



## Phantom pain and phantom sensations in upper limb amputees: an epidemiological study

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### Abstract

Phantom pain in subjects with an amputated limb is a well-known problem. However, estimates of the prevalence of phantom pain differ considerably in the literature. Various factors associated with phantom pain have been described including pain before the amputation, gender, dominance, and time elapsed since the amputation. The purposes of this study were to determine prevalence and factors associated with phantom pain and phantom sensations in upper limb amputees in The Netherlands. Additionally, the relationship between phantom pain, phantom sensations and prosthesis use in upper limb amputees was investigated. One hundred twenty-four upper limb amputees participated in this study. Subjects were asked to fill out a self-developed questionnaire scoring the following items: date, side, level, and reason of amputation, duration of experienced pain before amputation, frequencies with which phantom sensations, phantom pain, and stump pain are experienced, amount of trouble and suffering experienced, respectively, related to these sensations, type of phantom sensations, medical treatment received for phantom pain and/or stump pain, and the effects of the treatment, self medication, and prosthesis use. The response rate was 80%. The prevalence of phantom pain was 51%, of phantom sensations 76% and of stump pain 49%; 48% of the subjects experienced phantom pain a few times per day or more; 64% experienced moderate to very much suffering from the phantom pain. A significant association was found between phantom pain and phantom sensations (relative risk 11.3) and between phantom pain and stump pain (relative risk 1.9). No other factors associated with phantom pain or phantom sensations could be determined. Only four patients received medical treatment for their phantom pain. Phantom pain is a common problem in upper limb amputees that causes considerable suffering for the subjects involved. Only a minority of subjects are treated for phantom pain. Further research is needed to determine factors associated with phantom pain. © 2000 International Association for the Study of Pain. Published by Elsevier Science B.V. All rights reserved.

**Keywords:** Phantom pain; Phantom sensation; Phantom limb; Amputation; Prevalence; Determinant

### 1. Introduction

Pain and other sensations in an amputated or absent limb, so-called phantom pain and phantom sensations, are well-known phenomena. The short-term incidence of phantom pain is reported to be 72% in the immediate postoperative period (Jensen et al., 1983) and 67% 6 months after amputation (Carlen et al., 1978; Jensen et al., 1983). For phantom sensations, the short-term incidence is 84% in the immediate postoperative period and 90% 6 months after amputation

(Jensen et al., 1983). Differences in the incidence for phantom pain are reported for upper and lower limb amputees. In upper limb amputees a short-term incidence of phantom pain of 82% was found, while the short-term incidence of phantom pain in lower limb amputees was only 54% (Shukla et al., 1982). Estimations of the long-term prevalence of phantom pain and phantom sensations vary considerably. In selected subjects from the military service prevalences of 78% (Sherman et al., 1984), 73% (Steinbach et al., 1982) and 55% (Wartan et al., 1997) of phantom pain were found. In these studies, selection may have biased the estimates of the prevalence. Therefore, these prevalence numbers cannot be extrapolated to the entire population of amputees. In other populations estimates of prevalences of

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78% (Houghton et al., 1994), 59% (Pohjolainen, 1991; Jones and Davidson, 1995), 50% (Montoya et al., 1997) and 29% (Wilkins et al., 1998) were reported. The number of subjects in these study groups varied considerably, i.e. between 27 and 2750 (Table 1).

The purpose of this study is to estimate the prevalence and confidence interval of phantom pain and phantom sensations in upper limb amputees.

Several determinants have been suggested for phantom pain. These include pre-existent pain, amputation level, gender, dominance of the amputated limb, and prosthesis use.

It has been reported by several authors that the risk for phantom pain is higher in the case of pre-existent pain (Katz and Melzack, 1990). Jensen et al. (1985) found that preoperative pain is a risk factor for immediate postoperative phantom pain but not for long-lasting phantom pain. This finding is confirmed in a more recent study by Nikolajsen et al. (1997). In this study a relationship was found between preoperative pain and the incidence of phantom pain 1 week and 3 months after amputation, but not 6 months after amputation. Krane and Heller (1995) found in paediatric amputees that most subjects with phantom pain also experienced preoperative pain. Based on this kind of clinical study preoperative continuous regional analgesia was used to prevent postoperative phantom pain (Fisher and Meller, 1991). This intervention, however, failed to prevent postoperative phantom pain (Elizaga et al., 1994). In a short review Katz (1997) states that epidural anaesthesia started before and continued during and after the amputation seems to confer the most protection for the development of phantom pain. Nevertheless, this author also concludes that well controlled studies are required to establish the effects of preoperative pain control on the development of phantom pain.

In the previously mentioned study of Jensen et al. (1985) no relationship between the occurrence of phantom pain and gender was found. Weiss and Lindell (1996) on the other

hand found that women reported a greater intensity of phantom pain as compared with men.

