Patient information on phantom limb pain: a focus group study of patient experiences, perceptions and opinions

C. M. Mortimer, W. M. Steedman¹, I. R. McMillan¹, D. J. Martin and J. Ravey²

Abstract

Educating patients about their condition is regarded as a fundamental step in pain management. This study used focus groups with patients to explore their experiences and perceptions of the information on phantom pain that they received before and after amputation, and their views on improving this information. Thirty-one patients with a lower limb amputation attended one of seven focus groups. The majority reported phantom pain although there were individual variations in character, severity and persistence. There were wide variations in what people were told from occasional reports of good information to instances of people reporting little or no information from professionals. There were strong feelings that information should be given before or soon after amputation with a preference for verbal one-to-one explanations. Professionals, particularly nurses and surgeons, were regarded as the best source of information, although peer support was seen to be important. These findings indicate that people require timely up-to-date information on phantom pain which sensitively addresses the variability of the experience and provides the foundation for ongoing pain management. We propose that the information process could be improved by ensuring that professionals use standard information for patients derived from purposefully written sections in national guidelines.

Introduction

While non-painful phantom sensations have been accepted as a normal sequel to amputation, which should be discussed with patients, dispute remains about what patients should be told about phantom pain. Portenoy, for example, concluded that pre-operative education that addresses both phantom sensation and pain, plus attentive post-operative care that validates the patient’s experience and offers reassurance, is often the only pain management required (Portenoy, 1994). In contrast, a recent textbook of amputation surgery and practice suggested that patients should be told about phantom sensation, but that phantom pain should not be emphasized (Murdoch and Wilson, 1996). The text includes an anecdotal account of an amputee who was reported to develop pain only when on a ward beside another patient with phantom pain. Discussed in this Introduction are factors that contributed to conflicting beliefs about what patients should be told about the phantom experience.

The documented incidence of phantom pain has varied from 2% to nearly 100%. Reports of only a small minority (0.5–5%) experiencing severe persistent pain have led to advice against forewarning and the suggestion that those with pain should be told that it would eventually disappear (Henderson and Smyth, 1948; Robinson, 1996). There is now evidence that almost all amputees...
experience phantom sensations of the missing limb and as many as 90% experience phantom pain (Parkes, 1973; Sherman and Sherman, 1983; Sherman et al., 1984; Jensen et al., 1985; Houghton et al., 1994; Jensen and Rasmussen, 1994; Hill et al., 1995a; Nikolajsen et al., 1997). While people report a reduction in number and duration of episodes in the first 6 months, overall the number of people with pain and the intensity of episodes does not decrease significantly for up to 2 years (Jensen et al., 1985; Nikolajsen et al., 1997). In 70% of cases long-term pain leads to occasional withdrawal from work and social activity (Sherman et al., 1984).

Early theories about the underlying cause of phantom pain appear to have led to people being told that phantom pain was imagined or ‘in the head’. Myths surrounding the phantom experience, e.g. a report of a burning pain in a phantom leg resolved by taking the ashes of the limb and scattering them on a lake (Sherman, 1997), coupled with the apparent similarity to phantom illusions experienced by those in a psychotic state led authors to assume a purely psychological or imaginary origin (Ewalt et al., 1947; Henderson and Smyth, 1948). Phantom pain, particularly that which resembled past experience, was seen as an imposed sensation experienced by those not adjusting to the amputation (Henderson and Smyth, 1948). These beliefs were not universal. In the same era, Riddoch noted surprise at the refusal of the medical profession to accept a physiological basis for phantom pain and reported that many patients were apprehensive about discussing phantom pain for fear of being thought insane (Riddoch, 1941). A more recent survey of 2700 US veteran amputees found that 60% reported that a physician had stated or implied that phantom pain was ‘in the head’ (Sherman et al., 1984). A review of the literature relating to psychological factors that might influence phantom pain concluded that there was no definite evidence to suggest that personality disorders or other psychological factors are important in its development and that they are not more prevalent amongst those reporting pain (Sherman et al., 1987).

Educating the patient with prior general information about the amputation and rehabilitation process is an important step in reducing associated fears and anxieties, and is regarded as a good way of opening up lines of communication between the patient and professionals (Dernham, 1986; Rounseville, 1992). The inclusion of information, which allows the patient to prepare for the full range of phantom experiences, has been advocated (Dernham, 1986; Rounseville, 1992; Harwood et al., 1992; Patterson, 1994; Portenoy, 1994; Ward et al., 1998). Education has been shown to be an important component of the management of other chronic pain conditions including back pain and cancer pain (Turner and Romano, 1990; de Wit et al., 1997). In addition to relieving anxiety, dispelling myths and providing information about medication, education can form the basis of pain management (Turner and Romano, 1990).

