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# Incidence of Phantom Phenomena Including Phantom Limb Pain 6 Months After Major Lower Limb Amputation in Patients With Peripheral Vascular Disease

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AU1

**Objectives:** Contentions exist regarding the true incidence of phantom limb pain and other associated post-amputation phenomena. Recognizing and understanding these phenomena would assist in the rehabilitation of amputees. This study was designed to investigate all post-amputation phenomena in a homogenous group of amputees.

**Methods:** Prospective amputees were recruited prior to amputation of a lower limb due to peripheral vascular disease. All survivors were followed 6 months after surgery and interviewed to identify post-amputation phenomena, including phantom sensations, phantom limb pain, and stump pain.

**Results:** Sixty amputees were recruited and 52 survived until the 6-month interview. Phantom sensations were universal, and aspects of the nonpainful phenomena, including kinetic, kinesthetic, and exteroceptive components, were identified at varying rates within the sample. Phantom limb pain was found in 78.8% of the survivors, and 51.2% had stump pain. Super-added phenomena occurred in 15.4%. Links were found between phantom limb pain and stump pain ( $P = 0.01$ ) and phantom limb pain and the ability to move the phantom ( $P = 0.01$ ). No link was found between phantom limb pain and telescoping of the phantom ( $P = 0.47$ ).

**Conclusions:** Phantom phenomena are associated with many myths. This study starts to unravel myth from fact, but further study is required before this enigmatic condition and its influence on rehabilitation are fully understood.

**Key Words:** phantom limb pain, phantom sensations, stump pain, amputation

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Various post-amputation phenomena, including nonpainful phantom sensations, phantom limb pain (PLP), and stump pain, have been reported,<sup>1–13</sup> but contentions and myths remain surrounding these phenomena. Reasons are multifactorial but

may be due to the fluctuating nature of the condition, difficulties differentiating between the phenomena, variations of these phenomena in different amputee populations (ie, upper limb/lower limb; trauma/congenital),<sup>14</sup> and disparity in the methodologies of different studies.<sup>15</sup> Most previous studies have not explicitly differentiated between these, so the prevalence of each phenomenon remains disputed.

Phantom sensations are subdivided into kinetic, kinesthetic, exteroceptive, and super-added components. Phantom sensations are defined as “non-painful sensations referred to the missing limb.”<sup>16</sup> The prevalence of phantom sensation in different populations has been measured as 4% to 19.7% in congenitally limb-deficient individuals<sup>17–19</sup> and 53.1% to 100% in trauma/surgical amputees.<sup>17–30</sup> Kinetic properties describe the perception of movement within the missing limb. Amputees often refer to spontaneous movement as spasm,<sup>7</sup> while some report the conscious ability to move the phantom. A lack of movement has been thought to be associated with PLP.<sup>31</sup>

Kinesthetic perceptions are those associated with size, shape, and proprioception of the phantom limb. Commonly the phantom is exactly the same size and shape as the missing limb immediately after the amputation.<sup>32</sup> Over time, the phantom may gradually reduce in size and shorten into the residual limb (telescope) so that eventually only the foot, hand, or digits are left at the stump.<sup>25,33,34</sup> Hill proposed that telescoping occurred in one third of amputees.<sup>6</sup> An inverse relationship between telescoping and PLP has been reported,<sup>33–37</sup> but in the single study designed to investigate the phenomenon Montoya et al could not identify an association between the presence of telescoping and the absence of PLP.<sup>25</sup>

Although the phantom may be the same size and shape as the missing limb, at times its spatial position is abnormal or awkward.<sup>8,38–40</sup> This may be related to the position of the limb prior to amputation, especially in traumatic amputation,<sup>37</sup> which suggests a memory component to the phenomena. Abnormal proprioception of the phantom can have significant effects on prosthetic fitting and rehabilitation because an enormous effort of will is required to move a prosthesis that does not overlay the phantom.<sup>8,23,39,41–43</sup>

The exteroceptive component describes the feelings within the phantom. Examples are “pins and needles,” “tingling,” “tickling,” “itching,” “numbness,” and “like it is asleep.”<sup>6,12,18,24,25,37,44</sup> Super-added sensations are the sensation of an object such as a ring, wristwatch, or shoe still being present on the phantom<sup>38,45</sup> or the return of a painful condition

