

University of Groningen

## Phantom breast sensations and phantom breast pain

Dijkstra, P.U.; Rietman, J.S.; Geertzen, J.H.B.

*Published in:*  
EUROPEAN JOURNAL OF PAIN

*DOI:*  
[10.1016/j.ejpain.2006.01.002](https://doi.org/10.1016/j.ejpain.2006.01.002)

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2007

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Dijkstra, P. U., Rietman, J. S., & Geertzen, J. H. B. (2007). Phantom breast sensations and phantom breast pain: A 2-year prospective study and a methodological analysis of literature. *EUROPEAN JOURNAL OF PAIN*, 11(1), 99-108. <https://doi.org/10.1016/j.ejpain.2006.01.002>

### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

# Phantom breast sensations and phantom breast pain: A 2-year prospective study and a methodological analysis of literature

Pieter U. Dijkstra<sup>a,b,c,\*</sup>, Johan S. Rietman<sup>b,d</sup>, Jan H.B. Geertzen<sup>a,b</sup>

<sup>a</sup> Department of Rehabilitation Medicine, University Medical Center Groningen, University of Groningen, Hanzeplein 1, P.O. Box 30 001, 9700 RB Groningen, The Netherlands

<sup>b</sup> Northern Center for Health Care Research, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

<sup>c</sup> Department of Oral and Maxillofacial Surgery, University Medical Center Groningen, University of Groningen, The Netherlands

<sup>d</sup> Department of Rehabilitation Medicine, Martini Hospital Groningen, The Netherlands

Received 17 June 2005; received in revised form 10 January 2006; accepted 11 January 2006

Available online 17 February 2006

---

## Abstract

The first aim of this study was to assess prospectively the incidence of phantom breast sensations (PB sensations) and phantom breast pain (PB pain) in a sample of patients treated for breast cancer ( $n = 204$ ) by means of a modified radical mastectomy ( $n = 82$ ). Patients were assessed 6 weeks, 6, 12 and 24 months after mastectomy, by means of a questionnaire. After 24 months, assessments of 74 (90%) patients were available.

Two years after mastectomy, PB sensations were present in 19% ( $n = 14$ ) of the patients and PB pain was present in 1% ( $n = 1$ ) of the patients. Over time the percentage of patients with PB sensations remained relatively stable (around 20%) but for PB pain the percentage reduced from 7% to 1%. The amount of suffering as a result of PB sensations or PB pain was very limited. PB sensations and PB pain are of little clinical relevance in the 24 months following mastectomy.

The second aim of this paper was to analyse the influence of research methodology on the prevalences of PB sensations and PB pain previously reported.

Research design, assessment method and publication date were recorded. Data were weighted according to the number of women investigated. Linear regression analysis was performed to analyse the influences of methodology on the prevalences of PB sensations and PB pain.

Of the 29 studies identified, 23 were cross-sectional and 6 were prospective. In 17 studies patients were interviewed and in 12 studies a questionnaire was used.

A prospective design resulted in prevalences of PB sensations and PB pain averagely 8% lower respectively 9% higher than in cross-sectional studies. The use of an interview resulted in prevalences of PB sensations and PB pain averagely 13% lower respectively 5% lower than questionnaire use. Prevalences of PB sensations and PB pain reduce averagely with 0.08% respectively 0.13% per year since 1950.

It is concluded that research design and assessment method have a significant influence on reported prevalence of PB sensations and PB pain.

© 2006 European Federation of Chapters of the International Association for the Study of Pain. Published by Elsevier Ltd. All rights reserved.

**Keywords:** Breast cancer; Mastectomy; Phantom breast pain; Phantom breast sensations; Methodology

---

\* Corresponding author. Tel.: +31 50 3610297; fax: +31 50 3611708.

E-mail address: [p.u.dijkstra@rev.umcg.nl](mailto:p.u.dijkstra@rev.umcg.nl) (P.U. Dijkstra).

## 1. Introduction

The incidence of breast cancer in the Netherlands is 100/100,000 women per year (Visser et al., 2001). One out of 10 women will develop breast cancer, of which 79% will survive at least five years (Greenlee et al., 2001; Visser et al., 2001). The aim of breast cancer treatment is to obtain local tumour control, optimal lymph node staging with minimal treatment related morbidity, good functional result and if possible preservation of the breast. Post-treatment morbidity of breast cancer patients includes a reduced range of motion of the shoulder, swelling of the arm, and a reduced shoulder strength or grip strength (Rietman et al., 2003b, 2004). Additionally 55% of the women may experience some type of pain after breast cancer treatment (Maunsell et al., 1993). Different types of pain have been found after successful treatment of breast cancer including scar pain, neuropathic pain, neuroma pain and complex regional pain syndrome (Graham et al., 2002; Macrae, 2001; Vecht et al., 1989). After mastectomy, patients may also experience sensations or pain as coming from the amputated breast, known as phantom breast sensations (PB sensations) and phantom breast pain (PB pain) (Krøner et al., 1989, 1992). PB sensations are all sensations that are experienced in the amputated breast whereas PB pain are all sensations that are experienced in the amputated breast that are so intense that they are experienced as pain. The variation of prevalences of PB sensations and PB pain reported is substantial, ranging from 10% to 66% for PB sensations and from 0% to 53% for PB pain (Critchley, 1955; Lorenzoni and Heidenreich, 1982; Nail et al., 1984; Reuben et al., 2004) (Table 1). Looking at the 95% confidence interval of the prevalences, it can be seen that the confidence intervals of many studies do not overlap, indicating significant differences in prevalences found. These differences in outcomes may be attributed to assessment method (questionnaires and interviews), research design (cross-sectional and prospective) and differences in study population (inpatients just being operated, outpatients coming for regular appointment or unknown origin) (Table 1).

