

**Prevalence and characteristics of phantom limb pain and residual limb pain in  
the long term following upper limb amputation**

Deirdre M Desmond<sup>1,3</sup> PhD\* & Malcolm MacLachlan<sup>2,3</sup> PhD

<sup>1</sup> Department of Psychology, John Hume Building, National University of Ireland  
Maynooth, Maynooth, Co. Kildare, Ireland.

<sup>2</sup> School of Psychology, University of Dublin, Trinity College, Dublin, Ireland.

<sup>3</sup> Dublin Psychoprosthetics Group, Dublin, Ireland: [www.tcd.ie/psychoprosthetics](http://www.tcd.ie/psychoprosthetics)

\*Correspondence & Requests for Reprints:

Dr Deirdre Desmond, Department of Psychology, John Hume Building, National  
University of Ireland Maynooth, Maynooth, Co. Kildare, Ireland.

E-mail: [Deirdre.Desmond@nuim.ie](mailto:Deirdre.Desmond@nuim.ie)

Telephone: 353-1-708 6479 Fax: 353-1-708 4767

**Running title:** Pain following upper limb amputation

## **Abstract**

**Objectives:** This study aims to describe the prevalence and characteristics of phantom limb pain and residual limb pain following upper limb amputation.

**Methods:** One-hundred and forty-one participants (139 males; mean age 74.8 years; mean time since amputation 50.1 years) completed a self-report questionnaire assessing residual and phantom limb pain experience. **Results:** Prevalence of phantom limb pain during the week preceding assessment was 42.6% (60/141). Prevalence of residual limb pain was 43.3% (61/141). More than one third of these had some pain constantly or most days. Phantom limb pain was commonly described as ‘discomforting’ (31/60) and associated with ‘a little bit’ of lifestyle interference (23/60). Residual limb pain was most often described as ‘discomforting’ (27/61) or ‘distressing’ (19/61) and was typically associated with low to moderate levels of lifestyle interference. **Conclusion:** Assessment of multiple dimensions of post-amputation pain in the long term following upper limb amputation is warranted.

**Keywords:** Upper Limb Amputation; Phantom Limb Pain; Residual Limb Pain

## Introduction

Pain secondary to limb amputation is a common occurrence (Bosmans et al., 2007, Desmond and MacLachlan, 2006, Ephraim et al., 2005). Most research on phantom limb pain (PLP) and residual limb pain (RLP) has been conducted on samples composed of individuals with lower limb amputations (Ehde and Wegener, 2008). Relatively little research has focussed on the prevalence and characteristics of pain following upper limb amputation, perhaps due to its lower incidence. Analyses based on cases of lower limb amputation are of limited generalizeability; clear differences are evident in terms of primary underlying aetiologies, characteristic patient profiles and implications of prosthesis use. Amputations of the upper limbs typically result from traumatic injury and are characteristically sustained by young adults in good health. The majority of lower limb amputations are performed in cases of vascular insufficiency; patients are usually older than 60 years, comorbidities are common and the potential for ischemic pain is elevated (Pell and Stonebridge, 1999). Furthermore, lower limb prosthesis use involves greater intensity and impact of weight bearing.

The primary aim of the present study was to investigate experiences of PLP and RLP following upper limb amputation. The specific aims were to: (1) estimate the prevalence of PLP and RLP in a sample with acquired upper limb amputations; (2) investigate amputation-related and demographic factors associated with PLP and RLP; and (3) ascertain the average frequency, duration, and intensity of PLP and RLP episodes and associated lifestyle interference amongst individuals ~~individual's~~ actively experiencing these pain problems.

## **Study Design and Participants**

Members of the British Limbless Ex-Service Men's Association (BLESMA) were invited to complete a self-report, postal questionnaire. The study protocol was approved by the Ethics Committee of the authors' institution. Of the questionnaires distributed, 1,222 were returned (response rate = 49%); 1,072 contained sufficient data for analysis. Data from the 141 respondents with acquired upper limb amputation forms the basis of this study. Sample characteristics are outlined in Table 1.