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such as an ingrowing toenail that existed some time before the amputation.<sup>34,40</sup> Super-added sensations were identified by 5 of 68 amputees (7%) in one study.<sup>41</sup>

Stump pain has been reported in 6% to 76.1%<sup>6,15,19-22, 26-30,41,46</sup> of amputees, while the prevalence of PLP has been reported to be between 50% and 79.6%.<sup>9,15,19-23,25,26,28-30,46,47</sup> Some studies have reported that PLP and stump pain are correlated.<sup>9,18,46,48</sup>

Post-amputation care includes the need for significant rehabilitation, which can be influenced by phantom phenomena.<sup>49</sup> The huge variations in reported prevalence could influence treatment philosophy and resource allocation for the treatment of these potentially disabling phenomena and chronic pain conditions. Identification of the true incidence and fluctuation of PLP and the incidence of the other confounding post-amputation phenomena would assist in the process of fully understanding this enigmatic condition. This study was designed to overcome these issues by investigating a homogenous group of lower limb amputees.

## METHODS

The University and the local medical research ethics committees approved the study.

### Sample

Patients were recruited from one hospital in a city in Northwest England. They were included if they had consented to an above- or below-knee amputation due to peripheral vascular disease. Patients were excluded if they were confused or unable to communicate in the pre-amputation interview, or if they refused consent.

### Study Design

This was a prospective study of patients with peripheral vascular disease who required major lower limb amputation. Written consent prior to surgery was obtained when the concept of phantom phenomena was introduced. Amputees were interviewed 6 months after the surgery to identify the presence of post-amputation phenomena.

### Instruments

The survivors were interviewed using a phantom phenomena questionnaire that asked about all aspects of phantom phenomena (copies available from first author). Elucidation was provided if necessary. All amputees were asked about the presence of PLP and when it started. If PLP was present, the short-form McGill Pain Questionnaire<sup>50</sup> was completed for current and worst PLP. This included visual analog scale (VAS), Present Pain Intensity (PPI), and pain description, including total number of words and sensory/affective components. Identifying the number of attacks a day and the duration of each attack captured the fluctuating nature of PLP. To reflect our interest in PLP and to reduce potential confusion, this was not repeated for stump pain.

### Statistical Analysis

This was mainly descriptive, using SPSS version 10. Percentages of each phenomenon were calculated. Associations between PLP and the other post-amputation phenomena

were investigated using  $2 \times 2$  cross-tabulation (Fisher exact test) for the presence/absence of each phenomenon.

## RESULTS

Seventy-seven patients were referred over a 29-month period, and 59 (77%) were recruited into the study (Fig. 1). Of the 18 not included, 7 were confused, 4 had difficulty communicating, and 7 refused consent. The average age of the participants was 63.8 years (SD = 10.4), and 63% were male. Table 1 shows the reason for the peripheral vascular disease and therefore indirectly the reason for the amputation, and Table 2 shows the percentage of each type of amputation. Seven participants died between surgery and the 6-month follow-up interview, so 52 amputees completed the 6-month interview.

A nonpainful phantom was universal (100%) in the survivors. Kinetic aspects of the phantom were present in the majority. Spontaneous movement occurred in 65.4%, while 58.0% stated that they were able to move the phantom themselves. Less than half (44.2%) had spontaneous and willed movement. Telescoping was the most common kinesthetic aspect. It occurred in 67.3%, with 17.3% of the total describing the foot on the stump.

The majority (88.5%) stated that the phantom corresponded to the position of the missing limb. Amputees often had difficulty rationalizing whether a telescoped limb corresponded to the missing limb, so it was decided that a telescoped phantom was considered to have normal orientation if the residual phantom limb, foot, or toes were positioned correctly and in symmetry with the whole limb had it still been present. Abnormal orientations included flexed toes and misalignments of the foot or residual phantom limb.

