Characterising phantom limb phenomena in upper limb amputees

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Abstract
A systematic descriptive survey was carried out on a clinic population with acquired upper limb amputation in which clear distinctions were made between phantom experiences, pre-amputation pain and stump pain. It was found that of 76 participants 96% reported phantom experiences and 84% were currently experiencing phantom limb phenomena (PLP). Sixty-nine percent (69%) of those currently experiencing phantom phenomena stated that the phantoms were painful. Significant relationships were found between frequency of phantom experiences and side and level of amputation. In addition, the presence of ‘trigger’ points reported by a sub group of participants was found to be associated with the frequency of phantoms and painful phantoms. This finding could provide support for cortical reorganisation post amputation. It is suggested that detailed individual ‘profiling’ of phantom experiences is important and would have the following implications: it would contribute to existing knowledge and provide new insights into the central nervous system’s reorganisation post-amputation; it would provide an accurate way of representing amputees’ anomalous perceptions; it would alert health professionals to the presence, variety and extent of PLP following amputation.

Introduction
Phantom limbs, the experience of persisting sensory perceptions after limb amputation, are widely recognised but poorly understood phenomena. Most health professionals dealing with amputees accept that some of their patients feel that at least part of their amputated limb is still there. However few health professionals or the amputees themselves fully understand the characteristics and mechanisms of phantom phenomena or are aware of its prevalence amongst the amputee population.

A review of the literature reveals the extent of the disagreements surrounding phantom limb phenomena (PLP). The reported frequency of phantom limb varies considerably between studies with reported incidences as low as 2% to as high as nearly 100% being documented (Jensen and Rasmussen, 1994). The reported effects of phantom phenomena are also highly controversial. Montoya et al., (1997) state that the most distressing problem after amputation is the continuing experience of phantom limb sensations whereas Hill (1999) comments that the presence of a phantom limb is seldom distressing for an amputee.

A number of studies aimed at providing more information about PLP have been conducted. Many of these have used postal questionnaires to gain information from amputees about their phantom experiences (Hill et al., 1995; Houghton et al., 1994; Sherman et al., 1984) but there are inherent problems with questionnaires that rely on self reporting (Oppenheim, 1998). The most serious of those problems in the study of PLP is likely to be ambiguity. To avoid ambiguity it is essential to clearly define the different aspects of PLP; in particular, pain localised to the amputation stump, pain experienced in the absent part of the limb, and other sensory phenomena related to the absent limb must be distinguished (Jensen and Rasmussen, 1994). In a postal questionnaire it would provide support for cortical reorganisation post amputation.
would be extremely difficult to assess if these definitions had been clearly understood and if the participants reliably differentiated between them.

Two of the authors became aware of the complexity and impact of PLP following amputation whilst conducting other studies. Fraser (1998) found that in a study of users of upper limb prostheses 82% of the participants with acquired amputations reported phantom experiences. The majority of the participants in that study had been regular attendees of the Cambridge Disablement Services Centre (DSC). However, few had mentioned their PLP experiences to clinic staff and only in extreme cases was there any documentation at their experiences. Halligan (1999) reported on an innovative study which made use of digital photography to depict how amputees perceive their phantoms. This technique enabled accurate illustrations to be made of the phantom limbs experienced by amputees taking part in the study.

As a result of the findings of these studies and after reviewing the current literature on PLP it was decided that a detailed descriptive study of the presence, variety and impact of PLP following amputation was needed. In order to achieve this a wide-ranging interview schedule was devised and administered to amputees. As some studies report differences between upper and lower limb amputees with regards to PLP (Shukla et al., 1982), it was decided, in view of the authors' expertise, to restrict this study to acquired amputations of the upper limb. The intention is that information gained from this descriptive study could then be used to provide a format for a clinical questionnaire that would provide a 'profile' of individual amputees' phantom experiences and facilitate the systematic documentation and monitoring of changes in PLP following amputation.