Further the impact of PB sensations or PB pain is described highly variable. Some authors report that PB sensations and PB pain after mastectomy are minor issues in the process of coping with mastectomy while others state that PB sensations and PB pain are highly disturbing phenomena (Crone-Münzebrock, 1950; Downing and Windsor, 1984; Jamison et al., 1979; Jarvis, 1967).

The first aim of this study was to assess the incidence of PB sensations and PB pain sensations in a sample of Dutch post-mastectomy patients and to assess whether patients suffer from PB sensations and PB pain in a 24 month prospective study.

The second aim of this study was to analyse the influence of research methodology on the outcome of previously published prevalences of PB sensations and PB pain.

## 2. Materials and methods

### 2.1. Clinical study

In the period June 1999 to June 2001, patients with breast carcinoma stage I or stage II were asked to participate in a cohort study (Rietman et al., 2003a). From this group, all patients were selected who underwent a modified radical mastectomy.

Patients were recruited from two hospitals, the University Medical Center Groningen and the Martini Hospital Groningen. Informed consent was obtained from the participating patients. The Institutional Review Board (IRB) of both hospitals approved the protocol. Data regarding treatment characteristics were collected from the medical records.

Pain was assessed prior to surgery by means of a 10 cm Visual Analogue Scale (VAS). The patients were asked to mark their intensity of pain, of the last week on a 10 cm straight line (0 cm = no pain, 10 cm = worst pain imaginable). Three VAS's were used for average, least and worst pain of the last week. Additionally patients were asked to fill out the EORTC QLQ C30 and the QLQ-BR23 questionnaires (Aronson et al., 1993).

PB sensations and PB pain were assessed by means of a questionnaire. This questionnaire was given to the patients to fill out while the interviewer remained present to answer any questions. The questionnaire was based upon the one used previously to investigate phantom limb pain (Dijkstra et al., 2002; Kooijman et al., 2000). Patients were assessed at 6 weeks, 6, 12 and 24 months after mastectomy. The questionnaire assesses frequency of PB sensations and PB pain and the amount of trouble and suffering experienced (no, little, moderate, much, very much) related to PB sensations and PB pain, respectively. As risk factors for PB sensations and or PB pain the following therapy related variables were analysed, by means of  $\chi^2$  analyses; type of dissection (sentinel lymph node biopsy (SLNB), axillary lymph node dissection (ALND)), left or right sided mastectomy, post-operative infections (yes, no), seroma production (yes, no), radiotherapy (yes, no), axillary radiotherapy (yes, no), chemotherapy (yes, no), and loss of sensory function of the axilla (yes, no).

Additionally as pre-mastectomy risk factors, intensity of pain, average, least and worst pain prior to the mastectomy, age at mastectomy, scores of the EORTC-QLQ C30 and the QLQ-BR23 prior to the mastectomy were analysed using *t*-tests for independent

Table 1  
Overview of the papers published concerning phantom breast sensations and phantom breast pain

Author	Publication year	Population	Age (years)	Design	Method	Interval	n	n PBS	% PBS	95% CI	n PBP	% PBP	95% CI
Crone-Münzebrock	1950	In and outpatients	–	c	q	Few days to >5 years	49	24	49	37 to 63	13	27	16 to 40
Ackerly et al.	1955	–	30–66	c	i	7 months to 9 years	50	11	22	13 to 35	2	4	1 to 24
Critchley	1955	–	–	c	i	–	30	3	10	4 to 25	–	–	–
Bressler	1956	In and outpatients	–	c	i	Few days to 15 years	25	16	64	45 to 80	5	20	9 to 39
Simmel	1966	In and outpatients	28–81	c	i	4 days to 18 years	77	31	40	30 to 51	–	–	–
Jarvis	1967	Outpatients	27–86	c	q	–	104	24	23	16 to 32	8	8	4 to 14
Weinstein et al.	1970	In and outpatients	21–87 \$	c	i	1 day to 33 years	203	68	33	27 to 40	16	8	5 to 12
Jamison et al.	1979	W for W and ACS #	32–70	c	q	Median 10 months	41	22	54	39 to 68	18	44	30 to 59
Moore and Stayton	1981	–	–	c	i	–	40	13	33	20 to 48	–a	–	–
Christensen et al.	1982	Outpatients	≤45	c	i	6–21 months	31	11	31	21 to 53	2	6	2 to 21
Lorenzoni and Heidenreich	1982	–	–	c	i	–	203	35	17	13 to 23	0	0	0 to 2
Abraham and Llewellyn-Jones	1983	Outpatients	26–80	c	i	3 months to 17 years	65	33	51	38 to 63	3	5	2 to 13
Nail et al.	1984	–	31–86	c	q	1–25 years	218	–	66	–	–	–	–
Downing and Windsor	1984	Outpatients	33–97	c	i	Mean 2.6 years (s.d. 2.2)\$\$	82	25	30	22 to 41	6	7	3 to 15
Staps et al.	1985	Outpatients	33–89	c	q	Mean 5.3 years	89	29	33	24 to 43	21	24	16 to 33
Taylor et al.	1985	Outpatients from private oncology practice	29–78	c	i	2–60 months	49	6	12	6 to 24	–	–	–
Karydas et al.	1986	Outpatients	52.6 (s.d. 1.3)	c	q	1–36 months	62	34	55	43 to 67	–	–	–
Lierman	1988	R to R##	63.6 (s.d. 7)	p	i	1–12 months	20	12	60	39 to 78	–	–	–
Krøner et al.	1992	Outpatients	54, IQR 45–62	p	i	72 months	69	18	26	17 to 38	12	17	10 to 28
Polinsky	1994	R to R from 5 ACS Units ###	31–76	c	q	1.3–32 years	223	–	36	26 to 56	–	–	–
Aglioti et al.	1994	In and outpatients	35–78	c	i	2 days to 12 years	35*	14	40	26 to 56	–	–	–
Poma et al.	1996	Outpatients	30–89	c	q	2–16 years	97	29	30	22 to 40	3	3	1 to 9
Tasmuth et al.	1996	Outpatients	29–85	p	i	12 months	53	–	25	–	–	–	–
Tasmuth et al.	1999	Outpatients	<70	c	q	12 months	77	–	52	–	–	–	–
Baron et al.	2000	Outpatients	25–82	c	q	<1month	62	21	34	23 to 46	–	–	–
Baron et al.	2004	Outpatients	>18	p	q	24 months	77	23	30	21 to 41	–	–	–
Rothmund et al.	2004	Outpatients	55 (s.d. 11.6)	c	i	8 months to 25 years	39	11	28	17 to 44	9	23	13 to 38
Reuben et al.	2004	Outpatients	>18	p	i	6 months	19**	–	–	–	10	53	32 to 73
Dijkstra et al.	Current study	Outpatients	55.6 (s.d. 12.8)	p	q	24 months	74	14	19	12 to 29	1	1	0.2 to 7