A reduction of phantom pain in time is sometimes suggested (Jensen et al., 1983, 1985; Sherman et al., 1984; Melzack, 1992). However, until now there has been no evidence that the time since the amputation is associated with the prevalence or incidence of phantom pain. Flor et al. (1995) and Wartan et al. (1997) found no relationship between the occurrence of phantom pain and the time elapsed since the amputation.

Dominance has also been suggested as a potential determinant for phantom pain or phantom sensations, especially in the case of upper limb amputation. Shukla et al. (1982) investigated phantom sensations in 38 right-handed upper limb amputees. No association was found between the side of amputation and the presence of phantom pain. However, phantom sensations were reported more frequently in the case of amputation of the right arm as compared to an amputation of the left arm.

The second purpose of this study is to investigate factors associated with phantom pain and phantom sensations in upper limb amputees.

It is not known whether the experience of phantom pain or phantom sensations influences the use of a prosthesis. It can be hypothesized that fitting of a prosthesis, while experiencing phantom pain or phantom sensations, is uncomfortable. One could, for example, imagine the awkward situation in which the phantom limb has another shape or length than the prosthesis. Then one would expect a decrease in prosthesis use if phantom sensations are present. On the other hand, it is also possible that the presence of a prosthesis makes the experience of phantom pain or a phantom limb less bothering or strange. According to this hypothesis, one would expect a positive relation between these variables. In other words if phantom pain or phantom sensations are present, prosthetic use increases. Until now little evidence has been available from the literature that

Table 1  
Incidence and prevalence of phantom pain in different studies

	Incidence (%)	Prevalence (%)	Number of subjects
Carlen et al., 1978	67 (1–6 months)		73
Jensen et al., 1983	72 (immediate)		58
	76 (after 6 months)		58
Jones and Davidson, 1995		59	27
Houghton et al., 1994		78	338
Montoya et al., 1997		50	32
Pohjolainen, 1991		59	124
Sherman et al., 1984		78	2750
Shukla et al., 1982	82 (upper limb amputees)		34
	54 (lower limb amputees)		28
Steinbach et al., 1982		73	43
Wartan et al., 1997		55	525
Wilkins et al., 1998		29 (whole group)	60
		4 (congenital group)	27
		49 (acquired group)	33

prosthetic use is affected by phantom pain. Jones and Davidson (1995) found that phantom pain did not affect prosthetic usage or functional ability. Wartan et al. (1997) also found no differences between subjects reporting phantom pain and those without phantom pain concerning the use of a prosthesis. In their study only 8% of amputees experienced more phantom limb pain while using a prosthesis. Geraghty and Jones (1996) similarly reported only one case in a group of 32 subjects in which prosthetic use was ceased due to an increase of phantom pain. In contrast, Lotze et al. (1999) found that the frequent use of a myoelectric prosthesis may reduce or even prevent phantom pain.

The third purpose of this study is to investigate the relationship between phantom pain or phantom sensations and prosthetic use in upper limb amputees.

## 2. Subjects and methods

In the data base of an orthopaedic workshop (O.I.M., Haren, The Netherlands) 124 subjects with an upper limb prosthesis were identified. These subjects were invited by letter to fill in a questionnaire (Appendix A). This questionnaire was developed because no valid and reliable Dutch questionnaire assessing phantom pain, phantom sensations, and stump pain was available. Our questionnaire is partially based on two English questionnaires (Sherman et al., 1984; Wartan et al., 1997) and the questionnaire used by the Dutch Working Group of Users of Lower Limb Prostheses (SLWBG).

The questionnaire was used to assess the following: date, side, level, and reason of amputation, duration of experienced pain before amputation, frequencies with which phantom sensations, phantom pain, and stump pain are experienced, amount of trouble and suffering experienced, respectively, related to these sensations, type of phantom sensations, medical treatment received for phantom pain and/or stump pain and the effects of the treatment, self medication, and prosthetic use.

The answers to the questions were entered to the data base and checked manually for correct data entering. Data were processed anonymously.

### 2.1. Statistical analyses

Statistical analyses were performed using SPSS version 8. Univariate  $\chi^2$  and the Fisher exact tests were used to analyze the associations between dichotomous variables. The *T*-test for independent samples was used for analyzing interval and ratio data. A *P* value of  $\leq 0.05$  was considered statistically significant. The following factors potentially associated with phantom pain were analyzed: age, follow-up time (time between amputation and follow-up), gender (male/female), reason for amputation (accident or no accident), pain before the amputation (present or absent), phantom sensations (present or absent), stump pain (present or absent), level of amputation (above or below the elbow),

prosthesis use (prosthetic use less than 8 h per day or 8 h or more per day), type of prosthesis (use of a myoelectric prosthesis or not), dominance (was the amputated side dominant or not).

