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Phantom breast syndrome: The effect of *in situ* breast carcinoma

Christos J. Markopoulos [a], Areti C. Spyropoulou [b,*], Iannis M. Zervas [b], George N. Christodoulou [c], Charalabos Papageorgiou [b]

[a] *Breast Unit, Second Department of Propedeutic Surgery, Laiko General Hospital, University of Athens, Athens, Greece*
[b] *First Department of Psychiatry, Eginition Hospital, University of Athens, Athens, Greece*
[c] *Hellenic Psychiatric Association, Athens, Greece*

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ABSTRACT

Phantom breast syndrome (PBS) represents the experience of the continued presence of the breast, after mastectomy. Our aim was to assess PBS appearance by means of a structured questionnaire and to look into possible associations to disease and treatment parameters, in 105 women with breast cancer treated by mastectomy. PBS was recorded in 22.9% of the patients. In the majority of cases phantom experience had the size (88.9%), shape (76.5%) and weight (64.7%) of the normal breast and was localised in the entire breast (50%). Concerning disease parameters, no association with primary tumour size (T) or lymph node status was detected, but interestingly, *in situ* breast cancer (DCIS) was found to be more frequently associated with PBS, compared with invasive tumours. No significant associations of PBS with previous sensory experiences of the breast, radiotherapy or systemic treatment were assessed. The results are interpreted within the frame of Melzack's theory of a neuromatrix, assuming that PBS represents the continued existence, even after amputation, of a sensory engram of the breast. The absence of infiltration in primary tumour histology, probably through an unknown pathophysiological mechanism, might play a role for the significantly higher incidence of PBS in women undergoing mastectomy for DCIS.

1. Introduction

Phantom breast syndrome (PBS), which refers to the experience of the continued presence of the breast after its removal by mastectomy, is already known as a possible consequence of breast surgery (Jarvis, 1967; Jamison et al., 1979; Christensen et al., 1982; Krøner et al., 1989; Krøner et al., 1992). In a recent review of 29 previously published studies, the weighted mean prevalence for phantom breast sensations was estimated to be 36.5% (range: 10–66%), whereas phantom pain was reported by 10.9% (range: 0–53%) of breast cancer patients (Dijkstra et al., 2007). Studies specifically researching PBS are sparse, possibly because PBS does not cause the magnitude of clinical problems attributed to phantom limbs but seems rather to be a minor issue in the process of coping with breast cancer and mastectomy (Crone-Munzebrock, 1950; Moore and Stayton, 1981; Dijkstra et al., 2007; Spyropoulou et al., 2008). Thus, whereas PBS concerns a great number of breast cancer survivors, its clinical characteristics and the biological and psychosocial parameters related to its appearance and its formation are poorly appreciated. We recently reported that PBS is associated with higher scores of depressive symptomatology (Spyropoulou et al., 2008); a finding that was previously reported by Jarvis (1967).

Phantom sensations, after the amputation of a limb, are experienced more frequently than PBS and their prevalence range between 18% and 100% (Sherman and Sherman, 1983), whereas phantom limb pain occurs in 50–80% of limb amputees (Flor, 2002). Despite the obvious similarities between PBS and phantom limbs, it seems that the frequency and the impact on patient's quality of life are not the only characteristics that discriminate PBS and phantom limbs. Rothemund et al. (2004) proposed that phantom breast phenomena seem to differ from phantom limb phenomena in a variety of ways, such as time of onset or localisation. In their study the onset of phantom pain was found to be within the first 3 months after mastectomy, whereas phantom pain was localised mostly in the entire breast (Rothemund et al., 2004). In the case of limb amputees, phantom limb pain is localised mostly in the distal parts of the phantom limb and the incidence of phantom limb tends to decrease over time (Jensen and Rasmussen, 1994).

The present study was designed to assess PBS to detect its clinical characteristics, and to examine its possible associations with disease and treatment variables, menstrual history and time since mastectomy. Further, as it was hypothesised that experiencing sensory symptoms locally, at the breast, prior to mastectomy may constitute

* Corresponding author. First Department of Psychiatry, Eginition Hospital, University of Athens, 74, Vas. Sofias Ave., 11528, Athens, Greece. Tel./fax: +30 210 7297957.
E-mail address: arspyrop@yahoo.com (A.C. Spyropoulou).

