

# Perceptions of phantom limb pain in lower limb amputees and its effect on quality of life: a qualitative study

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#### Abstract

**Background:** Phantom limb pain (PLP) is a prevalent complication post-amputation. Currently, qualitative literature exploring the experience of PLP in amputees is sparse, and little is known about whether the educational needs of amputees are being met.

**Objectives:** To explore lower limb amputees' descriptive lived experiences of PLP, to understand how PLP affects quality of life and to determine whether amputees feel they are provided with adequate information about PLP.

**Methods:** A qualitative descriptive approach, situated under the constructivist paradigm was taken, consisting of cross-sectional semi-structured interviews. A purposive sample of 15 lower limb amputees, 1–3 months post-surgery with past or current experience of PLP were interviewed once about their experience of PLP. Interviews were audio-recorded, transcribed verbatim and analysed using Framework Analysis. Interviews were conducted while participants were inpatients at an amputee rehabilitation unit in London.

**Results:** Six key themes were identified during analysis, of which three were related to PLP and are reported on in this article (real and physical phantoms, living with a phantom and being informed). PLP had numerous painful qualities. The phantom felt real, with kinetic and kinaesthetic properties. PLP had multiple meanings to amputees, was considered a reminder of circumstances and could affect quality of life. Information provided about PLP was inadequate.

**Conclusion:** PLP can be a severe and annoying experience acting as a reminder of amputees' circumstances. Information provided about PLP is inadequate, with some amputees still perceiving PLP as mental and imaginary. Education about PLP and awareness and accessibility to non-pharmacological interventions needs to be improved.

#### Keywords

Qualitative research, phantom limb, interview, education, communication

# Introduction

Each year, approximately 5–6000 people undergo major limb amputation in England.<sup>1</sup> Phantom limb pain (PLP) and phantom limb sensations (PLS) are common complications post-amputation, and prevalence of PLP has been reported to be as high as 75–80%.<sup>2,3</sup> PLP is a chronic condition which may be present for many years.<sup>4</sup> It usually occurs within the first week of amputation, but can also occur years later.<sup>5</sup> Although generally it is assumed that PLP decreases slightly over time,<sup>6</sup> this is not always true.<sup>7</sup>

No association between age, gender, cause of limb loss of marital status has been identified.<sup>7</sup> No difference has been found between prevalence of PLP in two very

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Author	Date	Title	Journal	
Shukla GD, Sahu SC, Tripathi RP, Gupta DK.	1982	Phantom limb: a phenomenological study.	The British Journal of Psychiatry	
Mortimer C, Steedman WM, McMillan IR, Ravey J.	1998	Phantom pain II: patients' experiences, beliefs and knowledge.	British Journal of Therapy and Rehabilitation	
Mortimer CM, Steedman WM, McMillan IR, Martin DJ, Ravey J.	2002	Patient information on phantom limb pain: a focus group study of patient experiences, perceptions and opinions.	Health and Education Research	
Bosmans JC, Suurmeijer TPBM, Hulsink M, van der Schans CP, Geertzen JHB, Dijkstra PU.	2007	Amputation, phantom pain and subjective well-being: a qualitative study.	International Journal of Rehabilitation Research	
Björkman B, Arner S, Lund I, Hyden LC.	2010	Adult limb and breast amputees' experience and descriptions of phantom phenomena – a qualitative study.	Scandinavian Journal of Pain	
Björkman B, Arner S, Lund I, Hyden LC.	2012	Phantom phenomena – their perceived qualities and consequences from the patient's perspective.	Scandinavian Journal of Pain	
Evans CB.	2014	Content analyses of a priori qualitative phantom limb pain descriptions and emerging categories in mid- southerners with limb loss.	Rehabilitation Nursing	

Table 1. Qualitative studies identified in a systematic review describing the experience of phantom limb syndrome.