## 3. Results

Of the 124 subjects, three had died. Nine subjects returned the questionnaire without answering the questions because of reasons of privacy. Thirteen subjects did not respond for unknown reasons. The remaining 99 subjects (80%) returned the questionnaire. One subject reported an amputation of the left forearm and a partial amputation of the right hand. The presence of phantom pain, phantom sensations, and stump pain was equal for both sides. Information of only one arm was entered to the data base. In 72 subjects the amputation was acquired (acquired group) and in 27 subjects the limb defect was congenital (congenital group).

### 3.1. Congenital group (*n* = 27)

The congenital group with a median age of 30.5 years (inter-quartile range 9.3–52.9 years) consisted of 13 men and 13 women. For one subject the gender was not filled out in the questionnaire. In two subjects the defect was above the elbow, in one subject the defect was at the elbow, and in 21 subjects the defect was below the elbow. For three subjects this information was not available.

Phantom pain was not reported, and phantom sensation was reported only once in the congenital group. Stump pain was reported by three subjects of which one subject always experienced stump pain. None of them sought help for the stump pain or took medication for it.

### 3.2. Acquired group (*n* = 72)

The remaining part of this analysis/paper will focus on the acquired group. The acquired group, with a median age of 44.2 years (inter-quartile range 35.2–65 years) consisted of 15 women and 57 men. The median follow-up time (amputation-evaluation) was 19.1 years (inter-quartile range 6.4–32.1 years). The event most frequently leading to amputation was an accident (77%; Table 2). The mean

Table 2  
Events leading to amputation in the acquired group (*n* = 72)

Events	Number (%) of subjects
Accident	56 (78)
Cancer	11 (15)
Vascular disease	2 (3)
Infection	2 (3)
Paralyses of the arm	1 (1)

Table 3

The number and percentage of subjects in the acquired group ( $n = 72$ ) reporting phantom pain, phantom sensations, and stump pain

	Phantom pain (%)	Phantom sensations (%)	Stump pain (%)
Prevalence	37 (51)	55 (76)	35 (49)
95% CI <sup>a</sup>	39–63	66–86	37–60

<sup>a</sup> 95% confidence interval of the estimated prevalence.

(SD) age at which the amputation was performed was 26.7 (16.0) years.

Pain before the amputation was experienced by 10 subjects. One subject experienced pain 1–4 weeks before the amputation. Five subjects experienced pain 1–6 months before the amputation and three subjects experienced pain for more than 1 year before the amputation. One subject experienced pain before the amputation but with unknown duration. The level of the amputation was above the elbow in 27 subjects and below the elbow in 41 subjects. In four subjects the site of amputation was through the elbow.

The prevalence of phantom pain was 51%, of phantom sensations 76%, and of stump pain 48.6% (Table 3). The frequencies with which the subjects experienced phantom pain, phantom sensations, and stump pain, and suffering related to these sensations are summarized in Table 4. Forty-eight percent of the subjects experienced phantom pain a few times per day or more. Sixty-four percent of the subjects suffered moderately to very much from the phantom pain. The qualities of experienced phantom sensations are summarized in Table 5.

Medical treatment for phantom pain was given to four

subjects, including transcutaneous electrical nerve stimulation (TENS), medication, and injections. In two subjects medication and TENS were effective in reducing the pain. As self medication, ten subjects took pain medication, one subject took sleeping tablets and two subjects took alcoholic liquors to reduce phantom pain. Medical treatment for stump pain was given to five subjects of which four subjects underwent an operation and one subject received massage. In three subjects the operation was effective. Six subjects took pain medication.

In 20 subjects a spot was present which upon touching provoked phantom pain and stump pain. The arm prosthesis was used for more than 8 h per day by 52 subjects, for 4–8 h by three subjects, for less than 4 h per day by seven subjects and 14 subjects did not use the prosthesis on a daily basis or not at all. The prostheses used were cosmetic for most of the subjects (23), mechanic for 15 subjects and myoelectric for 19 subjects.

### 3.3. Factors associated with phantom pain and phantom sensations

Subjects experiencing phantom pain did not differ significantly from those subjects not experiencing phantom pain with respect to age and follow-up time (Table 6). Phantom pain was present in 36 out of the 37 subjects experiencing phantom sensations and in one out of the 17 subjects who did not experience phantom sensations (Table 7). The relative risk is therefore 11.3. The relative risk (RR) of experiencing phantom pain when having stump pain is about twice as high compared with those not experiencing stump pain (RR 1.9). No other factors associated with phantom pain could be identified (Table 7). Subjects experiencing phantom sensations did not differ

Table 4

Frequency with which phantom sensations, phantom pain and stump pain are experienced and the trouble or suffering experienced because of the sensations<sup>a</sup>