Despite support for education as an integral part of amputation pain management there is currently little evidence of specific recommendations on what information should be given about phantom pain and how this is best communicated. Furthermore, within the scientific literature and textbooks that are readily available to health professionals working in the rehabilitation of patients after amputation, there are considerable contradictions about the level and type of information that patients should be given.

Methods

The current study used focus group discussions to explore patients’:

- Experiences of phantom pain.
- Experiences and perceptions of the current information received on phantom sensation and pain.
- Perceptions and opinions about what patients should be told about phantom pain and areas of need in the development of patient information.

Focus groups are regarded as a useful technique for investigating a topic of concern to a group of people with shared experiences (Dawson et al.,
Patient information on phantom limb pain

The discussion, guided by a moderator, is used to generate qualitative data on the topic of interest to the researcher (Kitzinger, 1995). The shared experiences of people in the current study were that they had all undergone a lower limb amputation, and had recently undergone rehabilitation as inpatients and as outpatients attending an artificial limb appliances centre in central Scotland.

Subjects
A total of 31 subjects each took part in one of seven focus groups. Subjects were recruited from two sources. The first group were volunteers from a local Prosthetic Users Self-Help group (PUSH) \((n = 5)\). The remaining six groups (ALAC1–6) were made up from a convenience sample recruited from records for an Artificial Limb Appliances Centre (ALAC) in central Scotland \((n = 26)\). Participants in these six groups met the following criteria. It was more than 1 month but less than 5 years since their amputation, they were adults aged less than 75 years, they had a primary lower limb absent due to amputation rather than a congenital disorder, they had no other complicating medical condition and they lived within a practical distance of the focus group locations. Sixty-two subjects identified from ALAC records were contacted by telephone. Of these, 28 declined or were unwilling to take part, five were not suitable due to complicating conditions or re-amputation, two were deceased and one had moved away. Twenty-six people agreed to take part in focus groups ALAC1–6.

The focus group process
Lothian Research Ethics Committee granted ethical approval for this study. Participants were provided with written information about the focus group process, a consent form and a short researcher-designed questionnaire, which collected demographic details and basic information about phantom experiences. They were asked to complete the consent form and questionnaire, and bring them along to the group.

Focus groups were held at various locations convenient to the participants. Focus group discussions were guided by a moderator who on all but one occasion was accompanied by an observer who recorded the identity of the person speaking and made notes of non-verbal communications and points of interest. The discussions were audio-recorded with the permission of the participants. Discussion was structured around six areas relating to experiences of phantom sensation and pain, and the support and information provided throughout rehabilitation. The moderator used questions and prompts developed through observation and experience from an earlier study (Mortimer et al., 1998) to generate and facilitate discussion. Strategies to ensure trustworthiness of the data collection included expansion and rephrasing of questions to ensure detailed discussion within the focus groups (Krefting, 1991), and participant verification of the moderator’s summaries (Hammersley and Atkinson, 1983).

Analysis
The analysis of the focus group data followed steps recommended by Krueger (Krueger, 1997) (outlined in Figure 1). Within 24 h of the group the moderator listened to the recording and made detailed notes. In ALAC3 where no observer was present this process was carried out immediately after the discussion. The audio-recorded discussions were transcribed verbatim, and supplemented with information from the observer’s notes and the initial review of the audio-recordings.

Transcripts were loaded into QSR NUD*IST version 4 for categorization and coding. Data categorization used an iterative editing/template approach (Miller and Crabtree, 1994). The background literature, earlier findings (Mortimer et al., 1998) and current data informed the data categorization. Categories were updated and restructured through sequential and retrospective searching of the transcripts. In a second stage paper copies of the categorized data and full transcripts were reviewed. Charts were used to present a visual account of points raised and the frequency with which responses occurred, the data was searched to identify strength of feeling and patterns and singularities in the data, and written descriptions
Fig. 1. Analysis of focus group findings.
were developed to illustrate the concepts arising from this process. In the final stage the researcher resolved and interpreted the key themes or ‘big ideas’ emerging from the analysis and developed accounts to explain these interpretations (Krueger, 1997). Throughout the analysis a process of peer debriefing, where the data and interpretations of the key themes were shared and discussed with other research team members, ensured the reliability of the data categorization and findings (Krueger, 1997; Pope et al., 1999). In addition, care was taken to refer back to the full transcripts and written notes to minimize the potential for misinterpreting the context of the data.