Method

Prior to the main study, a pilot study was conducted. Ten (10) amputees were selected from the Cambridge DSC records of registered acquired upper limb amputees aged between 16 and 80. The consisted of a sub-sample varying in age, gender, level and side of amputation. Each of the potential participants was then contacted by letter explaining the purpose of the study and requesting their participation. This letter was followed up by telephone contact to ascertain that they were willing to take part in the study. Arrangements were then made to visit participants in their own homes or, if they had a pre-planned clinic appointment, to see them following this appointment. A semi-structured interview focusing on the individual's experience of PLP was conducted with each of the 10 participants and this was recorded on audio-tape following their permission to do so. A content analysis of the interviews was undertaken and responses sorted into broad categories. These categories were compared to those of Halligan et al.'s (1997) substantial structured interview used in a small number of single case studies of selected amputees known to be experiencing PLP. The information gained helped to develop the formats, headings, questions and sequencing of questions to be used in the structured interview in the main part of the study. The resulting interview was administered to the original 10 pilot participants. Following this, further revisions were made and ambiguous, inappropriate and uninformative questions were altered or removed.

The final interview consisted of 95 questions grouped under 12 headings. These headings were: 1. Personal history; 2. History of amputation; 3. Pre-amputation pain; 4. Post-amputation stump pain i.e. pain in the residual part of the limb; 5. Prosthetic history; 6. Phantom experiences; 7. Description of phantom limb; 8. Painful or unpleasant phantom experiences i.e. pain experienced in the amputated limb; 9. Non-painful phantom experiences; 10. Effect of environmental factors on phantom experiences; 11. Experiences of movement of the phantom limb; 12. General section including comments. The formats of the questions varied from those requiring a 'yes-no' response to quantified scales and qualitative open-ended questions. The interview schedule also included a line drawing of an upper limb on which the level of amputation could be marked and the position of the phantom limb drawn in. Areas of stump and phantom pain and other phantom sensations were also recorded on this diagram using different coloured pens.

Using the same method for contact as used in the pilot study, all unilateral upper limb amputees with acquired amputations who were registered with the Cambridge DSC were approached and asked to participate in the study.
Interviews were conducted at a time and place convenient for the participant. All the interviews were conducted by the first author. The computerised statistical package for social science data (SPSS) was used for the analysis. Relationships between variables measured on ordinal scales were analysed by means of Spearman's Rho. Relationships between variables where one of them had only nominal measurement were analysed using Mann-Whitney U. Relationships between two variables involving nominal measurement were analysed using Pearson Chi-Square.

The sample
A total of 111 potential participants were identified from clinic records. Of these 26 were uncontactable, 2 deceased, 1 too ill to participate and 6 unwilling to participate. Thus of the total contactable possible participants 76 (93%) participated.

The age of the participants ranged from 17 to 80 years with a mean of 55 years and a standard deviation of 15 years. Sixty-four (64) (82%) of the participants were male and 12 (16%) were female. The levels of amputation are shown in Table 1. The mean age at amputation was 30 years with a standard deviation of 15 years and ranged from 2 years to 64 years. The mean time since amputation was 25 years with a standard deviation of 18 years and ranged from 3 months to 59 years. Thirty-two (32) (42%) participants had a left-sided amputation and 44 (58%) had a right. Forty (40) (53%) participants had an amputation on their dominant side and 32 (42%) on their non-dominant side. (Three (3) participants considered they were ambidextrous before amputation and one had had his amputation at 2 years old before dominance could be firmly established. Forty-six (46) (61%) participants stated they were prosthetic wearers. Of these, 38 wore their prostheses for more than 8 hours a day.

Results
Phantom experiences
A total of 73 (96%) participants reported having had phantom experiences at some time since their amputation. Thirty-six (36) (49%) reported that these experiences had been frequent or continual. Forty-five (45) (67%) participants stated that they were aware of phantoms within 1 week post-amputation; by 8 weeks post-amputation, 58 (87%) were aware of phantoms; 9 reported times of initial awareness from 12 to as long as 260 weeks post-amputation. Six (6) of the participants could not recall when they first became aware of their phantoms.

Table 2 presents the changes in the frequency of phantom experiences post-amputation in those participants who stated that they had had phantom experiences. Of the 7 participants whose phantoms had disappeared, the minimum time to disappearance was 1 month and the maximum 35 years with a mean of 7 years and a standard deviation of 13 years.

Table 3 presents changes in intensity of the phantom experiences post-amputation in those participants who were experiencing phantoms at the time of interview. Sixty-four (64) participants stated that they were currently experiencing a phantom limb, 2 reported that they had a feeling that something was there but that it had no recognisable form. A significant relationship was found between the frequency of
Table 3. Changes in intensity of phantom experiences over time post-amputation.