different demographic groups.<sup>4</sup> However, a longitudinal study found the chance of suffering PLP was reduced in men and in lower limb amputees compared to women and upper limb amputees.<sup>6</sup>

Pain mechanisms involved in PLP include formation of neuroma and ectopic discharge. Peripheral noxious stimuli cause central sensitisation (increased spontaneous activity of dorsal horn neurons, increased responsiveness to afferent input, after discharge, expansion of receptive fields, wind-up a reduction in inhibitory processes and structural changes at the central nerve endings<sup>8</sup>). Cortically, there is reorganisation of areas including the somatosensory and motor cortex. Cortical fields which are deprived of input shrink, and receptive fields become smaller.<sup>9</sup>

Quantitative studies do not explore amputees' lived experience of PLP, and few qualitative studies exist (a systematic literature search of PubMed, AMED, CINAHL, MEDLINE, PsycINFO and ScienceDirect identified only seven studies (Table 1)). These studies report a range of experiences, attitudes and emotions associated with PLP but often do not report specifically on upper or lower limb amputation. Also, time since amputation often varies widely, and studies do not report on the effect of PLP on quality of life. No recent UK studies have explored whether information provided to amputees about PLP is adequate.

The aim of this study was developed through review of the literature and was to explore lower limb amputees' descriptive experiences of PLP, to understand how PLP affects quality of life and to determine whether amputees feel they are provided with adequate information about PLP. The study was nested in a larger study evaluating the feasibility of providing acupuncture for PLP.

#### Methods

The study was undertaken at the inpatient Amputee Rehabilitation Unit (ARU), Guy's and St Thomas' National Health Service (NHS) Foundation Trust, London, between December 2013 and June 2014. Ethical approval was granted by National Research Ethics Service (NRES) Committee London – Brent and London South Bank University. This crosssectional study employed a qualitative descriptive design situated under the constructivist paradigm and consisted of face-to-face semi-structured interviews.

In order to ensure some variation, purposive sampling was used and 15 participants recruited (the planned purposive sample quota is presented in Table 2). This number was deemed adequate taking into consideration the purpose of the research, the objective of the analysis and the time and resources available. Data saturation was anticipated to occur within this number of interviews. Potential participants were identified by ARU physiotherapists, approached by the researcher (who had no prior contact with the participants) and provided with verbal and written information about the study. All participants were advised to take a minimum of 24 hours before consenting to participate.

Inclusion criteria included male or female, 18 years or above, lower limb amputation (greater than a toe),

Sample quota						
	Vascular amputation	Trauma/disease/infection causing eventual amputation	Trauma/disease/infection causing immediate amputation			
Males						
≪65years	1-4	1–3	1–2			
>65years	1-4	1–3				
Females						
≪65years	1-4	1–3	0-2			
>65years	1-4	1–3				

Table 2. Purposive sample quota for selection of participants.

current or past experience of PLP, full cognitive ability (as assessed by the medical team) and ability to communicate in English. Exclusion criteria were severe other health complications.

All participants were interviewed once in a room where only the researcher (E.G.T.) and participant were present. Interviews were semi-structured, followed a topic guide (Figure 1), were audio-recorded and lasted approximately 1 hour. Interviews were structured to commence with demographic details, followed by a history of the events leading up to amputation and experience of PLP. The interview finished with discussion of the possibility of having acupuncture as an intervention and completing and providing feedback on outcome measures. Field notes were taken.

## Data analysis

As E.G.T. had prior knowledge of PLP and had carried out a systematic review on the lived experience of PLP, a completely naive stance was not taken, but overall, the study was considered inductive due to the nature of the interviews, the predominately open coding and the allowance for emergence of new categories. Framework analysis, developed by Ritchie and Spencer, was used to analyse data. Within 24 hours of the interview, E.G.T. listened to audio-recordings, completed field notes and transcribed interviews verbatim. The steps of framework analysis were followed:

- 1. *Familiarisation*. E.G.T. became familiar with the data.
- 2. *Coding*. A combination of open and predefined codes were used.
- 3. *Identifying an analytic framework.* Drawing on both a priori data (such as the interview topic guide) and emergent issues, categories were developed both inductively from the data and deductively.
- 4. *Indexing*. The analytic framework was applied systematically to all data.