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a probable background for developing PBS after breast amputation, this study also investigated the possible association of PBS with the former sensory history of the breast.

2. Patients and methods

2.1. Patients

A total of 105 women with breast cancer were included in this study. They all had been treated by mastectomy due to large primary tumour size, presence of multiple invasive tumours in the same or different quadrant of the breast — multifocal or multicentric disease — or extended ductal carcinoma *in situ*. They were all outpatients and were recruited during their post-surgical follow-up. The study was approved by the Hospital's ethical committee, and written informed consent was obtained from all patients at the time of recruitment.

Exclusion criteria were (a) a history of metastases, (b) time under 2 months since breast surgery and (c) breast conserving surgery. Women with metastatic cancer were excluded, as it was hypothesised that the concern about their medical condition would make the involvement with the study tasks, hard for them. Women who had breast surgery less than 2 months before the assessment were excluded in order to ensure sufficient wound healing, and to avoid post-surgical sequelae such as swelling, which might cause symptoms difficult to distinguish from phantom breast sensations. Finally, women who were treated by lumpectomy were excluded, as it would be impossible to differentiate whether sensations were originating from the site of the removed lump or from the residual breast tissue.

The mean age of the patients was 59.4 years (S.D. = 11.4, range: 38–86). Demographics of the total sample are presented in Table 1. Disease and treatment variables are presented in Table 3; at the time of the assessment, mean time since breast surgery was 2.57 years (S.D. = 2.29).

2.2. Assessment

A structured questionnaire was prepared inquiring about the presence of PBS and its phenomenology. PBS was defined as 'the painful or painless sensation of the presence of the whole or part of the amputated breast that was clearly distinguishable from cicatrix pain'. Appropriate information was provided during the interview, to ensure understanding, since inability to distinguish phantom sensations from other sensations or pain syndromes is hypothesised to be a possible explanation for the disparity in prevalence rates for PBS (Hill, 1999).

The questionnaire investigated the following demographic data: age, family status, number of children and educational level. The following data concerning participants' menstrual history were recorded: age of their last menstrual period (LMP), age at menarche and the existence of premenstrual syndrome. Premenstrual symptoms were categorised either as 'psychological' (e.g., anxiety, irritability, depression and sleep disturbance) or as 'local' symptoms (e.g., tenderness, pain and swelling of the breasts) (Rubinow and Roy-Byrne, 1984). Each participant who experienced PBS, was additionally asked about the qualities of PBS experience: whether it was pleasant, unpleasant or indifferent; the type of the sensations suffered; the apparent size, shape and weight of phantom breast; whether PBS involved the entire tissue of the breast, part of it, or only the nipple; and the diurnal variation of PBS (if it happened more often in the morning, afternoon, or night).

The patients' medical records were checked for disease and treatment variables: date of breast surgery; side of mastectomy; primary tumour size; histology (*in situ* or invasive carcinoma); lymph node status; and postoperative treatment (radiotherapy, chemotherapy and hormonal therapy). Time since mastectomy was calculated. Use of silicon prosthesis was also assessed, as well as cicatrix pain at the place of the scar.

The former sensory history of the breast was defined as the presence of painful or painless sensations locally at the breast, prior to mastectomy. In order to assess this, we recorded the following variables: 'local' premenstrual symptoms; history of breast feeding, and specifically the total lactation days; pre-operative symptomatology; and the subjectively remembered time period that the painful or painless pre-operative sensations occurred. Total lactation days were estimated by adding up the lactation days for each child. Pre-operative symptomatology was defined as painful or painless sensations prior to breast surgery, localised at the amputated breast. Pre-operative pain was recorded separately.

2.3. Statistical analysis

For statistical analysis the sample was divided into two groups: women who experienced PBS, either painful or painless, and women who had never experienced phantom breast sensations and phantom breast pain. Variables were first tested for normality with the Kolmogorov–Smirnov criterion. Normal variables are expressed as mean ± standard deviation (S.D.), while variables with skewed distribution are expressed as median (interquantile range). When the normality assumption was satisfied, the Student's *t*-test was used for the comparison of means of continuous variables between the two groups and the Mann–Whitney test when the distribution was not normal. Chi-square and Fisher's exact tests were used to explore the association of PBS with demographics, disease and treatment variables, as well as, the former sensory experiences from the breast.