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<th>Frequency</th>
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<td>Less intense</td>
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<td>Same</td>
<td>37</td>
<td>56</td>
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<tr>
<td>More intense</td>
<td>5</td>
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<td>Total</td>
<td>66</td>
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their experiences and level of amputation. Those with higher levels of amputation were more likely to experience a phantom limb frequently or continually (Spearman’s rho=.273 n=76, p<.02).

Eleven (11) (17%) of the 64 participants currently experiencing phantom limbs reported having ’trigger’ points which when touched initiated phantom experiences. These points were either on the skull, face, neck or chest. All 11 of these participants reported having phantom experiences frequently and also reported having painful phantoms but only 5 of the 11 stated that they experienced non-painful phantoms. There were a number of significant relationships between experiencing ‘trigger’ points and other variables. Participants with ‘trigger’ points were significantly younger than those without (Mann-Whitney U=122.0, p=.003), most falling into the youngest third of the age range. Those with ‘trigger’ points had significantly higher levels of amputation (U=139.0 p=.005); 10 had transhumeral above elbow amputation. They were significantly more likely to have amputations on the right side (X²=6.205, df=1 p<.02), this being true of 10 of the 11. They were also more likely to have experienced phantoms frequently or continually (U=133.0, p=.003) and were more likely to have experienced painful phantoms (X²=4.925, df=1 p<.03).

Description of phantom limb

Sixty-four (64) (84%) participants currently felt that all or part of their amputated limb was still there. Thirteen (13) (20%) considered that their phantom limb was similar in shape and form to their limb prior to amputation. Others reported differences such as missing parts and shortening (76%) or shrinking of the limb (35%). Twenty-four (24) (38%) stated that their phantom limb appeared weightless, 16 (25%) considered it to be lighter, 19 (30%) considered it to be the same weight as a normal limb and 6 (9%) considered it to be heavier. Twenty-four (24) (38%) reported that their phantom limb moved as a normal limb when they moved about. Others reported that it remained in a fixed position. Thirty-four (34) (53%) felt they could move their phantom. Of these, 18 (28%) felt as if they would be able to pick up objects with their phantom hand. Some 32 (50%) participants stated that they would prefer not to have a phantom limb, 26 (41%) did not much mind and 6 (9%) would prefer to keep their phantom limb.

Prosthetic wear

There were no significant relationships between wearing or not wearing prostheses and phantom experiences or painful phantoms. However there was a significant relation between prosthetic wear and the frequency of current phantom experiences. Prosthetic wearers currently experienced phantoms more frequently than non-wearers (U=497.5, p=.04).

Laterality

Significant relations were found between amputation of the dominant or non-dominant side and frequency of phantom experiences. Participants with amputations on their dominant side reported having had phantom experiences more frequently than those with amputation of the non-dominant (U=387.5, p=.002). Participants who were experiencing phantom limb at the time of interview were likely to have these experiences more frequently if they had an amputation on their dominant side than participants with a non-dominant sided amputation (U=397.0, p=.002). Participants with amputations of the dominant side tended to be more likely to have experienced painful phantom but that effect did not attain a conventional level of significance (X²=2.850, df=1, p<.10).

Painful and non-painful phantom experiences

Of the 73 participants who reported having experienced phantoms, 8 stated that they were aware that parts of their amputated limbs were still there but that they did not have any recognisable sensations from these phantoms. Forty-nine (49) (67%) reported having experienced painful sensations in their phantoms such as severe pins and needles, throbbing, shooting or burning pain. A significant relationship was found between having
experienced painful phantoms and level of amputation. Participants with painful phantom experiences had significantly higher levels of amputation than those whose phantoms were not painful \( (U=367.0, p=.007) \). Forty-four \((44) \) (60\%) participants reported currently experiencing painful sensations, 23 (31\%) rated the current pain as fairly severe to very severe and 18 (24\%) reported experiencing painful sensations daily. Only 9 of the participants currently experiencing painful sensations took medication to control the pain. None of these participants rated the medication as completely successful. There was no significant correlation between the severity of pain experienced and taking medication to control it. Thirty-one \((31) \) of the participants currently experiencing painful sensations reported having developed their own methods for reducing the pain, 30 of these participants rated their methods as moderately to completely successful. Only 17 (27\%) participants stated that they had discussed their experiences with a health professional. There was a significant relationship between experiencing painful phantoms and discussing these experiences with members of their family \( (X^2=6.402, df=1, p=.02) \). No significant relationship was found between experiencing painful phantoms and discussions with health professionals.