	Phantom pain (%)	Phantom sensations (%)	Stump pain (%)
<i>Frequency with which the sensations are felt</i>			
Always	9 (24)	22 (40)	6 (17)
A few times per hour	–	–	2 (6)
A few times per day	9 (24)	11 (20)	4 (11)
A few times per week	6 (16)	5 (9)	2 (6)
A few times per month	8 (22)	6 (11)	5 (14)
A few times per year	5 (14)	9 (16)	14 (40)
Unknown	1 (3)	2 (4)	2 (6)
<i>The amount of suffering (phantom pain, stump pain) and trouble (phantom sensations) experienced</i>			
Very much	2 (5)	3 (5)	1 (3)
Much	13 (35)	10 (18)	7 (20)
Moderately	9 (24)	18 (33)	13 (37)
Hardly	11 (30)	15 (27)	11 (31)
None	1 (3)	8 (15)	3 (9)
Unknown	1 (3)	1 (2)	–

<sup>a</sup> The percentages are calculated on the basis of the number of subjects experiencing the specific sensation: phantom pain ( $n = 37$ ), phantom sensations ( $n = 55$ ), and stump pain ( $n = 35$ ). Note that not all percentages add up to 100% due to rounding off of the percentages.

Table 5  
The number and percentage of subjects experiencing the different qualities of phantom sensations<sup>a</sup>

Quality of phantom sensations	Number (%) of subjects
Itching	14 (25)
Movement	21 (38)
Abnormal shape	5 (9)
Abnormal position	12 (22)
Something touching	4 (7)
Warmth	6 (11)
Cold	22 (40)
Electric sensations	23 (42)
Other sensations	19 (35)

<sup>a</sup> The percentages are calculated on the basis of the number of subjects experiencing phantom sensations ( $n = 55$ ). Some subjects experienced more than one type of phantom sensation.

significantly from those subjects not experiencing phantom pain with respect to age and follow-up time (Table 6). The risk of experiencing phantom sensations is higher for those experiencing stump pain as compared with those who do not experience stump pain (RR 1.2). Multivariate analyses did not reveal any other associated factors.

#### 4. Discussion

The results of this explorative study show that phantom pain is a common problem in upper limb amputees which results in moderate to very much suffering of the subjects

Table 6  
Age, duration of follow-up (time between the amputation and follow-up date) and the age at which the amputation was performed of the subjects who experience phantom pain ( $n = 37$ ), subjects who do not experience phantom pain ( $n = 35$ ), subjects who experience phantom sensations ( $n = 55$ ) and subjects who do not experience phantom sensations ( $n = 17$ ) of the acquired group ( $n = 72$ )<sup>a</sup>

	Yes: mean (SD)	No: mean (SD)	<i>P</i> value
<i>Phantom pain</i>			
Age (years)	48.4 (18.7)	50.3 (17.6)	0.671
Follow-up (years)	19.1 (18.3)	26.2 (19.2)	0.111
Age of amputation (years)	29.3 (14.7)	24.0 (17.3)	0.164
<i>Phantom sensation</i>			
Age (years)	47.6 (18.3)	55.3 (16.2)	0.124
Follow-up (years)	20.3 (17.8)	30.4 (20.5)	0.054
Age of amputation (years)	27.3 (14.3)	24.9 (20.9)	0.598

<sup>a</sup> No significant differences were found between the subjects experiencing phantom pain and those who do not with respect to age and follow-up. No significant differences were found between the subjects experiencing phantom sensations and those who do not with respect to age and follow-up. Result of *t*-test for independent samples. Note that the difference in follow-up time for those who experience phantom sensations and those who do not did not reach the level of significance. The data suggest, however, that there may be a trend that phantom sensations diminish with time.

involved. However, only very few subjects were treated for the pain.

The estimation of the prevalence of phantom pain of 51% found in our study confirms the results of earlier, smaller studies in which prevalence numbers of 59 and 50% were found (Jones and Davidson, 1995; Montoya et al., 1997). Due to a higher number of subjects in our study, the confidence interval of the estimated prevalence is somewhat smaller. Prevalence numbers of the other studies fit well in the confidence interval of our study. Results of our study are also consistent with an earlier, larger study in selected subjects from the military service (Wartan et al., 1997). In the studies of Sherman and Sherman (1983) and Sherman et al. (1984), also in selected subjects from the military service, a prevalence for phantom pain of 78 and 85% was reported. The explanation for the difference in prevalence in our study and the studies of Sherman is possibly the response rate. The response rates in the studies of Sherman were 61% (Sherman and Sherman, 1983) and 55% (Sherman et al., 1984) while in our study the response rate was about 80%. It is possible that the prevalence of phantom pain is higher in the responders than in the non-responders. The prevalence of about 80% in the studies of Sherman may therefore somewhat overestimate the 'true' prevalence because of the relatively low response rate. On the other hand it is common that the prevalence number may underestimate the true size of the problem. Other potential explanations for the difference in prevalence in our study and that of Sherman are cultural differences between the two populations and differences in the questionnaires used. The incidence is probably higher than the prevalence because subjects may experience phantom pain in episodes that are not represented in the prevalence.