**[Insert table 1 about here]**

## **Measures**

Participants completed the RLP and PLP sections of the Trinity Amputation and Prosthesis Experience Scales (TAPES), and demographic and amputation history questions. The TAPES is a multidimensional self-report instrument (Gallagher and MacLachlan, 2004, Gallagher and MacLachlan, 2000). The pain sections comprise questions relating to (a) whether pain is experienced; (b) frequency of pain episodes in the previous week; (c) average duration of typical pain episodes; (d) average intensity; and (e) extent to which pain interferes with normal lifestyle activities.

PLP was defined as "pain in the part of your limb that was amputated". RLP was defined as "pain in the remaining part of your amputated limb". 'Yes' and 'no' were the initial cut-off points applied ('no' represents no experience; 'yes' represents a wide range of pain experience from once per year to constant pain). Frequency and average duration of pain episodes in the previous week were assessed, thus a point prevalence estimate for PLP and RLP is also provided (i.e. active pain). Among those

with active pain, average intensity (mild, discomforting, distressing, horrible, excruciating) and extent of pain-related lifestyle interference (not at all, a little bit, moderately, quite a bit, a lot) were documented.

### **Data analysis**

Data were analyzed using descriptive statistics. Comparisons were conducted using chi-square and Mann Whitney U tests as appropriate.  $p < .05$  was chosen for statistical significance.

### **Results**

Using the yes/no cut-off point, ninety respondents (63.8%) reported PLP, 78 (55%) reported RLP, and 67 individuals (47.5%) reported both. Just 41 participants (29.1%) did not report PLP and/or RLP. Participants with and without PLP did not differ significantly with respect to level of amputation (above/below elbow), age, time since amputation, prosthesis use (yes/no) or extent of prosthesis use (< 8 hours daily,  $\geq$  8 hours daily) (all  $p$ 's  $> .05$ ). Similarly, individuals who experienced RLP did not differ from those who did not in terms of these variables. There was a significant association between PLP and RLP ( $\chi^2_{(1)} = 27.782$ ,  $p < 0.01$ ; OR 11.17). PLP was present in 66 of 78 participants who experienced RLP, and in 12 of the 32 individuals who did not experience RLP.

Prevalence of PLP during the week preceding assessment was 42.6% (60/141). The prevalence of RLP was 43.3% (61/141). Average frequency and duration of pain episodes in the week preceding the assessment are shown in Table 2. The duration of pain episodes was typically thirty minutes or less. More than one third of respondents

had some pain most days or constant pain. Forty six individuals (32.6%) reported both PLP and RLP in the week preceding assessment, thus 75 people (53.2%) reported at least one episode of either PLP and/or RLP in the week preceding the assessment.

**[Insert table 2 about here]**

Average pain intensity and resulting lifestyle interference are summarized in Table 3. Most respondents with PLP (51.7%) classified their pain as ‘discomforting’; 15% described it as ‘horrible’ or ‘excruating’. RLP was most often described as ‘discomforting’ (44.3%) or ‘distressing’ (31.1%). For both PLP and RLP, intensity ratings were moderately to strongly correlated with ratings of specific pain-related lifestyle interference ( $r = .509$  and  $r = .433$ , respectively,  $p < .001$ ). More than one third (38.3%) of respondents reported ‘a little bit’ of lifestyle interference as a result of PLP. More than one quarter of those with active RLP described the associated lifestyle interference as moderate.

**[Insert table 3 about here]**

## **Discussion**

PLP and RLP are common amongst individuals with acquired upper limb amputations. When pain types were initially dichotomised as absent/present, almost two-thirds of participants (64%) reported PLP, more than half (55%) reported RLP and 48% reported both. These estimates are consistent with results reported elsewhere (Fraser et al., 2001, Kooijman et al., 2000) but substantially lower than

figures reported by Ephraim and colleagues (2005); inclusion of participants at earlier post-amputation stages, i.e. < 5 years post-amputation, and the greater proportion of amputations attributed to disease in their sample may partially account for these differences. However, although some longitudinal studies on lower limb amputation suggest diminishing PLP and RLP with time (Jensen et al., 1985, Houghton et al., 1994), the timelines for these pain problems remain controversial.