The qualitative findings are presented as descriptive summaries and interpretations of the key themes, supported and illustrated by quotes from the raw data. Subject names are coded for confidentiality.

Findings are presented in the following broad topic areas:

1. Descriptions of the phantom pain experience.
2. Experiences and perceptions of the current information on phantom sensation and pain provided before amputation and during rehabilitation.
3. Perceptions and opinions about the need for and potential improvements to the content, timing, source and mode of communication of information on phantom pain to be given to patients undergoing amputation.

### Results

#### Demographic data

A summary of participant characteristics is given in Table I. Thirty-one people took part, 13 women and 18 men (age range 30–74 years, mean 70.5, SD 3.54). Seven subjects had above-knee amputations (five right and two left) and 22 had below-knee amputations (13 right and nine left). On two separate occasions people with bilateral amputations who arrived unheralded at the focus group were included in the discussion and subsequent findings. Amputation had been performed for one of four different reasons: peripheral vascular disease \( n = 24 \), trauma \( n = 3 \), cancer \( n = 2 \) and osteomyelitis \( n = 2 \). Subjects in the PUSH group were similar to those in the other six groups in age and reason for amputation, but differed in the time since amputation (PUSH: mean 63 months post-amputation, range 33–117, compared to the other groups: mean 25 months post-amputation, range 6–35).

#### Qualitative findings

Presented here are the qualitative findings summarized for all seven groups. (There was no obvious pattern of different concepts arising from the PUSH group compared with the other groups.) Where concepts have been derived from a one-off comment or discussion in only some groups, this is stated within the text.

**Descriptions of the phantom pain experience**

Twenty-seven of the 31 participants reported experiencing phantom pain. The status, severity and character of the pain experienced varied between individuals.

**Pain status and severity.** Described in Table II is the status and reported severity of phantom pain based on data from the individuals descriptions in the questionnaires and during the focus group discussion. Of those reporting current pain, eight described pain that was interpreted as severe and nine described pain interpreted as mild to moderate. Descriptions of current pain varied considerably, e.g. some described pain that had not reduced in intensity but did occur less frequently. The following subject discussed pain that he described as being of the same severity but that he no longer experienced every day:

...there might be 2 days a week it doesn’t happen and 2 days running it does you know there’s no real pattern... [041–ALAC1 32 months post-amputation]

Others suggested that episodes of current pain could differ in severity, e.g.:

I have a lot of pain still, a lot of phantom pain...it gives a wee bit one time or another but
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Table I. Summary of participant characteristics