- 5. Charting. Was thematic and clearly referenced.
- 6. *Descriptive analysis*. Data were classified under higher order labels.
- 7. *Mapping/interpretation*. Key characteristics of the data were identified.

NVivo 10 was used to develop the analytic framework and index transcripts. Excel was used during charting and descriptive analysis. To ensure credibility, respondent validation was obtained post transcription of interviews (transcripts were returned to participants for approval) and peer debriefing took place throughout the research process (N.R. and W.T.). To ensure dependability, two researchers (N.R. and E.G.T.) separately coded three transcripts and the results were compared. Also, two researchers (N.R. and E.G.T.) independently coded and indexed a transcript using the analytic framework.

# The researcher

The researcher (E.G.T.) was a chartered physiotherapist and acupuncturist with no relationship with participants prior to commencement of the study. Participants were unaware of her background.

# Results

A total of 17 lower limb amputees were approached, of which 16 agreed to participate. One dropped out after interview, and one interview was terminated early (due to participant fatigue). Demographics of participants included in the study are shown in Table 3. Throughout the duration of the study, no women  $\leq 65$  years were identified who had undergone amputation due to vascular pathology. Therefore, the original planned purposive quota was not fully achieved. Six key themes were identified during analysis, presented in Figure 2. This article reports only on the themes related to PLP.

Main questions
<ul> <li>Could you tell me about the events leading up to your amputation?</li> </ul>
Can you tell me about any pain you experienced prior to amputation in your amputated leg?
· Can you tell me about any experience of pain / sensations you have experienced since your
amputation in your amputated leg (phantom pain)?
<ul> <li>How does the phantom pain / sensations affect you in your day to day life?</li> </ul>
<ul> <li>What information were you given from anyone about phantom pain / sensations?</li> </ul>
<ul> <li>Can you tell me about any past experience you have had of acupuncture?</li> </ul>
<ul> <li>How would you feel about receiving acupuncture for the pain in your missing leg?</li> </ul>

Figure 1. Summary of the interview topic guide.

Table 3. Participant demographic information.

P ID	Age	Gender	Ethnicity	Amputation level	Time since amputation	Reason for amputation	Previous amputations
1	54	М	White British	BK	2m	V/U	No
2	58	М	Black British	AK	2m	V	No
3	84	F	White British	BK	2m	V/U	No
6	75	М	White British	AK	3m	V	No
7	26	М	White British	BK	1m	Т	No
8	62	М	White British	AK	1m	T/I	No
9	66	М	White Irish	AK	1m	V	No
10	60	М	White British	AK	1m	T/I	No
11	67	М	White British	ТК	1m	V/U	No
12	35	М	White Other	BK	3m	Т	No
13	54	F	White British	AK	1m	T/I	No
14	66	М	Mixed Caribbean	BK	1m	T/I	No
15	45	М	White British	BK	1m	V/U	No
16	82	F	White British	BK	1m	T/I	No
17	35	М	White British	ВК	1m	V/U	Yes (toes and part of foot)

P: participant; M: male; F: female; BK: below knee; AK: above knee; TK: through knee; m: months; V: vascular; U: ulcer; T: trauma; I: infection.