Most subjects that experienced phantom pain reported moderately to very much suffering. This finding is in contrast with the fact that only four subjects in our study received medical treatment for the phantom pain. This contrast between the size of the problem and the medical treatment given was earlier described by Machin and Williams (1998). These authors found that war veteran amputees accept high levels of pain and make little use of medical resources. The results of our study extend the finding of Machin in the sense that amputees overall make very little use of medical resources because of phantom pain. The explanation is possibly that it is almost generally accepted by the subjects and the physician that medical treatment is not effective in the case of phantom pain. Sherman and Sherman (1985) found that medical treatment was to some extent effective in only 1% of the amputees suffering from phantom pain. Of the 68 described methods in the literature only few were moderately successful (Sherman et al., 1980).

Besides phantom pain many amputees also experience phantom sensations. In our study we found a prevalence of 76%. The most commonly reported phantom sensations were cold, electric sensations and movement of the phantom limb. A significant association was found between the

Table 7  
Association between phantom pain, phantom sensations and possible associated factors<sup>a</sup>

Factor	Exposed	Phantom pain (%)	<i>P</i> value	Exposed	Phantom sensations (%)	<i>P</i> value
Phantom sensations <sup>b</sup>	Yes (54)	36 (67)	0.001		–	
	No (17)	1 (6)			–	
Stump pain <sup>b</sup>	Yes (35)	22 (65)	0.015	Yes (35)	30 (86)	0.043
	No (34)	12 (35)		No (34)	22 (65)	
Amputation dominant side <sup>b</sup>	Yes (42)	23 (55)	0.591	Yes (43)	35 (81)	0.223
	No (29)	14 (48)		No (29)	20 (69)	
Pain prior to amputation <sup>b</sup>	Yes (10)	6 (60)	0.590	Yes (10)	10 (100)	0.104 <sup>c</sup>
	No (61)	31 (51)		No (62)	45 (73)	
Amputation level <sup>d</sup>	Above elbow (27)	18 (67)	0.081	Above elbow (27)	22 (82)	0.568
	Below elbow (40)	18 (45)		Below elbow (41)	32 (76)	
Prosthetic use	<8 h/day (20)	14 (70)	0.059	<8 h/day (20)	17 (85)	0.286
	≥8 h/day (52)	23 (45)		≥8 h/day (52)	38 (73)	
Prosthesis type <sup>b</sup>	Myoelectric (18)	11 (61)	0.291	Myoelectric (19)	17 (90)	0.181 <sup>c</sup>
	Other (37)	17 (46)		Other (37)	26 (70)	
Gender <sup>b</sup>	Female (15)	10 (67)	0.204	Female (15)	12 (80)	0.711
	Male (56)	27 (48)		Male (57)	43 (75)	
Amputation reason accident <sup>b</sup>	Yes (55)	30 (55)	0.447	Yes (56)	43 (77)	0.882
	No (17)	7 (44)		No (16)	12 (75)	

<sup>a</sup> Phantom sensations and stump pain were identified as factors associated with phantom pain. The level of amputation did not reach the significance level of 0.05. The relative risk of experiencing phantom pain when experiencing phantom sensations is 11.3 compared with those who do not experience phantom sensations. The relative risk of experiencing phantom pain when experiencing stump pain is 1.9 compared with those who do not experience stump pain. Only stump pain was identified as a risk factor for phantom sensations. The percentages in parentheses indicate the percentage of subjects exposed to a factor (or not) experiencing phantom pain and/or phantom sensations. Multivariate analyses did not reveal any other associated factors.

<sup>b</sup> Note that not all figures add up to a total of 72 (acquired group) because not all subjects filled out the total questionnaire. As a result the figures of the first column 'exposed' and the second column 'exposed' are not identical.

<sup>c</sup> Results of Fischer's exact test because the expected count of 5 or less was present in 25% of the cells.

<sup>d</sup> For four subjects amputation was through the elbow. These subjects were excluded from the analysis.

prevalence of phantom pain and phantom sensations. The explanation is probably that phantom pain could be considered as a form of phantom sensation with a high intensity. In our questionnaire we described phantom pain accordingly. Our finding that in subjects without phantom sensations the time since the amputation was longer as compared with subjects who did not experience phantom sensations ( $P = 0.054$ ) suggests that phantom sensations may fade away over time.