Forty-nine \((49) \) (67\%) participants who reported phantoms stated that they had had experiences that they described as being non-painful such as itching, tickling or changes in temperature in their phantom. Thirty-eight \((38) \) (52\%) reported currently experiencing non-painful phantoms and 33 (45\%) reported currently experiencing both painful sensations and non-painful sensations. There was no significant relationship found between painful and non-painful phantom experiences. In summary, of the 73 participants reporting phantoms: 33 had experienced both painful and non-painful phantom sensations; 16 had experienced only painful sensations; 16 had experienced only non-painful sensations; 8 reported phantoms without recognisable sensations.

**Pre-amputation pain experiences**

Twenty-five \((25) \) (33\%) participants reported experiencing pain in their limb prior to amputation. Twenty-one \((21) \) rated the pain as fairly severe to very severe. Nineteen \((19) \) stated that they took medication often or continually to control the pain but none rated it as being completely effective. Nine \((9) \) rated it quite to reasonably effective. Following amputation, 17 \((63\%) \) reported painful phantom experiences. Ten \((10) \) (59\%) of these stated that the phantom pain was not at all similar to their pre-amputation pain. Overall no significant relationships were found between pre-amputation pain and the experience of painful phantom sensations post-amputation.

**Post-amputation stump pain**

Forty-two \((42) \) (55\%) participants reported being aware of pain in their stump immediately following amputation. Eighteen \((18) \) participants stated that at that time they were probably unaware of pain due to medication. Thirty-four \((34) \) (45\%) stated that they were currently free of stump pain, 32 \((42\%) \) experienced stump pain occasionally and 10 \((13\%) \) frequently or continually. No significant relationships were found between either immediate post-amputation stump pain or current stump pain and painful phantom experiences.

**Discussion**

This study has clearly shown that most upper limb amputees have phantom experiences and that there is a great variety in these experiences. In the majority of cases the phantoms appear within the first two months post-amputation. Some variation in the time may be accounted for by the fact that most amputees will be heavily medicated post-operatively and may only become fully aware of phantoms as the medication is withdrawn. However in this and other studies (Montoya et al., 1997) there is evidence that in a few cases phantoms may appear for the first time many years post-amputation.

Relationships between pre-amputation pain and post-operative stump pain have been found in a number of studies (Houghton et al., 1994; Hill, 1999; Gallagher and MacLachlan, 2000; Kooijman et al., 2000) but these factors did not reach significance in this study. This may be accounted for by careful distinctions being made between pre-amputation pain, stump pain and painful phantom experiences. Some participants did initially confuse the sources of pain but careful questioning helped to clarify their responses.
There have been a number of attempts to explain the neurophysiological mechanisms behind PLP (Katz, 1992). It is well documented that large areas of the human motor cortex are devoted to the control of the hand (Penfield and Rasmussen, 1950) and it has been found in a number of studies (Flor et al., 1995; Davis et al., 1998; Ramachandran and Hirsten, 1998; Halligan, 1999) that there is evidence to support reorganisation of deafferented areas of the central nervous system (CNS) post-amputation. It has been demonstrated that stimulation of the face, pectoral regions and skin areas in the stump of upper limb amputees can result in measurable activity in the somatosensory cortex that represents the amputated limb (Kew et al., 1997).

This study found 11 participants who stated they had ‘trigger’ points, all of whom experienced phantoms frequently or continually and these experiences had not changed over time. However they did report that the referred sensations did fade over time. All 11 had painful phantoms for which 5 took medication. Ten (10) had amputations of the right side and 10 had trans-humeral amputations. Eight (8) had birth dates after 1954 and fell into the younger third of the age group studied. All of these factors reached statistical significance. No relationship was found between non-painful phantoms and the presence of ‘trigger’ points.