Identifying the exteroceptive components was problematic. Although all participants said they had phantom sensations, some could not describe them. The embodiment of the phantom in some amputees was sometimes present without actual sensations. Overall, 51.9% described an exteroceptive component, with 50.0% of these describing pins and needles and 42.9% recounting itch. Five had more than one sensation. Super-added sensations occurred in 15.4%. All such

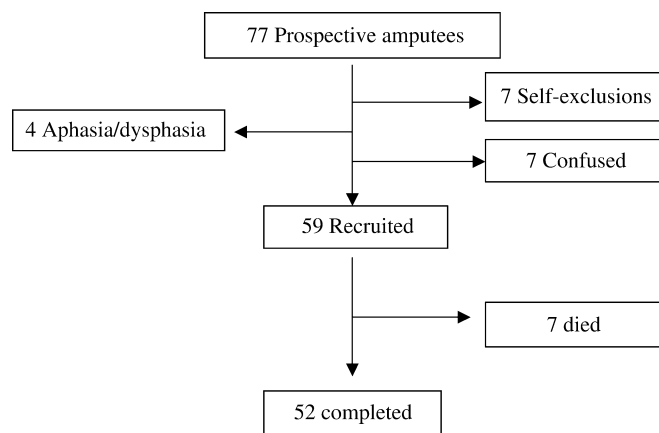


FIGURE 1. Flow chart of participants through the study.

**TABLE 1.** Causes of Peripheral Vascular Disease in the Participants

Cause of PVD	Percentage
Smoker	31.7%
Diabetes	35.0%
Smoker and diabetes	25.0%
Chronic ulceration	3.3%
Frostbite	1.7%
Unknown	3.3%

sensations were feelings as if the leg was clothed. Recurrence of past sensations was not reported in this sample.

PLP was reported in 92.3% in the first week after amputation and in 78.8% at the 6-month interview. None of the initially PLP-free amputees went on to develop it, whereas seven who had PLP in the first week lost it before the 6-month interview. Two of these lost the PLP within weeks, while five experienced it for months after the surgery. The VAS score of the PLP was 27 mm (SD = 16) for the current pain and 55 mm (SD = 26) for the worst pain. Four reported that their current PLP was also their worst, with one reporting the current PLP above 80 mm. In the majority, PLP intensity was reducing: 7 participants lost their PLP and 37 gave a lower current VAS score compared to the worst one. Of the other four, three reported the same score at both times, while the other scored slightly higher, 13 mm versus 12 mm.

A similar pattern was seen for the PPI and the three measures of pain description on the McGill questionnaire. The PPI reduced from 3.0 (distressing) to 1.8 (nearest to discomforting), while the number of sensory descriptors chosen dropped by nearly three. Few affective words were chosen to describe PLP at either time, and only two chose affective words for their current pain. The total scores were therefore mainly a representation of the sensory scores.

**T3** Table 3 shows the position of the PLP in the phantom. The majority (66.7%) experienced the pain in the foot and toes. Commonly PLP occurred 1 to 10 times per day (Table 4) and typically lasted for 1 to 9 minutes at a time (Table 5). However, some experienced continuous PLP, while others had it fewer than 10 times a month, but each bout could last for more than 10 hours.

More than half of the survivors (51.9%) had stump pain at the 6-month interview.

Using the Fisher exact test, no association was found between PLP and the presence of telescoping ( $P = 0.47$ ), the ability of the phantom to move itself ( $P = 0.48$ ), the exteroceptive component ( $P = 0.18$ ), and super-added

**TABLE 2.** Types of Amputation

Type of Amputation	Percentage
Below knee	45.8%
Above knee	49.1%
Bilateral below knee	3.4%
Bilateral above knee	1.7%

**TABLE 3.** Position of PLP Within the Phantom Leg

PLP Position	Incidence at 6 Months (%)
Toes	14.6
Foot	52.1
Lower leg	22.9
Whole leg	4.2
Combination	6.2

sensations ( $P = 0.67$ ). However, those with PLP were significantly more likely to have stump pain ( $P = 0.01$ ) and to be able to move their phantom ( $P = 0.01$ ).