Interestingly, one subject with a congenital limb defect reported phantom sensations that occurred several times a week and were experienced as 'moderately bothering'. The occurrence of phantom pain in subjects with a congenital limb defect was reported before by other authors (Weinstein and Sersen, 1961; Weinstein et al., 1964; Lacroix et al., 1992; Saadah and Melzack, 1994; Wilkins et al., 1998).

Stump pain appears also to be a very frequent problem, with a prevalence of 47%. Abramson and Feibel (1981) found a stump pain prevalence of only 15%, while Parkes (1973) found a prevalence of 50%, and Wartan et al. (1997) a prevalence of 56%. Stump pain in our study is associated with phantom pain and phantom sensations. Our finding supports the results of the review of Hill (1999). In this review on phantom limb pain it was noted that studies reporting a high prevalence of phantom

pain also found a high incidence of stump pain and vice versa. An explanation given by Hill is that subjects probably cannot distinguish between stump pain and phantom pain. On the other hand it is very well possible that stump pain triggers phantom pain, and that therefore these symptoms are difficult to distinguish. Twenty subjects in our study reported that they experienced a spot on the stump that induced phantom pain and stump pain upon touching. This finding suggests a neuroma as a potential cause of the pain in these subjects.

In our study five subjects used analgesics to reduce stump pain. Five subjects received professional help, which was successful in three cases. Although this finding is based on a small group, it is consistent with the findings of other studies. Overall, the treatment of stump pain tends to be more successful as compared with the treatment of phantom pain.

In the literature several determinants are suggested for the development of phantom pain. Jensen et al. (1985) found that pain before the amputation is a risk factor. This finding could not be confirmed by our study. Differences in follow-up may explain a different outcome. In the study of Jensen et al. (1985) the follow-up time was 6 months while in our study the mean time since the amputation is 19 years. Potentially the lack of association between the presence of preoperative pain and the

presence of phantom pain found in our study may be biased by memory problems, in the sense that subjects may have forgotten or may overestimate the pain before the amputation. Nikolajsen et al. (1997) found that patients after amputation tend to overestimate the intensity of the preoperative pain. In our opinion bias by memory problems in our study is not very likely, firstly because Nikolajsen et al. (1997) also report that inaccurate recall of pain intensity was not affected by the presence of phantom pain after 6 months. Secondly, in our questionnaire we did not ask about the intensity of preoperative pain but only the presence or absence of preoperative pain. Thirdly, in a post-hoc analysis we analyzed the follow-up time in subjects with preoperative pain and in subjects without preoperative pain. We found no significant difference between the groups; the mean (SD) follow-up time in subjects reporting preoperative pain was 16 (16) years and in subjects reporting no preoperative pain was 24 (19) years ( $P = 0.254$ ).

Also other suggested determinants, such as gender, dominance, age at the time of amputation, and level of amputation, could not be confirmed in our study. However, our data suggest a trend for an association between amputation level and phantom pain; subjects with an amputation above the elbow more frequently experience phantom pain than those with an amputation below the elbow. This association did not reach the statistical level of significance. Our finding that the follow-up time in the subjects experiencing phantom pain was similar to the subjects not experiencing phantom pain suggests that phantom pain does not fade away during the years. This was confirmed with post-hoc analysis using the Spearman rank correlation. No correlation between follow-up time and frequency of phantom pain was found ( $\rho = 0.153$ ,  $P = 0.202$ ).

Prosthesis use was very high in our study. Most subjects (72%) used their prosthesis every day for more than 8 h. This finding is in contrast to the findings of Jones and Davidson (1995) who found a prosthesis use of 8 h or more per day in only 37% of the subjects. This result of our study is probably biased by the fact that we recruited subjects from an orthopaedic workshop. Subjects who did not intend to use a prosthesis never visited the orthopaedic workshop and were therefore not present in our sample. In our study we found a trend for association ( $P = 0.059$ ) between prosthesis use and phantom pain in the sense that subjects with phantom pain used their prosthesis less than subjects without phantom pain. Post-hoc analysis calculating the Spearman rank correlation did not confirm this trend for association between the frequency of phantom pain and the frequency of prosthesis use ( $\rho = 0.181$ ,  $P = 0.132$ ), nor between the amount of suffering from phantom pain and the frequency of prosthesis use ( $\rho = 0.058$ ,  $P = 0.738$ ). This finding seems to be in contrast with the finding of Lotze et al. (1999) that prosthesis use is correlated with the intensity of phantom pain ( $\rho = -0.55$ ,  $P < 0.05$ ). However, we have some concerns about the methodology

