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## Patients After Mastectomy: The Prevalence of Phantom Breast Syndrome and its Effect on Depression

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## ABSTRACT

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**Background:** Phantom breast syndrome (PBS) following mastectomy is believed to be a complex psychological reaction to mastectomy but studies on PBS are limited. The study aims to determine the prevalence of phantom breast syndrome and the impact of this syndrome on patients suffering from depression following mastectomy.

**Methods:** A total of 272 women who had undergone mastectomy were interviewed using a structured questionnaire related to phantom breast sensation and depression caused by its effect by using ‘Hamilton Depression Scale’. SPSS Statistics v27 was used to analyze the data.

**Results:** Out of 272 females, 7.4% of the participants in our study reported having phantom sensations following surgery, 64.7% had Phantom Breast Syndrome, 37.5% had mild, 5.1% moderate, and 0.7% severe depression according to ‘Hamilton Depression Scale’. Univariate logistic regression revealed that females under 45 have a higher likelihood of developing phantom breast syndrome compared to those over 45 (OR=2.012, P=0.038).

**Conclusion:** Females with depression have a higher likelihood of experiencing phantom breast syndrome compared to females without depression.

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### INTRODUCTION

Carcinoma of the breast is the most frequently diagnosed cancer in females, ranking as the second leading cause of death according to the estimates.<sup>1</sup> In South Asia, Pakistan has the highest number of cases and notably one in nine women have experienced this illness at some point in their lives.<sup>2</sup> The standard surgical treatment for breast cancer is mastectomy and breast conservation surgery. Complications arising from breast cancer treatment are currently the focus of attention. Phantom Breast Syndrome (PBS) is one of the conditions that can occur following a mastectomy.<sup>3,4</sup> The incidence reported in the

literature varies, ranging from around 30% to as high as 80% of patients following mastectomy.<sup>5</sup>

Phantom Breast Syndrome (PBS) is a condition in which patients have a sensation of having residual mammary tissue which includes both non-painful sensations as well as phantom breast pain.<sup>6</sup> Phantom breast pain is a painful sensory perception of an already removed breast, whereas painless phantom breast sensation is a feeling of the presence of a removed breast.<sup>7</sup> PBS does not receive much attention and is often overlooked. PBS might persist for years after surgery.<sup>8</sup> It has a significant impact on the quality of life as a result of physical disability and emotional distress.<sup>9</sup>

As existing studies on persistent pain after breast cancer surgery are limited and there is considerable uncertainty, this study aims to determine the prevalence of phantom breast syndrome in patients following mastectomy and the impact of phantom

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breast syndrome on patients suffering from depression following mastectomy.

## METHODS

### *Study Design*

The current research is a cross-sectional questionnaire-based study. The study was conducted at Liaquat National Hospital in Karachi. All the patients with mastectomy without reconstruction who visited the Breast clinic of Liaquat National Hospital Karachi constituted the population of the study.

The sample size was calculated through Wan Nor Arifin's Sample Size Calculator (Available at <https://wnarifin.github.io/ssc/ss1prop.html>), considering the prevalence of PBS =22.9%<sup>10</sup> and a margin of error of 5%. The total calculated sample size was 272.

### *Inclusion Criteria*

- All those patients who underwent mastectomy or modified radical mastectomy without reconstruction.
- Only those patients who have been postoperative for 60 days and onwards.

### *Exclusion Criteria*

All those patients:

- who have been postoperative for less than 60 days
- who have undergone breast conservation surgery
- who have a diagnosis of a preexisting muscular disorder

### *Data Collection*

This study included 272 women who underwent mastectomy without breast reconstruction for breast cancer and were at least 2 months post-surgery. They were all the patients who visited the outpatient clinics of the Breast Surgery Department of Liaquat National Hospital and Medical College and were asked to take part in the study during one of their postoperative appointments. All participants provided written and informed consent for their participation. To avoid discrepancies in Phantom Breast syndrome (PBS) caused by different surgical strategies, only patients who underwent the same type of surgery- mastectomy without reconstruction- were included to ensure adequate wound healing and prevent confusion between phantom sensations and wound-related sensations in patients with less than a month postoperatively were excluded from the study. All these patients received appropriate chemotherapy, Anti Her 2, Radiation, and hormonal therapy as needed by their stage and biology of the disease. 1.