### DISCUSSION

The finding that all survivors were experiencing phantom sensations 6 months after amputation was unusual. Although often referred to as universal, phantom sensations were recorded at 100% in only one previous study.<sup>24</sup> Phantom sensations occurred in the majority of amputees in all recent studies, with Jensen et al's study<sup>20</sup> (which recruited predominately amputees with peripheral vascular disease) recording an incidence of 90.2%. The 100% finding in the present study could be due to the relatively small sample size. However, as the previous peripheral vascular disease study<sup>20</sup> recruited a similar number, it is probably more likely to be due to differences in the method. Both studies used post-amputation interviews, but the interview in this study sought to differentiate between all of the phenomena and was particularly thorough in its assessment of the exteroceptive component. For this reason it is considered that this result is likely to be more accurate. The potential for some amputees to "know" that the phantom was present without an exteroceptive description verifies previous work.<sup>51-53</sup>

At the 6-month interview, 78.8% of the survivors were experiencing PLP, which was close to the upper range reported in the literature. Jensen et al's study<sup>20</sup> recorded an incidence of 66.7% at the same time point. Once again, the detailed questioning used in our study was probably more likely to ascertain the true incidence, but variations between the samples may have also influenced these findings.

**TABLE 4.** Frequency of PLP Attacks 6 Months After Amputation

	n	%
Continuous	1	2.4
>10/day	5	12.2
>1 but <10	18	43.9
Once a day	2	4.9
<7/week	7	17.1
>10/month	3	7.3
<10/month	3	7.3
Other	2	4.9

Figures include only amputees with PLP at the 6-month interview.

**TABLE 5. Duration of PLP Attacks 6 Months After Amputation**

	n	%
Continuous	1	2.4
>10 hours	1	2.4
5–10 hours	1	2.4
1–5 hours	2	4.9
1 hour	4	9.8
30–59 minutes	1	2.4
10–29 minutes	12	29.3
1–9 minutes	14	34.2
<1 minute	3	7.3
Other	2	4.9

Figures include only amputees with PLP at the 6-month interview.

If all the amputees who died prior to the 6-month follow-up were pain-free, the minimum rate of PLP would have been 68.3%. Assuming that they all would have experienced PLP, the rate would have been 81.7%. The true incidence of PLP in this group of amputees is therefore between 68.3% and 81.7%.

Although the intensity of the PLP was reducing, the number and length of attacks was found to be on average one to nine per day, lasting up to 10 minutes each time. It was not possible to determine whether this was reducing, remaining constant, or increasing, because many found it too complicated to distinguish all of these potential variations.

Around half of the amputees (51.9%) had stump pain at the 6-month interview. Jensen et al's study found an incidence of 57% at the equivalent time after amputation. Within the post-amputation interviews, the amputees found it hardest to differentiate between stump pain and PLP. Without detailed questioning, the incidences of these two phenomena could have been significantly different. This fact may account for some of the variations within the literature. Overall, prior to the commencement of this study, few had reported the incidence of stump pain above 50%. Since 1999, however, all studies have found rates above 50%<sup>15,28–30</sup> and one reported it as high as 76.1%.<sup>30</sup>

An association was found between the presence of stump pain and PLP at the 6-month interview ( $P = 0.01$ ), which supports previous studies<sup>9,18,46,48</sup> and confirms the difficulty that amputees have in distinguishing them.

The incidences of kinetic, kinesthetic, exteroceptive, and super-added phenomena have not often been measured. The results from Jensen et al's study<sup>20</sup> and the current study are not similar. Six months after amputation, 14% versus 65% could move their phantom, 8% versus 58% had spontaneous movements and 5% versus 44.2% had both. In all cases, our study found the higher incidence. The differences in the samples are not enough to account for this disparity. Once more, it is possible that the different questions or method of questioning between the studies influenced these results. As Jensen et al did not publish their questions, it is not possible to make a comparison. However, the detail used in the questioning for this study makes it unlikely that any phenomena were missed. Further work is needed to elucidate these aspects of the phantom.