used by these authors. In their study prosthesis use was calculated by multiplying the 'type of prosthesis' (0, no prosthesis; 1, cosmetic prosthesis; 2, myoelectric prosthesis) with 'hours per day the prosthesis was used' and 'percentage of time the prosthesis was used' for activities. Multiplying a nominal variable such as type of prosthesis with another ordinal variable is not correct because the outcome is partly dependent on the labels chosen for the nominal variable. Furthermore, the two variables 'hours per day a prosthesis is used' and 'percentage of activities the prosthesis is used for' in their calculation are strongly correlated with each other ( $\rho = 0.856$ ,  $P < 0.001$ ). In our opinion, multiplying these two factors confounds the non-significant bivariate association between each factor separately and the intensity of phantom pain. We re-analyzed the data of Lotze et al. (1999) from their publication and found that also in their study there is only a trend for association between intensity of phantom pain and percentage use of the prosthesis ( $\rho = -0.497$ ,  $P = 0.070$ ) and for intensity of phantom pain and the hours per day the prosthesis was used ( $\rho = -0.458$ ,  $P = 0.099$ ). These results are more consistent with the results of our study. Use of a myoelectrical prosthesis versus another type of prosthesis was in our study not associated with the presence of phantom pain or phantom sensations. This finding is also in accordance with the finding of Lotze et al. (1999). The relationship between prosthesis use and the presence of phantom pain, especially the cause effect relation, needs to be studied in much further detail before it can be concluded that prosthesis use may prevent phantom pain.

In conclusion, phantom pain after upper limb amputation is a common problem. The determinants are still poorly understood.

#### Appendix A. Groningen Questionnaire Problems after Arm Amputation (GQPAA)

This questionnaire is meant to obtain information concerning complaints that may develop after the amputation of your arm. The questions deal with phantom sensations, phantom pain and pain in the stump.

Phantom sensations are: all non-painful sensations in the amputated part of the arm. Examples of phantom sensations are: sensations of a certain position of the arm, of something touching, of warmth or cold, or of movements of the amputated part of the arm.

Phantom pain is any of the above-mentioned phantom sensations or any other sensation in the amputated part of the arm which is so intense that it is experienced as painful.

Stump pain is any painful sensation in the stump.

For each question you can mark an answer for the right or left arm. If your right arm has been amputated, you fill in the column under right arm; if your left arm has been amputated, you fill in the column under left arm. If both arms have been amputated, both columns must be filled in.

1. Date that you fill in the questionnaire: ./. /. .

2. Date of birth ./. /. .

3. Male /Female  female  
 male

4. Before amputation you were  Left handed  
 Right handed

	Left arm	Right arm
5. When was your arm amputated? Please fill in month and year.	.....19.....	.....19.....
6. What was the amputation level?	<input type="checkbox"/> Shoulder <input type="checkbox"/> Upper arm <input type="checkbox"/> Elbow <input type="checkbox"/> Lower arm <input type="checkbox"/> Wrist <input type="checkbox"/> Other (Please specify): ..... .....	<input type="checkbox"/> Shoulder <input type="checkbox"/> Upper arm <input type="checkbox"/> Elbow <input type="checkbox"/> Lower arm <input type="checkbox"/> Wrist <input type="checkbox"/> Other (Please specify): ..... .....
7. What was the reason for amputation?	<input type="checkbox"/> Blood vessel disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Accident <input type="checkbox"/> Cancer <input type="checkbox"/> Congenital <input type="checkbox"/> Other, (Please specify) ..... .....	<input type="checkbox"/> Blood vessel disease <input type="checkbox"/> Diabetes <input type="checkbox"/> Accident <input type="checkbox"/> Cancer <input type="checkbox"/> Congenital <input type="checkbox"/> Other, (Please specify) : ..... .....
8. Did you experience pain in the arm before amputation?	<input type="checkbox"/> No <input type="checkbox"/> Yes If so, how long did you experience pain: <input type="checkbox"/> less than a week <input type="checkbox"/> 1 to 4 weeks <input type="checkbox"/> 1 to 6 months <input type="checkbox"/> ½ to 1 year <input type="checkbox"/> more than 1 year	<input type="checkbox"/> No <input type="checkbox"/> Yes If so, how long did you experience pain: <input type="checkbox"/> less than a week <input type="checkbox"/> 1 to 4 weeks <input type="checkbox"/> 1 to 6 months <input type="checkbox"/> ½ to 1 year <input type="checkbox"/> more than 1 year

The following questions are about **phantom sensations**.  
Phantom sensations are: all non-painful sensation in the amputated part of the arm. Examples of phantom sensations are: Sensations of a certain position of the arm, of something touching, of warmth or cold, or of movements of the amputated part of the arm.