Population: population from which patients were recruited, Age: age range to which the research sample was restricted, Design: design of the study, Method: assessment method, Interval: interval between surgery and investigation in cross-sectional studies and in prospective studies the interval over which the study was performed, PBS: phantom breast sensations, PBP: phantom breast pain, 95% CI: 95% confidence interval, c: cross-sectional study, Patients were assessed about current phantom breast sensations and phantom breast pain or in the past, p: prospective study, Patients were assessed at intervals to assess phantom sensations and phantom pain over time, q: questionnaire, i: interview, #: Half of the patients came from Women for Women self help recovery group and the other half came from the American Cancer Society (ACS), ##: Patients were recruited from the Reach to Recovery program of the American Cancer Society, ###: Patients were recruited from the Reach to Recovery volunteers of five American Cancer Society Units, -: not reported/not investigated, \*: subjects who received quadrantectomy were excluded, \*\*: The subjects were patients receiving with mastectomy in a control group of a RCT, \$: at the time of mastectomy, \$\$: pooled data, IQR: Interquartile range. Of the prospective studies the last recorded prevalence is entered in the table.

samples. Because data were skewed and the small number of patients experiencing PB pain all analyses were verified with the Mann–Whitney *U* test. Because of multiple comparisons, in total 34, for PB sensations as well as PB pain, a Bonferroni–Holm correction was applied.

## 2.2. Methodology analysis

For the methodological analysis several data bases Medline, Embase, Cinahl, Psycinfo were searched with “phantom” as free text word, combined with the term “or” with the data base specific term for phantom found in the thesaurus. Additionally the data bases were searched with “mastectomy” as free text word, combined with the term “or” with the data base specific term for mastectomy found in the thesaurus. These two searches were combined per data base using the term “and”. Papers were considered relevant if they described research in which the prevalence/incidence of PB sensations or PB pain was investigated in patients after mastectomy. Excluded were reviews, expert opinions, case-studies as well as papers not dealing with PB sensations or PB pain. The papers identified were retrieved from the library and were checked for relevant papers in the reference lists. The papers identified were read and the following items were assessed by the first author (PUD);

- year of publication,
- population from which the sample was selected (inpatients, outpatients or other),
- age of the populations studied,
- study design (cross-sectional study: patients were assessed about PB sensations and or PB pain, currently or in the past. Prospective study: Patients were assessed at intervals to assess PB sensations and or PB pain over time) for the remainder of this paper indicated as cross-sectional or prospective,
- method of assessment (interview or questionnaire),
- interval (time between mastectomy and research or in case of a prospective study the duration of the study),
- number of patients investigated,
- number of patients reporting PB sensations,
- number of patients reporting PB pain.

The results of this assessment were entered in a database. Some papers described the same cohort at different follow-ups. The paper describing the longest follow-up of that cohort was entered in the data base. Data per study were weighted according to the number patients participating in that study. By means of a linear regression it was analysed whether the prevalences found in literature (response variable) were related to, the time passed since publication, study design and method of assessment (predictor variables).

## 3. Results

### 3.1. Clinical study

During two years (1999–2001), 204 consecutive patients with invasive breast carcinoma, mean age 55.6 (s.d. 11.6) years, stage I ( $n = 87$ ; 42%), stage IIa ( $n = 86$ ; 41%) and stage IIb ( $n = 35$ ; 17%) entered the study. One patient was excluded from the study because she had a prophylactic mastectomy due to a positive family history for breast cancer. Five patients cancelled follow-up appointments before the 6-week assessment, of which one patient was treated elsewhere and the other 4 found the assessment protocol bothersome and chose to withdraw from the study. In total 198 patients completed pre- and the first post-operative assessments of which 82 received a modified radical mastectomy (mean age 56.6, s.d. 12.8) (Rietman et al., 2003a). These 82 patients were asked to fill out the questionnaire. Treatment related characteristics are summarised in Table 2. After the first follow-up (6 weeks), 1 patient died and 1 patient did not want to participate anymore. After the second follow-up (6 months), 1 patient died and 1 patient did not want to participate anymore. After the third follow-up (12 months), 1 patient died and 1 patient did not want to participate anymore and 1 patient could not be reached. One questionnaire was not filled out correctly making the number available questionnaires 74 at 24-month follow-up.