Similar to previous studies (e.g., Gallagher et al., 2001, Kooijman et al., 2000), a significant association between RLP and PLP emerged. One third of respondents not reporting PLP reported RLP, whereas 84.8% of those who experienced PLP also experienced RLP. Hill (1999) suggests the co-occurrence of RLP and PLP may result from an inability to distinguish between these pain types. On the other hand, RLP may trigger PLP, making it extremely difficult to separate these phenomena (Kooijman et al., 2000). Consistent with lower limb amputation research (e.g., Ehde et al., 2000), the PLP (42.6%) and RLP (43.3%) point prevalence estimates suggest the persistence of these pain conditions in the long term following upper limb amputation. Although the majority of respondents with active pain reported brief pain durations ( $\leq 30$  minutes), indicating pain was typically a transient phenomenon, a substantial proportion reported pain of significant frequency and/or duration. The most frequently endorsed pain intensity rating for both PLP and RLP was 'discomforting' – indicating that many individuals experienced relatively low level pain. However, almost one-third reported RLP to be 'distressing'; 15% of those with active PLP (9/60) reported pain of severe intensity (i.e. horrible or excruciating) and 13% with active RLP characterised their pain as severe.

Although PLP and RLP were common, for most they were not particularly intrusive. This is in keeping with the wider chronic pain literature where a non-linear association between pain intensity and interference has been noted (Jensen et al., 2001, Cleeland, 1984). Nonetheless, 15% of those with PLP and 19.7% of those with RLP reported ‘quite a bit’ or ‘a lot’ of interference as a consequence of such pain. Specific pain control intervention targeted at reducing pain intensity from levels that produce disruption (Jensen et al., 2001) is warranted for these subgroups.

The present study provides longer-term data and documents PLP and RLP characteristics in a larger sample of cases of upper limb amputation than has hitherto been reported. Nonetheless, several limitations of the study should be noted and the findings interpreted with caution. Participants in the current research represent a specialised sample, most respondents were veterans with combat-related amputations and all were BLESMA members; this may be a source of bias. Research is necessary to determine whether these findings generalise to the wider upper limb amputation population. Furthermore, the survey response rate and self-report nature of the design may be a source of bias.

Despite these limitations, the findings highlight the need to assess multiple dimensions of post-amputation pain following upper limb amputation. Furthermore, chronic pain problems may arise in regions beyond the amputated limb (Ehde et al., 2003); the prevalence and characteristics of such pain has not been consistently and systematically documented. Research on pain is a necessary first step toward the development of appropriate interventions (Ehde and Wegener, 2008).



## **Acknowledgments**

This research was funded by the Irish Research Council for the Humanities and Social Sciences and the British Limbless Ex-Servicemen's Association.

## References

- Bosmans, J. C., Suurmeijer, T. P. B. M., Hulsink, M., van der Schans, C. P., Geertzen, J. H. B. & Dijkstra, P. U. (2007) Amputation, phantom pain and subjective well-being: a qualitative study. *Int J Rehabil Res*, 30, 1-8.
- Cleeland, C. S. (1984) The impact of pain on the patient with cancer. *Cancer*, 54, 2635-2641.
- Desmond, D. M. & MacLachlan, M. (2006) Affective Distress and Amputation-Related Pain Among Older Men with Long-Term, Traumatic Limb Amputations. *J Pain Symptom Manage*, 31, 362-368.
- Ehde, D. M., Czerniecki, J. M., Smith, D. G., Campbell, K. M., Edwards, W. T., Jensen, M. P. & Robinson, L. R. (2000) Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Arch Phys Med Rehabil*, 81, 1039-1044.
- Ehde, D. M., Jensen, M., Engel, J., Turner, J., Hoffman, A. J. & Cardenas, D. (2003) Chronic pain secondary to disability: a review. *Clin J Pain*, 19, 3-17.
- Ehde, D. M. & Wegener, S. T. (2008) Management of Chronic Pain after Limb Loss. In Gallagher, P., Desmond, D. M. & MacLachlan, M. (Eds.) *Psychoprosthetics: State of the Knowledge*. London, Springer-Verlag.
- Ephraim, P. L., Wegener, S. T., MacKenzie, E. J., Dillingham, T. R. & Pezzin, L. E. (2005) Phantom Pain, Residual Limb Pain, and Back Pain in Amputees: Results of a National Survey. *Arch Phys Med Rehabil*, 86, 1910-1919.
- Gallagher, P., Allen, D. & MacLachlan, M. (2001) Phantom limb pain and residual limb pain following lower limb amputation: a descriptive analysis. *Disabil Rehabil*, 23, 522-530.