	Left arm	Right arm
9. How often do you experience phantom sensations? If you do not experience any phantom sensations at all, please continue to question 12.	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always
10. Which phantom sensations do you experience? You may indicate more options.	A sensation of: <input type="checkbox"/> itching <input type="checkbox"/> movement <input type="checkbox"/> abnormal shape <input type="checkbox"/> abnormal position <input type="checkbox"/> something touching <input type="checkbox"/> warmth <input type="checkbox"/> cold <input type="checkbox"/> electric sensations <input type="checkbox"/> other, (please specify): ..... .....	A sensation of: <input type="checkbox"/> itching <input type="checkbox"/> movement <input type="checkbox"/> abnormal shape <input type="checkbox"/> abnormal position <input type="checkbox"/> something touching <input type="checkbox"/> warmth <input type="checkbox"/> cold <input type="checkbox"/> electric sensations <input type="checkbox"/> other, (please specify): ..... .....
11. How much are you generally troubled by your phantom sensations?	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all

The following questions are about **phantom pain**.  
Phantom pain is any of the above-mentioned phantom sensations or any other sensation in the amputated part of the arm which is so intense, that it is experienced as painful.

	Left arm	Right arm
12. How often do you experience phantom pain? If you do not experience phantom pain at all, please continue to question 17.	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always
13. How much do you generally suffer from your phantom pain?	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all
14. Were you treated for your phantom pain?	<input type="checkbox"/> no <input type="checkbox"/> yes, (please specify): ..... .....	<input type="checkbox"/> no <input type="checkbox"/> yes, (please specify): ..... .....
15. Was the treatment for the phantom pain effective?	<input type="checkbox"/> no <input type="checkbox"/> yes If yes, what treatment ..... .....	<input type="checkbox"/> no <input type="checkbox"/> yes If yes, what treatment ..... .....
16. What do you take when you experience phantom pain? You may indicate more than one answer.	<input type="checkbox"/> nothing <input type="checkbox"/> pain medication <input type="checkbox"/> sleeping tablets <input type="checkbox"/> alcoholic drinks <input type="checkbox"/> other, (Please specify): ..... .....	<input type="checkbox"/> nothing <input type="checkbox"/> pain medication <input type="checkbox"/> sleeping tablets <input type="checkbox"/> alcoholic drinks <input type="checkbox"/> other, (Please specify): ..... .....

The following questions are about **stump pain**.  
Stump pain is any painful sensation in the stump.

	Left arm	Right arm
17. How often do you experience stump pain? If you experience no stump pain at all please proceed to question 23.	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always	<input type="checkbox"/> never <input type="checkbox"/> a few times a year <input type="checkbox"/> a few times a month <input type="checkbox"/> a few times a week <input type="checkbox"/> a few times a day <input type="checkbox"/> a few times per hour <input type="checkbox"/> always
18. How much do generally you suffer in general from your stump pain?	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all	<input type="checkbox"/> very much <input type="checkbox"/> much <input type="checkbox"/> moderately <input type="checkbox"/> hardly <input type="checkbox"/> not at all
19. Were you treated for your stump pain?	<input type="checkbox"/> no <input type="checkbox"/> yes, (Please specify): ..... .....	<input type="checkbox"/> no <input type="checkbox"/> yes, (Please specify): ..... .....
20. Was the treatment for the stump pain effective?	<input type="checkbox"/> no <input type="checkbox"/> yes If yes, what treatment ..... .....	<input type="checkbox"/> no <input type="checkbox"/> yes If yes, what treatment ..... .....
21. Do you have any spot on your stump that, when touched, induces stump pain en phantom pain?	<input type="checkbox"/> no <input type="checkbox"/> yes	<input type="checkbox"/> no <input type="checkbox"/> yes
22. What do you take when you experience stump pain? You may indicate more than one answer.	<input type="checkbox"/> nothing <input type="checkbox"/> pain medication <input type="checkbox"/> sleeping tablets <input type="checkbox"/> alcoholic drinks <input type="checkbox"/> other: (Please specify): ..... .....	<input type="checkbox"/> nothing <input type="checkbox"/> pain medication <input type="checkbox"/> sleeping tablets <input type="checkbox"/> alcoholic drinks <input type="checkbox"/> other: (Please specify): ..... .....

The following questions are about the use of the prostheses.

23. How often do you use your prosthesis? If you never use your prosthesis please proceed to question 28.
- daily, 8 hours or more  
 daily, 4 to 8 hours  
 daily, less than 4 hours  
 not daily (Please specify: ..... days per week)  
 never
24. Do you use your prosthesis when you are at home?
- yes  
 no
25. If yes, which type of prosthesis do you use at home?
- a cosmetic prosthesis  
 a mechanical prosthesis  
 an electrical prosthesis  
 other, (Please specify):  
 .....  
 .....
26. Do you use your prosthesis when you go out?
- yes  
 no
27. If yes, which type of prosthesis do you use when you go out?
- a cosmetic prosthesis  
 a mechanical prosthesis  
 an electrical prosthesis  
 other, (Please specify):  
 .....  
 .....
28. If you have any questions or comments please write them here.

Thank you very much for your cooperation!

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