Multiple logistic regression analysis was performed using stepwise backward elimination with *P* for removal equal to 0.1 and *P* for entry equal to 0.05, in order to find the best model fitting our data. All *P* values reported are two-tailed, the significance level was set at 0.05 and analyses were done using the Stata statistical package (version 6).

Table 1
Sample characteristics and data concerning menstrual history of the total sample and the two subgroups of patients.

Sample characteristics		Total *N* (%)	PBS *N* (%)	No PBS *N* (%)	*P*
Age in years	38–50	39 (37.1)	13 (33.3)	26 (66.7)	
	51–66	33 (31.4)	7 (21.2)	26 (78.8)	
	67–86	33 (31.4)	4 (12.1)	29 (87.9)	0.099‡
Education	<7 years	42 (40.0)	8 (19.1)	34 (80.9)	
	7–12 years	45 (42.9)	13 (28.9)	32 (71.1)	
	>12 years	14 (13.3)	2 (14.3)	12 (85.7)	0.394‡‡
	Missing data	4 (3.8)			
Family status	Married	72 (68.6)	17 (23.6)	55 (76.4)	
	Single	9 (8.6)	2 (22.2)	7 (77.8)	
	Divorced–widow	21 (20.0)	4 (19.1)	17 (80.9)	0.927‡‡
	Missing data	3 (2.8)			
Number of children	None	22 (21.0)	6 (27.3)	16 (72.7)	
	1	16 (15.2)	3 (18.8)	13 (81.3)	
	≥2	63 (60.0)	14 (22.2)	49 (77.8)	0.838‡‡
	Missing data	4 (3.8)			
Age of last menstrual period (in years)		48.1 (4.7)	48.0 (4.9)	48.3 (3.9)	0.844**
Age of menarche (in years)		13.0 (1.6)	13.1 (1.7)	12.8 (1.3)	0.569**
Premenstrual 'psychological symptoms'	No	43 (41.0)	10 (23.3)	33 (76.7)	
	Yes	43 (41.0)	13 (30.2)	30 (69.8)	0.465‡
	Not assessed	19 (18.1)			
Regular use of silicon prosthesis	No	19 (18.1)	0 (0.0)	19 (100.0)	
	Yes	80 (76.2)	24 (30.0)	56 (70.0)	0.005‡‡
	Not reported	6 (5.7)			
Cicatrix pain	No	62 (59.1)	16 (25.8)	46 (74.2)	
	Yes	40 (38.1)	8 (20.0)	32 (80.0)	0.500‡
	Not assessed	3 (2.9)			

‡Chi-square test.
‡‡Fisher's exact test.
**Student's *t*-test.

Table 2
Former sensory history of the breast in the total group and the two subgroups, with or without PBS.

Sensory history of the breast		Total *N* (%)	PBS *N* (%)	No PBS *N* (%)	*P*
Premenstrual syndrome (local symptoms)	No	35 (33.3)	6 (17.1)	29 (82.9)	
	Yes	61 (58.1)	16 (26.2)	45 (73.8)	0.308[a]
	Not reported	9 (8.6)			
Breast Feeding	No	18 (17.1)	5 (27.8)	13 (72.2)	
	Yes	62 (59.1)	11 (17.7)	51 (82.3)	0.338[b]
	Missing data	25 (23.8)			
Duration of breast feeding in months, median (interquantile range)		6.0 (0.4–11)	3.1 (0.0–8.0)	6 (1.3–11.0)	0.268[c]
Pre-operation symptomatology	No	61 (58.1)	11 (18.0)	50 (82.0)	
	Yes	43 (41.0)	13 (30.2)	30 (69.8)	0.146[a]
	Not assessed	1 (0.9)			
Pre-operation pain	No	18 (17.1)	6 (33.3)	12 (66.7)	
	Yes	25 (23.8)	7 (28.0)	18 (72.0)	0.707[a]
	Not assessed	62 (59.1)			
Time of pre-operation pain (months)	≤1	12 (27.9)	3 (25.0)	9 (75.0)	
	2–6	10 (23.3)	3 (30.0)	7 (70.0)	
	>6	16 (37.2)	5 (31.3)	11 (68.8)	1.000[b]
	Not reported	5 (11.6)			

[a] Chi-square test.
[b] Fisher's exact test.
[c] Mann–Whitney test.