The percentage of patients experiencing PB sensations was more or less constant (about 20%) except 12 months after surgery (14%) and the number of

Table 2  
Treatment and treatment related characteristics of 82 women who underwent mastectomy because of breast cancer

	% (n) <sup>a</sup>
<i>Side of mastectomy</i>	
Left	38 (31)
Right	62 (51)
Bilateral	–
<i>Loss of sensory function axilla</i>	
Radiotherapy <sup>b</sup>	23 (19)
Chest wall	22 (18)
Axilla	13 (11)
<i>Treatment axilla</i>	
SLNB	21 (17)
ALND	80 (65)
Seroma	16 (12)
Infections <sup>c</sup>	6 (6)
Chemotherapy	38 (31)

SLNB: sentinel lymph node biopsy; ALND: axillary lymph node dissection.

<sup>a</sup> Data were not available for all patients thus the number of valid observations is sometimes less than 82.

<sup>b</sup> In total 19 patients received radiotherapy of which 18 received radiotherapy to the chest wall and 18 received it to the axilla.

<sup>c</sup> Infections needing treatment with antibiotics.

patients experiencing PB pain gradually reduced from 7% to 1% (Table 3). The amount of trouble related PB sensations and the amount of suffering related to PB pain was limited. The percentage of patients who had experienced PB sensations during some time in the 24-month period (2-year period prevalence) after mastectomy was 36%. For PB pain this percentage was 13% (Table 3).

None of the treatment related factors was significantly associated with PB sensations or PB pain (Table 4). The results of the *t*-test for independent samples and the Mann–Whitney *U* were similar. None of the pre-mastectomy risk factors were significantly related to PB sensations or PB pain (Table 5).

### 3.2. Methodology analysis

In total 29 studies were identified of which 23 were cross-sectional and 6 (including the current) were

Table 4

Treatment related factors and phantom breast sensations and phantom breast pain

		PBS (%)	<i>p</i>	PBP (%)	<i>p</i>
Treatment axilla	ALND	35	0.525	11	0.772
	SLNB	24		18	
Mastectomy	Left	29	0.341	7	0.340
	Right	39		16	
Infections	Yes	50	0.631	33	0.433
	No	33		13	
Seroma	Yes	33	1.000	0	0.434
	No	31		13	
Radiotherapy	Yes	32	1.000	16	0.884
	No	33		11	
Chemotherapy	Yes	42	0.293	7	0.356
	No	28		16	
Loss of sensory function (axilla)	Yes	38	0.168	6	0.571
	No	17		14	

PBS: phantom breast sensations, PBP: Phantom breast pain, ALND: axillary lymph node dissection, SLNB: sentinel lymph node biopsy, *p*: significance of the differences in percentages, results of  $\chi^2$  test.

Table 3

Phantom breast sensations and phantom breast pain at 6 weeks, 6 months, 12 months and 24 months

Time after mastectomy ( <i>n</i> )	6 weeks (82)	6 months (80)	12 months (78)	24 months (74)	Total period
<i>Phantom breast sensations (PBS)</i>					
A few times a year	2	3	6	9	
A few times a month	5	5	3	3	
A few times a week	7	4	1	–	
A few times a day	2	1	–	–	
A few times per hour	–	1	–	–	
Always	2	2	1	2	
Present but frequency unknown	–	–	1	–	
Total	22% (18/82)	20% (16/80)	14% (12/78)	19% (14/74)	36% (27/74)
95% CI of total	14 to 32	13 to 30	9 to 25	12 to 29	26 to 48
New cases/reappearance	18/–	7/–	1/2	2/1	
Trouble by PBS		– <sup>a</sup>			
Very much	–	–	–	–	
Much	–	–	–	–	
Moderate	1	–	–	–	
Little	6	6	6	5	
No	11	9	6	9	
<i>Phantom breast pain (PBP)</i>					
A few times a year	1	1	1	1	
A few times a month	2	–	1	–	
A few times a week	1	4	–	–	
A few times a day	2	–	–	–	
A few times per hour	–	1	–	–	
Always	–	–	–	–	
Total	7% (6/82)	8% (6/80)	3% (2/78)	1% (1/74)	13% (9/74)
95% CI of total	3 to 15	4 to 15	1 to 9	0.2 to 7	7 to 22
New cases	6	4	–	–	
Suffering from PBP			– <sup>b</sup>		
Very much	–	–	–	–	
Much	–	–	–	–	
Moderate	1	1	–	–	
Little	4	4	1	1	
No	1	1	–	–	

N: number of patients available during follow-up.

<sup>a</sup> One patient with phantom sensations did not fill out the amount of suffering.

<sup>b</sup> One patient with phantom pain did not fill out the amount of suffering.

Table 5  
Potential risk factors for phantom breast sensations and phantom breast pain