<table>
<thead>
<tr>
<th>Focus group</th>
<th>Subject code</th>
<th>Time since amputation (months)</th>
<th>Gender</th>
<th>Reason for amputation</th>
<th>Level of amputation</th>
<th>Age (years)</th>
</tr>
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<tbody>
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<td>F</td>
<td>PVD</td>
<td>L+RBK</td>
<td>73</td>
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<td>028</td>
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<td>M</td>
<td>trauma</td>
<td>LBK</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>029</td>
<td>117</td>
<td>F</td>
<td>cancer</td>
<td>LBK</td>
<td>30</td>
</tr>
<tr>
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<td>33</td>
<td>F</td>
<td>PVD</td>
<td>RBK</td>
<td>54</td>
</tr>
<tr>
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<td>034</td>
<td>67</td>
<td>M</td>
<td>PVD</td>
<td>LAK</td>
<td>68</td>
</tr>
<tr>
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<td>PVD</td>
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<td>69</td>
</tr>
<tr>
<td></td>
<td>041</td>
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<td>M</td>
<td>trauma</td>
<td>LBK</td>
<td>62</td>
</tr>
<tr>
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<td>F</td>
<td>PVD</td>
<td>LAK</td>
<td>71</td>
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<td>PVD</td>
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<td>LAK</td>
<td>68</td>
</tr>
<tr>
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<td>M</td>
<td>PVD</td>
<td>RBK</td>
<td>70</td>
</tr>
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<td>LBK</td>
<td>38</td>
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<td>RAK</td>
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<td>PVD</td>
<td>RBK</td>
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<td>PVD</td>
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<td>F</td>
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<td>L+RBK</td>
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<td>RBK</td>
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<td>F</td>
<td>trauma</td>
<td>LBK</td>
<td>46</td>
</tr>
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<td>M</td>
<td>osteomyelitis</td>
<td>RBK</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td>062</td>
<td>11</td>
<td>M</td>
<td>cancer</td>
<td>RAK</td>
<td>48</td>
</tr>
<tr>
<td></td>
<td>058</td>
<td>22</td>
<td>F</td>
<td>PVD</td>
<td>RBK</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>059</td>
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<td>M</td>
<td>PVD</td>
<td>RBK</td>
<td>65</td>
</tr>
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<td>M</td>
<td>PVD</td>
<td>RBK</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td>064</td>
<td>14</td>
<td>M</td>
<td>PVD</td>
<td>RAK</td>
<td>70</td>
</tr>
<tr>
<td></td>
<td>065</td>
<td>14</td>
<td>F</td>
<td>PVD</td>
<td>RBK</td>
<td>69</td>
</tr>
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<td>ALAC6</td>
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<td>M</td>
<td>PVD</td>
<td>RBK</td>
<td>72</td>
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<tr>
<td></td>
<td>070</td>
<td>6</td>
<td>F</td>
<td>PVD</td>
<td>LBK</td>
<td>47</td>
</tr>
<tr>
<td></td>
<td>068</td>
<td>7</td>
<td>F</td>
<td>PVD</td>
<td>RBK</td>
<td>70</td>
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<tr>
<td></td>
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<td>15</td>
<td>F</td>
<td>PVD</td>
<td>LBK</td>
<td>68</td>
</tr>
<tr>
<td>Mean</td>
<td>28 months</td>
<td>F 13</td>
<td>70.5 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>6–117 months</td>
<td>M 18</td>
<td>3.54</td>
<td>Range</td>
<td></td>
<td>30–74 years</td>
</tr>
</tbody>
</table>

PVD, peripheral vascular disease; AK, above the knee; BK, below the knee.

other times it gets really terrible I can hardly bear it, the pain. [065–ALAC5 14 months post-amputation]

Pain character. Peoples’ descriptions of pain were diverse including shooting, shocking, sticking, stabbing, burning, cramping and crushing, and pain resembling past experience. Some people described experiencing more than one type of painful sensation in the phantom, e.g.:

But I do get maybe once or twice a week either a sharp stabbing pain or just a gripping sticking a needle in your leg and the toes in the vice feeling. [062–ALAC4]