#### Real and physical phantoms

This theme describes the physicality and the realness of the phantom. PLP was usually experienced distally, location could be described precisely and PLP was perceived as real and physical (as if it still belonged to the intact body). Numerous descriptions, usually metaphorical, were used to describe quality and revealed suffering. The most frequently described quality was the feeling of the phantom being tightly bound/being in a vice. Most participants described a whole variety of qualities of pain and non-painful sensations. PLP was usually described as constant and intensity varied from mild to excruciating pain:

I feel as though, at the moment the sensation I get is I feel as though my foot is tightly bandaged and I can't do much about it ... it's odd it's as though I want to undo the bandages and make the feeling go away. (P16)

I did say once if I had a, I know its stupid thing to say, but if I had an axe I would chop the foot off. That's how bad it is. But of course I haven't got a foot to chop off! (P13) Many participants felt PLP had improved since onset (but was not necessarily still improving). Six participants reported changes in quality and location of pain, including feeling an increased variety of sensations, PLP moving distally/proximally and covering a larger area.

Participants generally had a very real perception of the missing limb. A total of 14 participants described feeling the limb was still present, and some forgot their limb had been amputated. One had fallen because of this:

I've got toe nails as well, you know, on this one ... I feel as if I've got a shin there, and toenails and an ankle. (P3)

and I'll go to automatically move my leg and then I'll think you silly sod it's not there! (P1)

Participants tried using the phantom, for example, to itch/scratch and take a shoe off the residual limb. Phantoms could move to varying degrees. Six participants experienced altered perception of where the phantom was in space or distortion of the phantom and one reported telescoping:

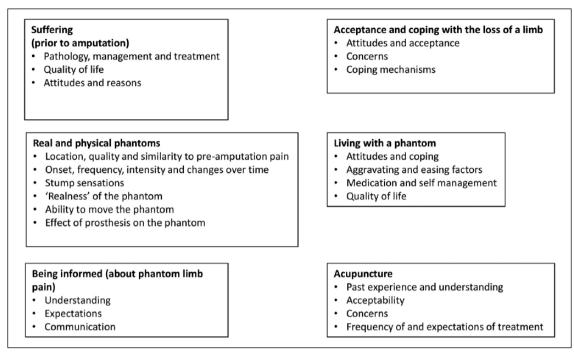


Figure 2. Key themes identified.

I feel like I can open the toes and spread the toes ... I can sit there and move the toes up and down and left and you know, I'm doing it now! (P12)

# Living with a phantom

This theme describes attitudes towards PLP, effects of PLP on quality of life and management of PLP. These were grouped under one theme because they all described how PLP affected amputees on a daily basis. PLP was generally considered annoying/frustrating as pain was in a limb which was no longer present and was considered a constant reminder of circumstances:

but it was so annoying. I mean how could I have a pain down there. It was so annoying! (P9)

It's a constant reminder of what's happened. (P7)

However, four participants viewed PLP positively and did not necessarily want it to completely resolve, while others found it bizarre, weird and fascinating. PLP was viewed positively when it was considered better than the pre-amputation pain, when the amputee liked having sensations in the missing limb, when it was perceived as 'good pain' and when the amputee was glad just to be alive:

it's just there, it's trying to tell me where my foot is, which is good. So, it's good pain if that makes sense. (P15)

Makes me feel glad I'm alive really ... As long as you are feeling something! (P6)

Approximately half of participants had disturbed sleep due to PLP. This impacted on performance in physiotherapy, mood, tiredness and decision-making. Most participants found PLP did not affect rehabilitation, and several found physiotherapy and wearing a pneumatic post-amputation mobility aid (PAMaid) helped:

When I get there and they put on the balloon on the foot [PAMaid], it all goes. (P14)

Eleven participants reported PLP affected wellbeing or mood. PLP caused worrying, dark thoughts, depression, feeling 'miserable and down' and made participants act illogically and be withdrawn. Feelings could be mild 'sod this it's doing my head in' to severe:

when it gets really bad I don't want to do anything. I don't want to eat, I don't want to do anything at all. I just want to be free of the pain. Um and if I was on the second floor of a building I'd probably want to jump out of the window because the pain just gets so much you can't cope with it. (P10)

PLP affected activities of daily living, state of mind and concentration and was considered tiring and wearing. Additionally, three participants reported PLP affected relationships:

Cause you are in pain ... you become irrational, you become snappy, you become less patient with people even though you may not have a reason for it. (P12)

Most frequently reported aggravating factors included lack of occupation, thinking about PLP and exercise, but exercise could both aggravate and ease symptoms. Distraction eased symptoms and a variety of techniques were employed, but participants were not always able to distract themselves:

I was told by a couple of doctors that you should try and think about something else ... and I've tried to get my mind on other things like reading the paper or looking at TV or whatever but I can't concentrate on it because this pain just kills it. (P10)

Stump techniques were used by six participants, including shaking the stump, rubbing/massaging the stump, hitting the stump. Medication was often not perceived as helpful or only helped for a number of hours. Only three participants had also been treated with non-pharmacological treatments (mirror therapy or graded motor imagery):

they've said you are on as much medication as you can be on really and it's all the sort of stuff that helps hopefully treat phantom pain. It's not touching it yet. (P13)

Coping strategies involved acceptance of PLP. This was generally due to the feeling that because the pain was in a phantom limb, there was nothing that could be done.

#### Being informed

This theme describes participants' understanding of PLP and access to information. Generally, participants either expected or were not surprised to have PLP/PLS and expected it to resolve over time (years). These expectations often arose from speaking to other amputees. Participants had varied understanding of PLP. Participants generally expressed understanding that peripheral nerve damage due to amputation would result in pain. Cortical influences were always included in participant descriptions, but were not always scientifically grounded:

You know if you cut through all of those nerves and those nerves still think there are feet and toes and there's legs there it's quite confusing for the nerves, very confusing for the brain. So it all makes sense why the pain is there. (P7)

Despite awareness of peripheral and cortical influences, views were expressed by three participants that mental state was a contributing factor or cause:

I thought I won't get that. Idiots get that. I just thought its only mental people who get that  $\dots$  I just took it as a mental thing. (P8)

Participants generally felt there was lack of access to doctors, information provided was inadequate and did not come from the medical team. Only three participants were satisfied with the information provided. Participants/families had to seek out information. A number of resources were accessed, including the Internet, films and books. Families were sometimes needed to access and print out information:

The only people who have explained it to me is other patients. But no doctors or nothing mentioned anything to me about the pain. (P9)

## Discussion

The first theme described the physicality and realness of the phantom. Findings were consistent with other literature which reports that PLP is generally experienced in the distal portion of the limb<sup>8</sup> where there is the most extensive innervation density and cortical representation in the somatosensory cortex.<sup>10</sup> Some descriptions used to describe the quality of PLP were similar to other qualitative findings, giving a vivid picture of suffering emphasising the reality of the experience.

Exteroceptive perceptions experienced were similar to those described in other studies.<sup>10</sup> Telescoping was probably only experienced by one participant due to the short time frame between amputation and interview. As found in previous qualitative studies, kinetic perceptions were experienced and the amputated limb felt real and present. This may partly be due to changes in cortical representation in the somatosensory cortex and due to motor commands and the parietal lobe containing one's body image.<sup>11</sup> Increased awareness of the complexity of PLP and exteroceptive, kinetic and kinaesthetic sensations may improve understanding of the complexity of being an amputee.

The second theme discussed amputees' attitudes towards PLP, effects of PLP on quality of life and management of PLP. Unsurprisingly, PLP was often viewed as annoying, but it was not anticipated that some amputees would view PLP positively. It has been reported that a phantom and prosthetic can interlace into a single bodily structure and a phantom can aid the use of a prosthetic.<sup>12</sup> Awareness that PLP may be viewed positively and be wanted should be taken into account before trying to treat/resolve it.

Although not reported in other qualitative studies, sleep was frequently reported to be disrupted. A strong link exists between sleep and stress.<sup>13</sup> Insufficient sleep is associated with the development of chronic disease such as depression, diabetes, obesity and heart disease.<sup>14</sup> Amputation is in itself a stressful experience, and amputees often already have chronic conditions. Poor sleep may exacerbate these factors as well as affecting performance and productivity.