	PBS no	PBS yes	<i>p</i>	PBP no	PBP yes	<i>p</i>
	Mean(s.d.)	Mean(s.d.)		Mean(s.d.)	Mean(s.d.)	
Number of children	2.0(1.3)	2.0(1.2)	0.953	2.0(1.3)	1.8(1.4)	0.585
Age at mastectomy	58.2(12.9)	53.3(12.4)	0.102	56.5(13.4)	56.9(8.9)	0.936
VAS current	0.2(0.6)	0.6(1.4)	0.111	0.3(0.9)	0.4(1.2)	0.763
VAS least	0.1(0.5)	0.1(0.4)	0.967	0.1(0.4)	0.2(0.6)	0.667
VAS maximum	0.4(1.0)	1.3(2.4)	0.084	0.7(1.7)	0.6(1.6)	0.862
<i>EORTC QLQ-C30</i>						
Global health status	80.5(21.7)	78.2(14.2)	0.632	80.0(20.3)	77.5(13.1)	0.702
<i>Functional scales</i>						
Physical functioning	91.0(11.3)	92.2(9.8)	0.637	91.8(10.7)	88.7(11.8)	0.392
Role functioning	94.2(13.3)	91.3(15.3)	0.390	92.6(14.6)	98.3(5.3)	0.840
Emotional functioning	72.7(20.9)	66.7(22.8)	0.251	72.1(21.3)	61.7(22.3)	0.154
Cognitive functioning	88.2(15.9)	83.3(15.6)	0.202	87.1(16.0)	83.3(15.7)	0.488
Social functioning	92.1(17.3)	90.4(12.7)	0.648	92.3(16.1)	86.7(13.1)	0.299
<i>Symptom scales</i>						
Fatigue	15.2(19.5)	18.7(22.2)	0.487	15.5(20.0)	22.2(22.8)	0.327
Nausea	6.7(19.4)	4.7(9.0)	0.625	6.4(17.8)	3.3(7.0)	0.589
Pain	6.6(14.6)	12.7(18.2)	0.119	8.3(15.7)	10.0(17.9)	0.759
Dyspnea	5.5(14.0)	6.9(13.8)	0.664	5.8(14.0)	6.7(14.1)	0.854
Insomnia	23.0(28.6)	28.0(28.3)	0.472	22.9(28.1)	36.7(29.2)	0.152
Appetite loss	7.9(16.9)	14.7(21.7)	0.133	9.0(17.9)	16.7(23.6)	0.230
Constipation	6.1(18.2)	1.2(6.5)	0.200	4.7(16.2)	3.3(10.5)	0.798
Diarrhea	4.8(14.9)	5.1(12.3)	0.934	5.1(14.5)	3.3(10.5)	0.702
Financial problems	1.8(7.6)	0.0(0.0)	0.230	1.4(6.8)	0.0(0.0)	0.514
<i>Symptom scale</i>						
Side effects	7.5(9.1)	9.9(10.3)	0.303	8.2(9.8)	8.5(7.4)	0.941
Breast symptoms	11.4(14.6)	15.0(17.8)	0.384	12.1(15.6)	15.0(17.0)	0.600
Arm symptoms	4.1(10.0)	8.0(12.6)	0.143	5.5(11.0)	4.4(10.7)	0.783
Hair loss	16.7(19.2)	20.0(29.8)	0.853	19.0(26.2)	16.7(23.6)	0.912
<i>Functional scale</i>						
Body image	95.4(11.1)	88.0(19.8)	0.107	94.7(12.7)	81.5(21.6)	0.107
Sexual functioning	19.9(18.6)	20.3(23.5)	0.934	21.1(19.9)	13.3(21.9)	0.262
Future	58.0(27.6)	51.4(27.8)	0.331	56.9(28.2)	50.0(23.6)	0.467
Sexual satisfaction	57.1(18.7)	57.6(26.2)	0.957	57.8(21.3)	50.0(23.6)	0.622

PBS, phantom breast sensations; PBP, phantom breast pain; *p*, significance of the differences in means (independent *t*-test) after Bonferoni–Holm correction.

Table 6  
Results of multivariate linear regression to analyse influence of research methodology on reported prevalence of phantom breast sensations and phantom breast pain

Response variable	Predictor variables	$\beta$	95% CI $\beta$	Explained variance (%)
Prevalence of phantom breast sensations	Interview (yes = 1, no = 0)	−13.0	−14.3 to −11.8	19.3%
	Prospective study (yes = 1, no = 0)	−8.2	−10.6 to −5.8	
	Years after 1950 (per year)	−0.08	−0.13 to −0.03	
	Constant	46.2	44.2 to 48.3	
Prevalence of phantom breast pain	Interview (yes = 1, no = 0)	−5.2	−6.4 to −4.0	10.4%
	Prospective study (yes = 1, no = 0)	9.4	7.5 to 11.3	
	Years after 1950 (per year)	−0.13	−0.18 to −0.08	
	Constant	16.8	15.1 to 18.6	

prospective. In 17 studies patients were interviewed and in 12 studies a questionnaire was used. In 25 studies PB sensations was investigated and in 17 studies PB pain was investigated (Table 1). In total 2052 women were

assessed for PB sensations and 1293 women were assessed for PB pain. The weighted mean prevalence for PB sensations was 36.5% (range 10–66%). For PB pain the weighted mean prevalence was 10.9% (range 0–53%).

In studies with a prospective design prevalence of PB sensations was averagely 8% lower and prevalence of PB pain was averagely 9% higher than in cross-sectional studies. In studies using an interview prevalence of PB sensations and PB pain was averagely 13% lower respectively 5% lower compared to studies using a questionnaire. The prevalences of PB sensations and PB pain reduce averagely with 0.08% respectively 0.13% per year since 1950 (Table 6).

## 4. Discussion

### 4.1. Clinical study

Prevalence of PB sensations, on a group level, after mastectomy remains relatively stable over time but within patients, PB sensations may disappear and reappear. This finding is in contrast with those of previous authors who found an increase over time (Krøner et al., 1989, 1992). Cross-sectional studies suggest a fading away of PB sensations over time, based upon the observation that patients with a short follow-up report more often PB sensations than patients with a longer follow-up. However, our prospective observations did not confirm this suggestion. Remarkably some patients in our study experienced the PB sensations for the first time in the period between 6-month and 24-month follow-up (Table 2). This pattern of occurrence of PB sensations confirms the findings of a more recent study (Baron et al., 2004). For comparison of prevalences of PB sensations over time the prospective studies are summarised in Fig. 1.