Pain could be constant, e.g.:
Patient information on phantom limb pain

<table>
<thead>
<tr>
<th>Code</th>
<th>Time since amputation (months)</th>
<th>Phantom pain Status</th>
<th>Severity</th>
<th>Character</th>
</tr>
</thead>
<tbody>
<tr>
<td>020</td>
<td>41 past</td>
<td>mild</td>
<td>past wound</td>
<td></td>
</tr>
<tr>
<td>028</td>
<td>57 current/worse</td>
<td>severe/daily</td>
<td>jumping</td>
<td></td>
</tr>
<tr>
<td>029</td>
<td>177 current/same</td>
<td>severe/constant</td>
<td>stabbing/shooting</td>
<td></td>
</tr>
<tr>
<td>030</td>
<td>33 current/same</td>
<td>moderate/daily</td>
<td>cramping/jumping</td>
<td></td>
</tr>
<tr>
<td>034</td>
<td>67 current/same</td>
<td>moderate/daily</td>
<td>shooting</td>
<td></td>
</tr>
<tr>
<td>040</td>
<td>35 none</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>041</td>
<td>32 current/same</td>
<td>severe/episodic</td>
<td>shooting/past wound</td>
<td></td>
</tr>
<tr>
<td>042</td>
<td>25 past</td>
<td>mild/–</td>
<td></td>
<td></td>
</tr>
<tr>
<td>043</td>
<td>30 past</td>
<td>mild/–</td>
<td>juddering</td>
<td></td>
</tr>
<tr>
<td>049</td>
<td>16 current/same</td>
<td>severe/daily</td>
<td>shock</td>
<td></td>
</tr>
<tr>
<td>051</td>
<td>23 current/less</td>
<td>severe/–</td>
<td>shooting</td>
<td></td>
</tr>
<tr>
<td>046</td>
<td>11 current/less</td>
<td>moderate/episodic</td>
<td>shooting</td>
<td></td>
</tr>
<tr>
<td>044</td>
<td>9 none</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>056</td>
<td>16 past</td>
<td>severe/daily/episodic</td>
<td>severe tingling</td>
<td></td>
</tr>
<tr>
<td>055</td>
<td>18 past</td>
<td>severe/constant</td>
<td>indescribable</td>
<td></td>
</tr>
<tr>
<td>056</td>
<td>16 current/same</td>
<td>severe/daily</td>
<td>pins and needles/burning</td>
<td></td>
</tr>
<tr>
<td>045</td>
<td>21 current/less</td>
<td>mild/–</td>
<td>tingling</td>
<td></td>
</tr>
<tr>
<td>061</td>
<td>24 past</td>
<td>severe/–</td>
<td>shooting</td>
<td></td>
</tr>
<tr>
<td>060</td>
<td>21 current/–</td>
<td>mild/–</td>
<td>–</td>
<td></td>
</tr>
<tr>
<td>062</td>
<td>11 past</td>
<td>moderate/episodic</td>
<td>cramping/spasms</td>
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</tr>
<tr>
<td>058</td>
<td>22 none</td>
<td></td>
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<td>063</td>
<td>16 current/–</td>
<td>mild/–</td>
<td>cramping</td>
<td></td>
</tr>
<tr>
<td>064</td>
<td>14 past</td>
<td>mild/–</td>
<td>dull</td>
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<tr>
<td>065</td>
<td>14 current/less</td>
<td>severe/constant</td>
<td>pins and needles/indescribable</td>
<td></td>
</tr>
<tr>
<td>067</td>
<td>21 current/–</td>
<td>mild/–</td>
<td>cramp</td>
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<tr>
<td>070</td>
<td>6 current/less</td>
<td>moderate/episodic</td>
<td>indescribable</td>
<td></td>
</tr>
<tr>
<td>068</td>
<td>7 current/less</td>
<td>severe/daily</td>
<td>burning</td>
<td></td>
</tr>
<tr>
<td>048</td>
<td>15 past</td>
<td>severe</td>
<td>–</td>
<td></td>
</tr>
</tbody>
</table>

It’s there constantly your aware of it, you know, the ache is dulled quite a bit... [030–PUSH]

It was more common, however, for people to describe intermittent pain of a shooting nature or of a past painful experience.

Oh yes I still get, but its not a pain as such, its just like a shock, because sometimes I’m sitting and my leg goes (jerk action) and my sister will say is that your phantom pains again... [051–ALAC2]

...for months before the amputation I had a toe nail which gave me a bit of trouble on one side... it was ingrown a bit and I can still feel that most nights when I go to bed and lie down... [059–ALAC4]

Interpretation—descriptions of the phantom pain experience. The high occurrence of phantom pain within this sample and the openness with which people discussed their experiences emphasized the normality of the phantom pain experience within this group. Individuals recalled a variety of phantom pain experiences in terms of character, duration and severity. Interestingly it did not always follow that those who had an amputation for a
greater length of time were those who described the least pain. The pain experienced by individuals varied but could be generally characterized as burning type, crushing type, shooting type or pain that resembled a past experience.

Experiences and perceptions of the current information

The discussion about the current information that people had received before amputation and during rehabilitation highlighted three key themes: (1) information did not always come from a professional, (2) examples of information from a professional that had been helpful and (3) dissatisfaction with the information given.

Information did not always come from a professional. Although many people reported finding out about phantom phenomena either before or soon after amputation, it was notable that this had not always been through a professional. It was frequently reported that most, and sometimes all, information came from other patients or family and friends.

They (professionals) didn’t make a point of getting a group of prospective amputees and telling them what they could expect. The information I gathered was just from other patients... [040–ALAC1]

Well I didn’t know what it was (phantom pain) but the lady in the next bed eventually told me... [048–ALAC6]

Helpful information from a professional. A few people reported that a professional had taken time to discuss phantom pain with them, e.g.:

...my surgeon went to every length to explain what was likely. He said it was possible that you don’t get them, some people do, some people don’t, but it is quite possible that you will get phantom pains after your amputation. He also described the length of time that you might have them for, up to a year. [062–ALAC4]

Another reported being given information before amputation and being asked questions about phantom pain afterwards:

...it was actually then the nurse that was dealing with me at the time she says you’ll probably get the sensation which is called phantom pain after your amputation. She said some people get it directly and some people wait and just get it through time. [053–ALAC3]

LATER

I was asked every day, they came round with chart and asked you different things...and did you have any phantom pain... [053–ALAC3]

Dissatisfaction with the information given by professionals. There was considerably more discussion of dissatisfaction with the information that professionals had given. Some suggested that professionals told them that phantom pain was just something that happened and that nothing could be done.