### *Tools for evaluation*

A structured questionnaire adopted from a Danish study<sup>9</sup> (translated both into Urdu and English) was used for the assessment of the feeling of having a mastectomy-removed breast, either in its entirety or in part. A clear division was established between postoperative pain and phantom breast pain or sensations, including burning, itching, etc. Depression among those patients was assessed using the Hamilton Depression Scale.<sup>10</sup> The provoking and relieving factors that were asked were i. Emotional states (e.g. sadness, occasional weeping, frequent weeping, extreme symptoms) ii. Feelings of guilt (delusion and hallucination of guilt) iii. Insomnia iv. Work and interests (loss of interest, decreased productivity, absence from work) v. Retardation (slowness of thought, speech and activity, apathy, and stupor vi. Agitation vii. Anxiety. Each item on the questionnaire was scored on a 3 or 5-point scale and the total score was compared to the corresponding descriptor.

### *Statistical Analysis*

IBM SPSS Statistics v27 was used to analyze the data. For quantitative data, the mean and standard deviation were calculated, whereas frequency and percentage were provided for qualitative variables. Fisher's exact test and Chi-square were used to examine any associations between the qualitative variables. Odd ratios were computed using univariate binary logistic regression. P-values with less than 0.05 were regarded as significant.

## RESULTS

There were 272 female participants in the current study with an average age of  $54.43 \pm 10.46$  years. Most of the females (86%) were housewives. In addition, 3.3% of the female population were from rural areas, while 96.7% were from urban areas. Of the 272 females, 137 (or 50.4%) reported having discomfort in the axilla, side of the thorax, breast, or arm on the side of the operation. Of the 137 female participants, 52.6% experienced discomfort in the breast region, 24.8% on the side of the thorax, 37.2% in the axilla, and 36.5% in the arm. The average severity of the pain was  $3.66 \pm 1.92$ . Out of 272 females, 27.7% reported almost everyday pain, 22.6% reported pain 1-3 times a week and 49.6% reported less frequent pain.

Of the 272 females, 93 (or 34.2%) reported having discomfort or sensory abnormalities in the arm on the surgery side, the thoracic side, the breast area, or the axilla. Among the seventy-two percent of the ninety-three female patients who reported experiencing sensory disturbances or discomfort in the breast area:



19.4% on the thorax side, 40.9% in the axilla, and 24.7% in the arm had these symptoms. Each of the patients reported experiencing these symptoms in one of the four locations. According to Table 1, 7.4% of the female participants in our study reported having phantom sensations following surgery, and 64.7% reported having Phantom Breast Syndrome.

The mean Hamilton Rating Scale for Depression (HDRS) score was  $7.551 \pm 4.875$ . Table 1 shows that out of 272 females, 43.4% had depression. Table 2 compares the items of the Hamilton Rating Scale for Depression (HDRS) in patients with and without Phantom breast syndrome. As shown in Table 3, we discovered a significant association between Phantom breast syndrome and age group ( $P=0.036$ ), but not between residence ( $P=0.725$ ) and depression ( $P=0.204$ ).

Through univariate logistic regression, it was discovered that females under 45 have a higher likelihood of developing phantom breast syndrome compared to those over 45 ( $OR=2.012$ ,  $P=0.038$ ). Additionally, it was discovered that compared to females from urban regions, females from rural areas have a lower likelihood of phantom breast syndrome ( $OR=0.673$ ,  $P=0.561$ ).