The number of patients experiencing PB pain reduced over a 24-month period of time from 7% to 1%. This reduction is in contrast with the findings of Krøner et al. who found an increase in PB pain after 72 months

(Krøner et al., 1989, 1992). Looking at the percentages of PB pain in other studies, our prevalence is considerably lower (Table 1). This difference in prevalence might be explained by our research design. Many authors performed a cross-sectional study in which patients were asked whether they had ever experienced PB sensations or PB pain, currently or in the past. In fact these authors assessed a period prevalence. When the period, over which the prevalence is assessed, is longer, generally the period prevalence increases because every incident is included even if it has occurred only once in that period. To illustrate this phenomenon, in our study the 24-month-period-prevalence is 17% higher than the prevalence at 24 months for PB sensations for PB pain this differences is 12% (Table 3).

Prevalences of phantom pain or phantom sensations after limb amputation are generally higher than those reported after mastectomy. The prevalence of phantom sensations after limb amputation ranges from 18% to 100% (Carlen et al., 1978; Pohjola, 1991). The prevalence of phantom pain after limb amputation ranges from 59% to 85% (Pohjola, 1991; Sherman and Sherman, 1983). The prevalences of PB sensations and PB pain reported is ranges from 10% to 66% for PB sensations and from 0% to 53% for PB pain (Critchley, 1955; Lorenzoni and Heidenreich, 1982; Nail et al., 1984; Reuben et al., 2004). Within limb amputees the prevalence of the phantom sensations and phantom pain is higher in lower limb amputees compared to upper limb amputees (Dijkstra et al., 2002). Cortical reorganisation is thought to be an important underlying mechanism in the perception of phantom sensations and phantom pain (Ramachandran and Hirstein, 1998). The higher prevalences of phantom sensations and phantom pain in limb amputees compared to those of breast amputees may be the result of difference in cortical representation of limbs and breast on the primary somatosensory cortex. Both arm and leg are represented on the primary somatosensory cortex in a larger area than the breast (Aglioti et al., 1994). Additionally, limb perception strongly relies on sensory sub-modalities such as proprioception and joint sensibility, whereas breast perception does not rely on these modalities (Aglioti et al., 1994). It is also possible that women after mastectomy report less easily phantom sensations or phantom pain than limb amputees. This topic will be elaborated upon in the methodology discussion.

Overall, the amount of trouble related PB sensations and the amount of suffering related to PB pain was limited, confirming that PB sensations or PB pain play a minor role in the lives of patients in the two years after mastectomy. During the filling out of the questionnaire patients who experienced PB sensations or PB pain explicitly told the interviewer that these sensations were not an issue in their lives. Also in previous studies little distress was reported as a result of PB sensations

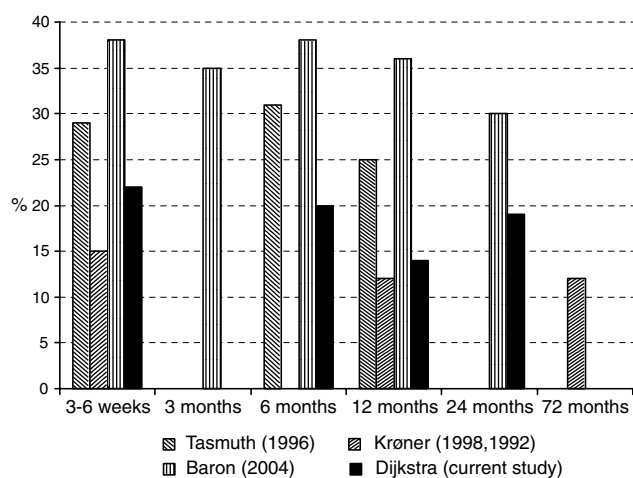


Fig. 1. Prevalences of phantom sensations after mastectomy in prospective studies.



(Crone-Münzebrock, 1950; Moore and Stayton, 1981). For lower and upper limb amputees the percentages of subjects who were substantially bothered by phantom limb sensations or phantom limb pain are considerably higher. In lower limb amputees 23% reported to be impeded (much or very much) by phantom limb pain (Borsje et al., 2004). In upper limb amputees 41% reported to be suffering (much or very much) from phantom limb pain and 21% reported to be troubled by phantom limb sensations (Kooijman et al., 2000).

Potential risk factors were analysed for the group who experienced PB sensations any time during the 24-month follow-up and for the group who experienced PB pain any time during follow-up. No risk factors were identified for PB sensations. Pain prior to mastectomy was not related to PB sensations or PB pain.

#### 4.2. Methodology

Research design, prospective or cross-sectional significantly influence the prevalences of PB sensations and PB pain reported in literature. Cross-sectional studies produce higher prevalences for PB sensations and lower prevalences for PB pain compared to prospective studies. The assessment method has also a strong influence on the outcome of the prevalences of PB sensations and PB pain. A questionnaire overestimates the prevalences compared to an interview. A very small but significant influence of time was found. The prevalences found of older studies are higher than the prevalences in more recent studies. Looking at the explained variance of the regression analyses it is clear that also other variables contributed to differences in the prevalences (Table 6). However, these other variables possibly influencing the estimation of prevalences could not be analysed because these variables were described sketchily in a substantial amount of studies. For instance the population (inpatients or outpatients) from which the study sample was drawn was not described in 5 studies. In some studies the study population was drawn from a Reach for Recovery Group of the American Cancer Society or a Women for Women Self Help Group. It is quite probable that these latter groups are more aware of PB sensations and PB pain because of their participation in these groups. Further the circumstances of the assessments differed considerably, in some studies patients were assessed during psychological treatment while in other studies patients were assessed during standard follow-up or the investigator visited the women at home. In different studies it was found that patients amputated at a younger age more often experience PB sensations than patients amputated at an older age. This difference in experiencing PB sensations is possibly related to the menstrual cycle (Ackerly et al., 1955; Crone-Münzebrock, 1950; Jamison et al., 1979; Wein-