I was surprised at the lack of knowledge, although I think most of all the lack of interest by the medical staff in the hospital. The phantom pains they’re just, I think they said well you know it’s part of the job and that’s it put up with it. [034–PUSH]

There was dissatisfaction with how the topic of phantom pain was addressed. For example, either a professional just asked about phantom pain and gave no further information or, more commonly, people eventually asked a professional and had received an unsatisfactory response.

I think purely by asking they inferred that they had told you but they hadn’t. [049–ALAC2]

No they’ve always shown amazement, when you mention it [phantom pain]. They say somebody else said that, they never tell you. [060–ALAC4]

Until you get your ward rounds and then you tell the doctors [about the phantom] and they just sort of laugh and say that was to be expected. [070–ALAC6]

Others expressed surprise at the reality and persistence of phantom pain compared to what they been
led to expect by professionals or had heard from other amputees.

My first reaction was really surprise, I’d been told that this could happen but I was still not fully prepared for it. [041–ALAC1]

I was surprised how real the pain seemed, it was real and now I realize, but then I was surprised at the level of pain particularly in the toes. [062–ALAC4]

Interestingly, only twice did people recount being told that the phantom pain was imaginary, e.g.:

For the first 2 weeks after the accident yes I had terrible, terrible phantom pain but there is nothing that you can do for it and one of the nurses effectively told me it was all in your head it’s your imagination just grin and bear it. [061–ALAC4]

*Interpretation—*experiences and perceptions of the current information.* Though there were illustrations of good practice, there was no evidence to suggest that people were consistently receiving high-quality information from professionals. Frequently, people appeared to have relied either solely or initially on other patients for information rather than on professionals. The information received from professionals was often perceived as inadequate and had left people surprised by their experiences and uncertain about the likely character and persistence of phantom pain. Only occasionally did people report receiving advice about pain management and sometimes people recounted being told that nothing could be done to help and they would just have to put up with it.

*Perceptions and opinions about the need for and potential improvements to information*

*Need for information.* There was an almost unanimous feeling that people undergoing amputation should be given information about both phantom sensation and phantom pain, although in one group there was some initial discussion about whether pre-warning would make a person more or less likely to experience pain. The over-riding sentiment was that information was needed to reassure people that both phantom sensation and phantom pain were normal and to prevent falls by warning that the limb may feel very real.

...they didn’t tell you early enough, you experienced it especially the foot still being there and they then try and get you to stand up. I think they should be telling you that very soon...that you have to be very careful. [046–ALAC2]

If it helps you to understand what you’re trying to tackle...if you’re forewarned or something like that or counselled then you know what the problem is. You don’t worry and say I wonder if it’s so and so is starting up again... [059–ALAC4]

*Content of information.* There was a strong desire for factual information about the phantom sensation and pain, including the likely time scale, onset and character of phantom pain. There was, however, discussion in all groups about the variability in the phantom experience associated with strong feelings that this needed to be accounted for in the information given, e.g.:

There again it’s like this variation, what could they say that covered everybody’s, because everybody has it worse or better or longer or shorter to different degrees. [049–ALAC2]

LATER

...whatever they say it would have to be a general thing and that more or less covered all eventualities for the nervous [person]... [049–ALAC2]

The main desire was for initial information that reassured the patient that their phantom experiences were normal. There were, however a few requests for later, more detailed information explaining the cause of phantom phenomena and discussing available treatments and ways of coping with the phantom pain.

*Timing of information.* The benefits and disadvantages of providing information both pre- and post-operatively were discussed. Although some
favoured information pre-operatively others thought that it could be alarming.

You’d probably alarm people... [053–ALAC3]

I don’t really think I would want to know. [056–ALAC3]

Others felt that pre-operatively there was too much going on for information to be taken in.

