prevalence of PBS in this study varied between 18% and 35% in the six treatment groups. This is in agreement with prior studies where the prevalence of PBS varied between 10% and 66% [5]. This variation was primarily due to an uneven age spread in the groups because the women who receive chemotherapy in general

are younger than the women who receive other kinds of treatment. Another nationwide Danish study of post-operative sequelae in long-term breast cancer survivors reported that 24% of mastectomised women experienced PBS [4], but this study included other treatment principles effective between 1990 and 2000. A literature analysis from 2007 found that about 36% of mastectomised women experienced PBS, but, again, this study was also based on 25 studies published in the 1950-2007



TABLE 3

Phantom breast sensation adjusted for age, axillary procedure, pain in the breast area, chemotherapy and radiotherapy.

	Women, n (%)		Adjusted ^a OR (95% CI)	p value
	with PBS	without PBS		
Age			1.03 (1.010-1.050)	0.0026*
<i>Pain in the breast area</i>				
Yes	169 (40)	255 (60)	2.999 (2.251-3.997)	< 0.0001*
No	123 (19)	534 (81)	1 (reference)	
<i>Axillary procedure</i>				
ALND	222 (26)	628 (74)	0.645 (0.420-0.991)	0.0456*
SLND	70 (30)	161 (70)	1 (reference)	
<i>Radiotherapy^b</i>				
ATRT + LRRT	162 (26)	458 (74)	0.907 (0.630-1.307)	0.6013
No	130 (28)	331 (72)	1 (reference)	
<i>Chemotherapy^c</i>				
Yes	138 (30)	324 (70)	0.909 (0.638-1.295)	0.597
No	154 (25)	465 (75)	1 (reference)	

ALND = axillary lymph node dissection; ATRT = anterior thoracic radiotherapy, radiotherapy corresponding to the ipsilateral anterior thoracic wall; CI = confidence interval; LRRT = locoregional radiotherapy, radiotherapy corresponding to periclavicular, axillary level 3 and for right-sided breast cancers, the internal mammary nodes; PBS = phantom breast sensation; SLND = sentinel lymph node dissection.

a) Adjusted for age, pain in the breast area, axillary procedure, radiotherapy, and chemotherapy.

b) Radiotherapy with 48Gy over 24 fractions.

c) Chemotherapy: cyclophosphamide, epirubicin and fluorouracil.

*) Statistically significant ($p \leq 0.05$).

Young woman after right-sided mastectomy.



period during which treatment principles which were different from those valid in the period spanned by the present study [6]. Thus, the prevalence of PBS may be lower in more recent studies than in early studies [5]. The decline in the prevalence of PBS in recent studies suggests that the occurrence of PBS depends on various treatment factors such as implementation of “modified radical mastectomy”, a surgical technique where the major and minor pectoral muscles are spared.

The time interval after the mastectomy for which the PBS prevalence has been reported has varied markedly and PBS is known to have an intermittent character and to occur in the first months to years after mastectomy [3, 5]. The prevalence in each study must therefore be assessed in relation to the actual time interval which, therefore, hampers direct comparison of the prevalence of PBS across studies.

The association between low age and PBS has previously been debated. However, the results of our study (1,131 women) are similar to those reported in another previous nationwide study (the calculation of this association is based on 1,270 out of 1,316 women) [4], but different from those of other studies which have shown no association between low age and PBS in smaller study populations of 39 and 110 women [5, 10, 11, 14, 17]. The causes for the high prevalence of PBS among young women remain unknown. Studies have shown that the peripheral nerves degenerate with age [19]. This may be a physiological explanation for the decline of PBS with age. Also, young women may be more focused on the body's signals than elderly women and therefore better notice and remember PBS.

The odds ratio for PBS and pain in the breast area showed that women who experienced PBS had a three times higher prevalence of pain than other mastectomised women. This association is likely to be caused by phantom breast pain, but the questionnaire did not pro-

vide distinct questions to differentiate between phantom breast pain and pain in the breast area.

No association was found between chemotherapy and PBS or between radiotherapy and PBS. This is in accordance with results reported by other studies [4, 5, 14, 16].

Women who receive ALND have a lower prevalence of PBS than women receiving SLND. To our knowledge, this association has not previously been reported. An explanation might be that women undergoing SLND are more sensitive to minor symptoms than women undergoing ALND because major symptoms appear less frequently in the SLND group. The difference in prevalence of PBS in the two groups was significant when calculated by multivariate logistic regression ($p = 0.0456$); however, the difference between the two groups was insignificant when a regular χ^2 test ($p = 0.19$) was used.

A previous study revealed that some patients did not want to mention their PBS experience to their physician in fear of being considered “insane” [16]. This underlines the importance of patient information to prevent incorrect conception of the PBS phenomena.

In conclusion, the prevalence of PBS during the first 1-3 years after mastectomy was 26% (18-35%), and it was highest among young women while other treatment principles had less or no influence on the prevalence of PBS.

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