- Gallagher, P. & MacLachlan, M. (2000) Development and psychometric evaluation of the Trinity Amputation and Prosthesis Experience Scales (TAPES). *Rehabil Psychol*, 45, 130-154.
- Gallagher, P. & MacLachlan, M. (2004) The Trinity Amputation and Prosthesis Experience Scales and quality of life in people with lower-limb amputation. *Arch Phys Med Rehabil*, 85, 730-736.
- Hill, A. (1999) Phantom limb pain: a review of the literature on attributes and potential mechanisms. *J Pain Symptom Manage*, 17, 125-142.
- Houghton, A. D., Nicholls, G., Houghton, A. L. & Saadah, E. (1994) Phantom pain: natural history and association with rehabilitation. *Ann R Coll Surg Engl*, 76, 22-5.
- Jensen, M. P., Smith, D. G., Ehde, D. M. & Robinsin, L. R. (2001) Pain site and the effects of amputation pain: further clarification of the meaning of mild, moderate, and severe pain. *Pain*, 91, 317-322.
- Jensen, T. S., Krebs, B., Nielson, J. & Rasmussen, P. (1985) Immediate and Long-Term Phantom Limb Pain in Amputees: Incidence, Clinical Characteristics and Relationship to Pre-Amputation Limb Pain. *Pain*, 21, 267-278.
- Kooijman, C. M., Dijkstra, P. U., Geertzen, J. H. B., Elzinga, A. & van der Schans, C. P. (2000) Phantom pain and phantom sensations in upper limb amputees: an epidemiological study. *Pain*, 87, 33-41.
- Pell, J. P. & Stonebridge, P. (1999) Association between Age and Survival Following Major Amputation. *Eur J Vasc Endovasc Surg*, 17, 166-169.

**Table 1: Characteristics of the study participants (n =141)**

| <b>Characteristic</b>      | <b>n</b>   | <b>%</b>    | <b>Mean (SD)</b> | <b>Observed<br/>range</b> |
|----------------------------|------------|-------------|------------------|---------------------------|
| <b>Gender</b>              |            |             |                  |                           |
| Male                       | 139        | 98.6        |                  |                           |
| Female                     | 2          | 1.4         |                  |                           |
| <b>Cause of amputation</b> |            |             |                  |                           |
| Active combat              | 93         | 67.4        |                  |                           |
| Training accident          | 17         | 12.3        |                  |                           |
| Other accident             | 24         | 17.4        |                  |                           |
| Other                      | 4          | 2.9         |                  |                           |
| <u>Trauma total</u>        | <u>138</u> | <u>97.9</u> |                  |                           |
| Cancer                     | 1          | 1.0         |                  |                           |
| Other                      | 1          | 1.0         |                  |                           |
| <u>Disease total</u>       | <u>2</u>   | <u>1.4</u>  |                  |                           |
| Not specified              | 1          | 0.7         |                  |                           |
| <b>Amputation level</b>    |            |             |                  |                           |
| Hand                       | 18         | 12.8        |                  |                           |
| Both hands                 | 6          | 4.3         |                  |                           |
| Below elbow                | 34         | 24.1        |                  |                           |
| Through elbow              | 8          | 5.7         |                  |                           |
| Above elbow                | 68         | 48.2        |                  |                           |
| Bilateral arm              | 4          | 2.8         |                  |                           |
| Level unspecified          | 3          | 2.1         |                  |                           |