It is recognised that 11 participants represent only 25% of the participants who stated that they were currently experiencing phantom pain but these findings could provide partial support for those of Flor et al. (1995; 1998) who demonstrated that there was a direct relationship between the amount of cortical reorganisation found and phantom limb pain but found no relationship between cortical reorganisation and non-painful phantom. Further support for cortical reorganisation might come from the significant relationship found between level of amputation and both the frequency of phantom experiences and painful phantoms. Higher amputations would lead to larger areas of the cortex being deafferented and therefore greater areas available for potential reorganisation. Condes-Lara et al. (2000) postulate that cortical representation is related to the comparative size of the amputated areas. Support could also come from the finding that there was a relationship between prosthetic wear and frequency of phantom experiences. Using a prosthesis would facilitate sensory stimulation of the skin of the stump in contact with both the prosthetic socket and the activating mechanisms for controlling functional prostheses particularly in the pectoral region. Handedness has also been associated with asymmetry in cortical representations. Triggs et al. (1999) found significant asymmetry between right- and left-handed subjects such that right-handers had a larger cortical representation of the fingers and thumb than left-handers. In this study participants with amputations on their dominant side were found to have phantoms significantly more frequently than those with amputations on their non-dominant side and that they were also more likely to experience painful phantoms. From these findings it would be possible to conclude that amputees with high level amputations on their dominant side are more likely to experience painful phantoms and that this may be associated with larger areas of CNS reorganisation.

Most studies of CNS reorganisation have been have been done on relatively small numbers of amputees and none have fully provided insight into why some amputees develop severely painful phantoms whilst others only mildly painful or non-painful phantoms. However as more sophisticated non-invasive techniques become available it may be possible to monitor changes in the deafferented cortex of individuals with newly acquired amputations. This information could provide new insights into the perceptual correlates on CNS reorganisation and eventually lead to ways of preventing unwanted reorganisation.

It might conceivably be argued that an alternative explanation of the relationships found between amputations of the dominant side, higher levels of amputation and phantom pain could lie with psycho-social affects of more functionally disabling amputations. This study did not attempt to assess functional disability but interestingly no significant relationships were found between level of amputation and side of amputation and participants perceived effects of PLP on the quality of their lives or their choice as to whether they would prefer not to have PLP.

Despite the prevalence of phantoms, only 21 (28%) participants reported having been given any information about PLP. Those who were given information reported that no explanation as to why they were experiencing phantoms was
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provided. They were told that phantoms were not unusual and would disappear in time. However this study found only 7 participants reported that their phantoms had disappeared; the majority of participants stated that the frequency and intensity of their experiences remained the same (Tables 2 and 3). Despite the prevalence of PLP, only 17 (26%) of participants stated they had discussed their experiences with health professionals. The emotional state of amputees immediately post-amputation is well documented (Shukla et al., 1982; Sherman, 1994). This may in part account for the initial reluctance of amputees to talk about phantoms for fear that this would provide evidence that their mental health was unstable. However this reluctance to talk about phantoms continued. When initially approaching amputees to take part in this study a number spontaneously commented that they would probably be thought to be crazy if they told people about their experiences. A third of participants in this study had never discussed their phantom experiences with anyone. In response to an open-ended question about what might have helped them most when dealing with PLP the most frequent responses were 'knowing what to expect', having more information about PLP, and being reassured that having phantom experiences was normal.

Until the mechanisms underlying PLP are fully understood and effective methods of controlling the phenomena are found the majority of amputees will be left to cope with their phantoms on their own. No participant in this study had found that any treatment provided had been fully successful. This finding has been supported by other studies (Sherman, 1989). Most amputees in this study had developed their own methods of dealing with PLP but only after having spent considerable time searching for a solution. Successful methods mainly involved distractors or active training in ignoring the phantom. In order to help amputees to adapt to living with PLP it is important that the existence, impact and complexities of the phenomena are recognised by all health professionals dealing with amputees. The amputees and their close family should be given the opportunity to discuss the problem and they should not be left with the unfounded fear that they are going mad.

This study showed that there was considerable variability in phantom experiences amongst the clinic population of upper limb amputees. Standard documentation and detailed profiling of individual PLP experiences would help to demonstrate trends and changes that occur over time. Such documentation should become routine clinic procedure and could lead to a body of knowledge becoming available that would aid the understanding of PLP and eventually lead to its effective management and control.

Conclusions

This study has shown that most upper limb amputees will experience, and have to continue to live with, phantom limb phenomena but that there is considerable variety in these experiences. Currently the provision, by health professionals, of information and support for amputees in dealing with PLP appears inadequate. There is a need to improve the gathering of information relating to PLP in order both to gain a better understanding of the mechanisms underlying these phenomena and to improve the quality of services to amputees.

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