In contrast to females without depression, those experiencing mild depression have a higher likelihood of encountering phantom breast syndrome ( $OR=1.250$ ,  $P=0.411$ ). Conversely, females dealing with depression have a higher likelihood of experiencing phantom breast syndrome compared to those without depression ( $OR=1.114$ ,  $P=0.673$ ). Detailed results of the odds are presented in Table 3.

## DISCUSSION

Breast cancer survivors who underwent mastectomy often experience depressive and unmotivated feelings in their daily lives. The existence of phantom breast syndrome is an additional phenomenon that may worsen their suffering.<sup>10</sup> Due to the loss of their breast, each of them went through some level of mourning, and the cancer context was mentioned frequently in all their accounts of their experiences.<sup>11</sup>

Our study aimed to find out its prevalence among post-mastectomy women and its effect on depression among them.

We found out that 64.7% of women were affected by phantom breast syndrome. Medina *et al.* conducted a study in which patients were observed in two different follow-up visits.

The first visit, which was done at 45 days, showed that 44.3% of the patients suffered from phantom breast syndrome (PBS).

**Table 1.** Baseline characteristics of study population (n=272)

	N (%)
Age (years); mean± std. dev	54.43±10.46
Occupation	
Business Woman	1(0.4)
Doctor	6(2.2)
Educationalist (Retired)	1(0.4)
Homemaker	6(2.2)
Housewife	234(86)
Job	1(0.4)
Machine Technician	1(0.4)
Principal	4(1.5)
Retired Teacher	4(1.5)
Teacher	14(5.1)
Residence	
Rural	9(3.3)
Urban	263(96.7)
Feel pain in the area of the breast, the axilla, the side of the thorax, or the arm on the surgery side	
Yes	137(50.4)
No	135(49.6)
Do you feel pain in the area of the breast (n=137)	72(52.6)
Feel pain on the side of the thorax(n=137)	34(24.8)
Feel pain in the axilla (n=137)	51(37.2)
Feel pain in the arm (n=137)	50(36.5)
How intense is the pain on average; mean± std. dev (n=137)	3.66±1.92
How frequent is the pain (n=137)	
Almost every day	38(27.7)
1-3 times a week	31(22.6)
Less frequently	68(49.6)
Experience sensory disturbances or discomfort in the breast area, the axilla, thorax side, or the arm on the surgery side	
Yes	93(34.2)
No	179(65.8)
Experience sensory disturbances or discomfort in the breast area (n=93)	67(72)
Experience sensory disturbances or discomfort on the thorax side (n=93)	18(19.4)
Experience sensory disturbances or discomfort in the axilla (n=93)	38(40.9)
Experience sensory disturbances or discomfort in the arm (n=93)	23(24.7)
Experience phantom sensation after surgery	
Yes	20(7.4)
No	252(92.6)
HDRS Score; mean± std. dev	7.551±4.875
Depression by HDRS Scale	
Yes	118(43.4)
No	154(56.6)
Depression severity (n=118)	
Mild depression (8-16)	102(37.5)
Moderate depression (17-23)	14(5.1)
Severe depression (≥24)	2(0.7)
Phantom Breast Syndrome	
Yes	176(64.7)
No	96(35.3)