| <b>Characteristic</b>         | <b>n</b> | <b>%</b> | <b>Mean (SD)</b> | <b>Observed<br/>range</b> |
|-------------------------------|----------|----------|------------------|---------------------------|
| <b>Gender</b>                 |          |          |                  |                           |
| Male                          | 139      | 98.6     |                  |                           |
| Female                        | 2        | 1.4      |                  |                           |
| <b>Cause of amputation</b>    |          |          |                  |                           |
| Active combat                 | 93       | 67.4     |                  |                           |
| Training accident             | 17       | 12.3     |                  |                           |
| Other accident                | 24       | 17.4     |                  |                           |
| Other                         | 4        | 2.9      |                  |                           |
| Age (years)                   |          |          | 74.83 (11.36)    | 39-91                     |
| Time since amputation (years) |          |          | 50.12 (13.48)    | 5-63                      |
| Prosthesis users              | 101      | 71.6     |                  |                           |

**Table 2: Average frequency and average duration of phantom and residual limb pain for those who experienced pain in the past week.**

| <b>Pain Characteristic</b>                   | <b>N (%)</b> |
|--|--------------|
| <b><i>Phantom Limb Pain*</i></b>             |              |
| <b>Frequency</b>                             |              |
| Constant                                     | 10 (16.7)    |
| Daily or most days                           | 15 (25.0)    |
| More than 3 times                            | 15 (25.0)    |
| One to three times                           | 14 (23.3)    |
| Often/occasionally/regularly/several times   | 6 (10.0)     |
| <b>Duration</b>                              |              |
| Seconds                                      | 7 (11.7)     |
| Minutes                                      | 19 (31.7)    |
| Half an hour                                 | 5 (8.3)      |
| Hours  | 7 (11.7)     |
| 24 hours                                     | 1 (1.7)      |
| All the time                                 | 10 (16.7)    |
| Varies                                       | 5 (8.3)      |
| <b><i>Residual Limb Pain<sup>#</sup></i></b> |              |
| <b>Frequency</b>                             |              |
| Constant                                     | 10 (16.4)    |
| Daily or most days                           | 15 (24.6)    |
| Five or more times                           | 9 (14.8)     |
| Three or four times                          | 6 (9.8)      |
| One to three times                           | 11 (18.0)    |
| <b>Duration</b>                              |              |
| Seconds                                      | 12 (19.7)    |
| Minutes                                      | 15 (24.6)    |
| Half an hour                                 | 3 (4.9)      |
| Hours  | 9 (14.8)     |

---

|              |           |
|--------------|-----------|
| Varies       | 5 (8.2)   |
| 24 hours     | 2 (3.3)   |
| Days         | 1 (1.6)   |
| All the time | 13 (21.3) |

---

\*Percentages are based on n=60. # Percentages are based on n=61.

**Table 3: Pain intensity and lifestyle interference associated with pain**

| <b>Intensity</b>              | <b>Phantom Limb Pain, n (%)*</b> | <b>Residual Limb Pain, n (%)#</b> |
|-------------------------------|----------------------------------|-----------------------------------|
| Mild                          | 7 (11.7)                         | 7 (11.5)                          |
| Discomforting                 | 31 (51.7)                        | 27 (44.3)                         |
| Distressing                   | 12 (20.0)                        | 19 (31.1)                         |
| Horrible                      | 4 (6.7)                          | 6 (9.8)                           |
| Excruciating                  | 5 (8.3)                          | 2 (3.3)                           |
| <b>Lifestyle interference</b> |                                  |                                   |
| Not at all                    | 15 (25.0)                        | 17 (27.9)                         |
| A little bit                  | 23 (38.3)                        | 15 (24.6)                         |
| Moderately                    | 11 (18.3)                        | 16 (26.2)                         |
| Quite a bit                   | 4 (6.7)                          | 7 (11.5)                          |
| A lot                         | 5 (8.3)                          | 5 (8.2)                           |

\*Percentages are based on n=60. # Percentages are based on n=61.