Unlike previous studies, we found that lower limb amputees who could move their phantom were more likely to have PLP ( $P = 0.01$ ). This has not been measured in lower limb amputees before. However, anecdotal accounts from upper limb amputees suggest that PLP is associated more with a fixed phantom.<sup>7,40,54</sup> Further investigation is required to confirm this as a real phenomenon, but this finding may be indicative of a pain memory. Initially limb ischemia manifests as intermittent claudication or pain on movement of the leg, which worsens to continuous pain in critical limb ischemia. The original link between pain and movement may be crystallized within pain pathways over time (in this sample, the pain had been present for an average of 13 months), becoming an aspect of the phantom once the leg is amputated. Upper limb amputees are likely to have had pain for a shorter period of time, which may be the reason for PLP being linked to a fixed phantom in these cases. Future studies should look into this aspect of PLP.

The literature hints that PLP reduces as a phantom telescopes, but this study found that PLP was as likely to be present in a telescoped phantom as in a full phantom ( $P = 0.47$ ). It was apparent that the intensity of the PLP was reducing and that some phantoms were telescoping. It was not possible from this study to determine whether PLP reduced correspondingly to telescoping. It is possible that the belief that telescoping reduces PLP could be a misinterpretation of the fact that the two phenomena occur simultaneously. One previous study found no association between PLP and telescoping in a group of 32 amputees.<sup>25</sup> Together with the current study, which was the largest so far to test this phenomenon, it could be said that the link between telescoping and PLP is not supported.

Exteroceptive sensations included pins and needles (50.0%) and itching (42.9%). The total exteroceptive component measured by Jensen et al was only 15%, a large variation. When discussing this element with amputees, description was often difficult. Many found it hard to describe the embodiment of the phantom without an exteroceptive component. Some were able to categorically state the awareness of the phantom without additional sensation. The phantom was always accepted as "self" and incorporated volume.<sup>40,53</sup> Variations in percentages between studies could be due to the higher level of PLP in the current study or the complications of language. PLP has often been associated with higher levels of exteroceptive sensations, but no link was found between them here ( $P = 0.18$ ). This means that the differences in the results may be due to the vagaries of the language used to describe the phantom. It may be difficult for some to describe an entity that has only volume. Sensation may need to be used to assist in the process of communicating the phantom as an entity. As this study used an in-depth form of questioning, it is likely that the findings are accurate.

The high report of itching is interesting in terms of the mechanism of both PLP and itch. It has been found that similar areas of the brain, including the premotor areas, are involved in both sensations.<sup>55,56</sup> Itch is also recognized as a symptom of neuropathic pain and is measured as one component of the neuropathic pain scale.<sup>57</sup> The link between the mechanisms may go some way toward explaining why some neuropathic pains are associated with itch.

Super-added sensations are rarely studied. Katz and Melzack<sup>38</sup> reported a rate of 7%, half the rate found in this study. However, the two samples were dissimilar, as Katz and Melzack<sup>38</sup> investigated the phenomenon mainly in upper limb amputees. They found sensations such as the presence of a ring on a finger or the memory of a pain associated with an injury to a fingernail or toenail. All super-added sensations in the current study were associated with the feeling of the leg being clothed. No previous pains or sensations were reported. It is possible that these amputees had not experienced any painful injuries to their feet or legs prior to their amputation, and hence any other type of super-added sensation could not be expected. The differences in percentages between studies may also be explained by the difference between the size of the brain area associated with the upper and lower limb. A much greater area of the brain is used by the arm than the leg in the somatosensory cortex, so more super-added sensations of the kind reported by Katz and Melzack<sup>38</sup> would be expected in upper limb amputees.

### CONCLUSIONS

The incidence and relationships between phantom phenomena in a homogenous group of amputees have been determined. The complexities of these post-amputation sequelae have yet to be fully explored. Future studies need to take this into account at the design stage. More detailed monitoring of PLP intensity, duration, number of attacks, and the onset of telescoping is required to confirm or dispel the link between them. The link between PLP and stump pain has been confirmed, while the new finding that lower limb phantoms are more likely to be painful when the amputee can move them needs to be replicated.

These results give an appreciation of the true incidence of all post-amputation phenomena within a group of patients with peripheral vascular disease. It is hoped that this contributes to the process of understanding and will influence rehabilitation for these patients in the future.

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