**Table 2.** Comparison of the HDRS scale items score in patients with and without phantom breast syndrome

Item#	Description	Total score	Phantom Breast Syndrome		P-value
			Median (IQR)		
			Yes	No	
1	Depressed mood	0(0-1)	0(0-1)	0(0-1)	0.589
2	Feelings of guilt	0(0-0)	0(0-0)	0(0-0)	0.679
3	Suicide	0(0-0)	0(0-0)	0(0-0)	0.452
4	Insomnia: Early in the Night	0(0-1)	0(0-1)	0(0-1)	0.956
5	Insomnia: Middle of the Night	0(0-1)	0(0-1)	0(0-1)	0.617
6	Insomnia: Early hours of the Morning	0(0-1)	0(0-0.75)	0(0-1)	0.363
7	Work and Activities	0(0-1)	0(0-1)	0(0-1)	0.749
8	Retardation	0(0-0)	0(0-0)	0(0-0)	0.209
9	Agitation	0(0-1)	0(0-1)	0(0-1)	0.956
10	Anxiety Psychic	0(0-2)	0(0-2)	0(0-1)	0.682
11	Anxiety Somatic	0(0-1)	0(0-1)	0(0-1)	0.076
12	Somatic Symptoms Gastro-Intestinal	0(0-0.75)	0(0-1)	0(0-0)	0.287
13	General Somatic Symptoms	1(0-1)	1(0-1)	0(0-1)	0.010*
14	Genital Symptoms	0(0-0)	0(0-0)	0(0-0)	0.819
15	Hypochondriasis	0(0-0)	0(0-0)	0(0-0)	0.920
16	Loss Of Weight	0(0-1)	0(0-0)	0(0-1)	0.293
17	Insight	2(0-2)	2(0-2)	2(0.25-2)	0.745
Overall HDRS Score		7(4-10)	7(4-10)	6(3-10)	0.567

Mann-Whitney U test was applied.

\*Significant at 0.05 level.

However, the last follow-up, done at 2 years, indicated that only 18.2% were positive.<sup>12</sup> Likewise, another study in 2014 stated a very low prevalence of PBS among patients at 3 different intervals (6 weeks, 6 months, and 12 months).<sup>13</sup> A correlation was seen between phantom breast syndrome and depression in a study which revealed that women suffering from PBS scored higher on the depression scale, which signifies a correlation between PBS and depression.<sup>14</sup> Our study found 37.5% of them suffered from mild depression, whereas 5.1 were categorized as moderately depressed and only 0.7% of the patients

fell under the category of severe depression. Another correlation was seen in a study in which a psychological examination was done and those women with PBS were found to have a highly distorted sense of body and diminished sexual performance as compared to those without PBS.<sup>15,16</sup>

Tasmuth *et al.* studied all those patients who underwent modified radical mastectomy and found out that after one year, one-fourth of them complained of phantom sensations, whereas 23% of them, along with these sensations, complained of pain as well.<sup>17</sup>

**Table 3.** Association and Odds ratio for Phantom Breast Syndrome

	Phantom Breast Syndrome		P-value	Un-Adjusted	
	Yes	No		Odds Ratio (95% CI)	p-value
Age Group					
≤45 years	45(25.6)	14(14.6)	0.036*	2.0121(1.040-3.894)	0.038
>45 years®	131(74.4)	82(85.4)			
Residence					
Rural	5(2.8)	4(4.2)	0.725	0.673(0.176-2.566)	0.561
Urban®	171(97.2)	92(95.8)			
Depression					
Yes	78(44.3)	40(41.7)	0.673	1.114(0.674-1.843)	0.673
No	98(55.7)	56(58.3)			

The Chi-square/fisher exact test was applied.

Uni-variate logistic regression was applied.

®Reference category.

\*Significant at 0.05 level.

Björkman *et al.* reported that women in their study found difficulty in localizing their phantom breast pain and sensations in comparison to their other body parts.<sup>18</sup> A case report on a post-mastectomy patient

who presented 2 months postoperatively emphasized the importance of phantom breast pain and the need to get it acknowledged among physical medicine and rehabilitation physicians.<sup>19</sup>





Here, in our study we can conclude that phantom breast syndrome is being observed significantly in post-mastectomy patients and depressive symptomatology has a correlation with phantom breast syndrome in females with mastectomy.

#### Limitations

This is a single-center study and a multicenter study with long-term follow-up may give more insight into the change in the level of depression and phantom breast syndrome.

#### CONCLUSION

Females with depression have a higher likelihood of experiencing phantom breast syndrome compared to those without depression.

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#### ETHICAL CONSIDERATIONS

The study protocol was approved by the ethical review committee and research committee (0902-2023 LNH-ERC). Patient identification was kept confidential.

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#### CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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