stein et al., 1970). Thus age is a potential risk factor for PB sensations. However, age of the study population was described inadequately in many studies. Age ranges were generally described, sometimes completed with the mean age (Table 1). Seldom were mean and standard deviation provided or median and interquartile ranges. Similarly, time interval between mastectomy and research was seldom described adequately, despite that this interval is a factor associated with PB sensations and PB pain because of the fading away phenomenon. Looking at the ranges of these intervals it is clear that the interval between mastectomy and research differs between the studies. As a consequence prevalences of PB sensations and PB pain reported in the literature reflect period-prevalences over different periods of time as already mentioned. Thus analysing the influence of other variables on the outcome was impossible due to lack of information in the studies.

In some studies patients after lumpectomy of the breast were assessed for PB sensations or PB pain. In our clinical study we excluded these patients because we felt that patients with a lumpectomy can hardly be expected to differentiate between the part of the breast still present and the part removed. Further in the methodological analysis data of patients after lumpectomy of the breast were excluded from analysis for the estimation of the overall prevalence for the same reason.

Finally some studies only provided percentages of patients suffering from PB sensations and PB pain without describing the actual number of patients investigated and the actual number of patients suffering from it. As a consequence no 95% confidence interval could be calculated.

Despite these shortcomings in PB sensations and PB pain research, three variables were significantly related to the prevalences found; design of the research, method of assessment and years since 1950. The discrepancy that cross-sectional studies result in a higher prevalence of PB sensations and a lower prevalence of PB pain compared to prospective studies cannot be explained satisfactorily. It can be hypothesised that in cross-sectional studies the prevalence might be over-estimated especially if the patient is asked if she has experienced PB sensations or PB pain now or in the past. But why this mechanism might result in different outcomes for PB sensations and PB pain is not clear. Consequences of the use of a questionnaire might be that patients feel safe to answer the questions about PB sensations and PB pain. Additionally patients might confuse, in a questionnaire, PB sensations and PB pain with other post-mastectomy sensations and report incorrectly to be suffering from PB sensations or PB pain. Consequences of an interview might be that the interviewer unwillingly introduces bias on the basis of his own hypothesis about the prevalence or the patients do not feel free to report

PB sensations or PB pain, sensations that are hard to understand by a patient. An advantage of an interview is that the interviewer can explain what type of sensations and pain is actually meant by PB sensations and PB pain.

In our clinical study a questionnaire was used. The interviewer was present to answer any questions if necessary. This study design up was used to prevent confusion between PB sensations and PB pain with other post-mastectomy sensations. Because the interviewer was an independent observer we feel that we created a rather “safe” situation for the patients to report PB sensations or PB pain if present. Despite this study design it is still possible that more patients had PB sensations and PB pain but did not report it because they were afraid to report it. Not reporting phantom sensations or phantom pain is frequently described in lower limb amputees. These amputees do not report phantom sensations or phantom pain to their physician because they were afraid they might be labelled insane and it might endanger medical care to the stump (Sherman and Sherman, 1985). This argument does not hold for the current clinical study because the interviewer was not one of the surgeons who had operated the patients.

Because of a lack of a gold standard to assess PB sensations and PB pain an estimation of the amount of bias introduced by our study design cannot be performed. The reduction of the prevalence over time might be explained by less extensive surgery for breast cancer treatment in recent years. In the fifties and the sixties together with the affected breast the major pectoralis muscle was also resected. (Crone-Münzebrock, 1950) Today surgery does not involve the major pectoralis muscle anymore unless ingrowth of the tumour makes it necessary (Fisher et al., 1981; Madden et al., 1972).

A consequence of the outcome of this analysis is that an assessment instrument should be developed which is valid, reliable and responsive. Recently a questionnaire was developed to assess 18 sensations in the arm and chest region after breast cancer treatment (Baron et al., 2000). This questionnaire was assessed for its psychometric properties and was found to be reliable and valid. To that questionnaire one item was added to assess PB sensations. However, that specific item was not included in the psychometric analysis thus leaving researchers still with empty hands.

In conclusion, PB sensations after mastectomy occur in about a fifth of the patients and PB pain decreases over time after mastectomy. PB sensations and PB pain are of little clinical relevance in the 24 months following mastectomy.

Research design, assessment method and time have a significant effect on prevalences of PB sensations and PB pain reported in literature. A valid, reliable and respon-

sive instrument should be developed to assess PB sensations and PB pain.