PLP did not usually affect rehabilitation and some found wearing a PAMaid helped. This may be due both to rehabilitation acting as a form of distraction and because functionally effective prostheses can improve PLP.<sup>15</sup>

PLP affected wellbeing and mood. Pain and depressive symptoms commonly occur together, and chronic pain ( $\geq 6$  months) has been strongly associated with major depressive disorder. Ephraim et al.<sup>3</sup> found 28.7% of amputees had symptomatology of depression, and amputees with pain were more likely to have symptoms of depression than those without pain. Pain needs to be better managed to avoid the development of chronic pain and associated negative effects on wellbeing and mood.

Aggravating factors frequently included lack of occupation, thinking about PLP and exercise. Lack of occupation and thinking about PLP may cause emotionally triggered pain (exposure to isolated aspects of memories related to amputation revoke or worsen associated PLP<sup>16</sup>). Pain may also have been aggravated due to peripheral and central sensitisation,<sup>17</sup> disinhibition of pain mirror systems<sup>16</sup> and somatosensory maps and cortical reorganisation.<sup>8</sup> As found in other studies, distraction and stump techniques eased PLP. Distraction may help reduce emotionally triggered pain. Stump techniques may be effective through reducing muscle tension in the residual limb and through stump desensitisation.

Unsurprisingly, medication was not always effective. The efficacy of gabapentin from placebo-controlled trials is not robust. Amitriptyline and memantine are reported to not be effective, and the effectiveness of other medications remains unclear.<sup>18</sup> Mirror therapy and graded motor imagery may be effective interventions,<sup>19</sup> and amputees may benefit from improved access to these non-pharmacological alternatives.

The third theme described participants' understanding of PLP and access to information. Although participants generally did include descriptions of cortical and peripheral changes in their understanding of PLP, there were indications of a lack of thorough understanding. As found in previous studies, participants suggest there is a lack of provision of thorough patient education about PLP. Neuroscience education can decrease pain ratings, increase physical performance and decrease perceived disability and catastrophising in musculoskeletal patients.<sup>20</sup> This approach could be used to educate amputees about PLP.

## Limitations

Credibility may have been reduced due to the researcher not being able to spend prolonged periods of time with amputees or being a 'member of the group'. However, lack of prolonged engagement may encourage openness. The research did not include formal member checks (findings are presented to participants) or referential adequacy (a portion of data is archived and post development of preliminary findings is analysed to test validity of these findings), but member checking is disputed due to ethical reasons and because participants may have changed their viewpoint over time. The purposive quota was not completely met, so reducing transferability of findings. Differences in gender, ethnicity and level of amputation were not explored in this study. Lack of methodological triangulation may make results less creditable and confirmable. Although the research was not audited, it was transparent and all steps during the research process were recorded to ensure it was auditable. The sample size was small, and determining whether theoretical data saturation had been met was challenging. However, as no new concepts emerged in the final interviews, it was considered achieved. Future studies may benefit from having a more homogenous sample. This sample may not be representative of all those with PLP, but this could be researched further.

### Conclusion

Findings provide insight for clinicians on the lived experience of PLP. Numerous painful 'real' qualities are experienced with PLP, and descriptions depict suffering. PLP is a continual reminder of circumstances and can affect quality of life including sleep, fatigue mood and relationships. This should be considered clinically during therapeutic encounters, and amputees should be given appropriate information on these potential associations. Phantoms can feel real, with kinetic and kinaesthetic properties. There is still a perception that PLP is due to mental state, and education needs to be improved to help both patient understanding and management of PLP. The study has identified the need for future research to gain insight into the educational needs of amputees and to evaluate the awareness and accessibility of non-pharmacological interventions which have evidence of effectiveness.

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