## References

- Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85:365–76.
- Ackerly W, Lhamon W, Fitts W. Phantom breast. *J Nerv & Ment Dis* 1955;121:177–8.
- Aglioti S, Cortese F, Franchini C. Rapid sensory remapping in the adult human brain as inferred from phantom breast perception. *Neuroreport* 1994;5:473–6.
- Baron RH, Kelvin JF, Bookbinder M, Cramer L, Borgen PI, Thaler HT. Patients’s sensations aftr breast cancer surgery: A pilot study. *Cancer Practice* 2000;8:215–22.
- Baron RH, Fey JV, Borgen PI, Van Zee KJ. Eighteen sensations after breast cancer surgery: A two-year comparison of sentinal lymph node biopsy and axillary lymph node dissection. *Oncol Nurs Forum* 2004;31:691–8.
- Borsje S, Bosmans JC, van der Schans CP, Geertzen JHB, Dijkstra PU. Phantom pain a sensitivity analysis. *Disabil Rehabil* 2004;26:901–4.
- Carlen PL, Wall PD, Nadvorna H, Steinbach T. Phantom limbs and related phenomena in recent traumatic amputations. *Neurology* 1978;28:211–7.
- Critchley M. Quelques observations relatives a la notion de la conscience du moi corporel. *L’encéphale* 1955;44:501–31.
- Crone-Münzebrock A. Phantomgefühl und Phantomschmerz nach Mammaamputation. *Langenbecks Arch u Dtsch Chir* 1950;266:569–75.
- Dijkstra PU, Geertzen JHB, Stewart R, van der Schans CP. Phantom pain and risk factors: a multivariate analysis. *J Pain Symptom Manage* 2002;24:578–85.
- Downing R, Windsor CW. Disturbance of sensation after mastectomy. *Br Med J (Clin Res Ed)* 1984;288:1650.
- Fisher B, Wolmark N, Redmond C, Deutsch M, Fisher ER. Findings from NSABP Protocol No. B-04: comparison of radical mastectomy with alternative treatments. II. The clinical and biologic significance of medial-central breast cancers. *Cancer* 1981;48:1863–72.
- Graham LE, McGuigan C, Kerr S, Taggart AJ. Complex regional pain syndrome post-mastectomy. *Rheumatol Int* 2002;21:165–6.
- Greenlee RT, Hill Harmon MB, Murray T, Thun M. Cancer statistics, 2001. *CA Cancer J Clin* 2001;51:15–36.
- Jamison K, Wellisch DK, Katz RL, Pansau RO. Phantom breast syndrome. *Arch Surg* 1979;114:93–5.
- Jarvis JH. Post-mastectomy breast phantoms. *J Nerv & Ment Dis* 1967;144:266–72.
- Kooijman CM, Dijkstra PU, Geertzen JHB, Elzinga A, van der Schans CP. Phantom pain and phantom sensations in upper limb amputees: an epidemiological study. *Pain* 2000;87:33–41.
- Krøner K, Krebs B, Skov J, Jorgensen HS. Immediate and long-term phantom breast syndrome after mastectomy: incidence, clinical characteristics and relationship to pre-mastectomy breast pain. *Pain* 1989;36:327–34.
- Krøner K, Knudsen UB, Lundby L, Hvid H. Long-term phantom breast syndrome after mastectomy. *Clin J Pain* 1992;8:346–50.
- Lorenzoni E, Heidenreich W. Zum Phantompfinden nach Ablatio mammae. [Phantom sensations following mastectomy]. *Geburtshilfe Frauenheilkd* 1982;42:63–5.
- Macrae WA. Chronic pain after surgery. *Br J Anaesth* 2001;87:88–98.
- Madden JL, Kandalaf S, Bourque RA. Modified radical mastectomy. *Ann Surg* 1972;175:624–34.

- Maunsell E, Brisson J, Deschenes L. Arm problems and psychological distress after surgery for breast cancer. *Can J Surg* 1993;36:315–20.
- Moore GE, Stayton D. Phantom breast sensations. *Arch Surg* 1981;116:482–3.
- Nail L, Jones LS, Giuffre M, Johnson JE. Sensations after mastectomy. *Am J Nurs* 1984;84:1121–3.
- Pohjolainen T. A clinical evaluation of stumps in lower limb amputees. *Prosthet Orthot Int* 1991;15:178–84.
- Ramachandran VS, Hirstein W. The perception of phantom limbs: The D.O. Hebb lecture. *Brain* 1998;121:1603–30.
- Reuben SS, Makri-Judson G, Lurie SD. Evaluation of efficacy of the perioperative administration of Venlafaxine XR in the prevention of postmastectomy pain syndrome. *J Pain Symptom Manage* 2004;27:133–9.
- Rietman JS, Dijkstra PU, Geertzen JHB, Baas P, De Vries J, Dolsma W, et al. Short-term morbidity of the upper limb after sentinel lymph node biopsy or axillary lymph node dissection for Stage I or II breast carcinoma. *Cancer* 2003;690–6.
- Rietman JS, Dijkstra PU, Hoekstra HJ, Eisma WH, Szabo BG, Groothoff JW, et al. Late morbidity after treatment of breast cancer in relation to daily activities and quality of life: a systematic review. *Eur J Surg Oncol* 2003;229–38.
- Rietman JS, Dijkstra PU, Debreczeni R, Geertzen JHB, Robinson DPH, De Vries J. Impairments, disabilities and health related quality of life after treatment for breast cancer: a follow-up study 2.7 years after surgery. *Disabil Rehabil* 2004;26:78–84.
- Sherman RA, Sherman CJ. Prevalence and characteristics of chronic phantom limb pain among American veterans. Results of a trial survey. *Am J Phys Med* 1983;62:227–38.
- Sherman RA, Sherman CJ. A comparison of phantom sensations among amputees whose amputations were of civilian and military origins. *Pain* 1985;21:91–7.
- Vecht CJ, Van de Brand HJ, Wajer OJ. Post-axillary dissection pain in breast cancer due to a lesion of the intercostobrachial nerve. *Pain* 1989;38:171–6.
- Visser O, Coebergh JWW, Schouten LJ, van Dijck JAAM. Incidence of cancer in the Netherlands 1997, Ninth report of the Netherlands Cancer Registry, 2001.
- Weinstein S, Vetter RJ, Sersen EA. Phantoms following breast amputation. *Neuropsychologia* 1970;8:185–97.