So would the best time perhaps be after you’ve had the operation? [MODERATOR–ALAC5]

Yes at that time (before), you’re just not compos mentis with what’s going on around about you to be quite honest. [065–ALAC5]

You’ve got enough to cope with getting your leg off. [070–ALAC6]

I think after it, because before the thought of having it off is uppermost in your mind. [048–ALAC6]

The compromise discussed was that information should be given soon after amputation or before when considered suitable or if requested by the patient.

Source and mode of communicating information.

Both professionals and other people with an amputation were identified as a good source of information on phantom pain.

The professionals favoured were the nursing staff or the consultant surgeon involved early on in the rehabilitation process. Less frequently physiotherapists, occupational therapists and, in the longer term, prosthetists and general practitioners were regarded as good sources of information.

One group specifically identified the need for better long-term support and information, possibly provided through a counsellor:

And it is going to have to be a counsellor with contact number... So then when you’re in a position emotionally to think okay what was said about that aspect that you can phone up and say what was it you said or you can make an appointment. [029–PUSH]

A couple of one-off comments emphasized the need for the professionals concerned to have a good knowledge of the subject, e.g.:

...just the same way that the nursing staff are dealing with a wide range of problems if they had a one sheet briefing on dealing with amputees that got into their training somewhere so they had something even if it was a few bullet points so they weren’t completely lost when it came to it. [062–ALAC4]

The role of other amputees in providing both information and support was discussed in all groups. People recalled experiences of incidental support through other patients during physiotherapy sessions and on the ward, and discussed incidents of more formal support as either recipients or as peer supporters.

The main support for a peer providing information about phantom pain was that another person with an amputation would be the only person capable of understanding the phantom experience, as illustrated by the following discussions:

No, you want somebody there somebody you can talk to. [057–ALAC3]

There is nobody that can tell anyway unless they’ve had their leg off themselves to tell you what it’s like. [056–ALAC3]

It doesn’t come well from a whole person. [058–ALAC4]

LATER

...you’ve just had your leg off and you see someone with two legs, you know that they have no idea what you can feel and they can say oh I understand, but they don’t, they haven’t got a clue. [058–ALAC4]

Limitations of using peers as a source of information were identified. In particular, it was felt that they could alarm the patient or give distorted impressions based on their own experiences.

As long as they know what they’re talking about. I don’t think I would necessarily want to see somebody who’s had an amputation
because then you’re going to perceive that as what you’re going to look like good or bad. [029–PUSH]

You’ve got to size up the person very carefully, just to see what you can say and what you can’t say, some people get a bit alarmed. You can just over step the mark, and as I say this chap I said to him about the phantom pains he was quite amazed that he could understand... [053–ALAC3]

One group suggested that a solution to this could be to train people for this role:

I think the amputees could maybe come from a chosen group and they would have to be prepped up and have a really bright outlook on it as well... [060–ALAC4]

One way to do it would be to train up some amputees to do it. [058–ALAC4]

In all groups there was a strong feeling that one-to-one verbal contact was most appropriate mode of communicating information, particularly in the first instance.

Somebody not to talk above your head, to talk to you, not over you. [030–PUSH]

Well I suppose the nurse or the sister should tell you, after you come out of the anaesthetic you know, when you get your wits back about you... [055–ALAC3]

LATER

I think it’s a lot easier on the patient to tell them verbally instead of giving written information which they might not understand. [057–ALAC3]

Written or video information were mentioned, but were not regarded as a useful way of giving initial information on phantom pain.

You’re not in a state to read anything or watch anything. [061–ALAC4]

Interpretation—perceptions and opinions about the need for and potential improvements to information. The strong desire for information on both phantom sensation and pain for all patients undergoing amputation is congruent with evidence that this need was not currently being addressed. People require individual up-to-date information that sensitively addresses the acknowledged variability of the phantom experience. There was a strong preference for information to be delivered verbally either before or soon after amputation. Written information was not rated highly as the initial mode of communication although it was regarded as a possible way of providing more details about phantom pain at a later stage in the rehabilitation process.

Professionals involved in the early stages of rehabilitation such as the nurses and surgeons were seen to be in an appropriate position to offer information. There was, however, a strong feeling that peers had an important role to play in providing information although there was recognition that they may give the wrong impression or overwhelm the patient. An over-riding factor was that the person providing information, either professional or peer, needed to be trained to perform this role.

Discussion

The current study has shown that phantom sensation and phantom pain are significant parts of the amputation experience which should be addressed by professionals before amputation and throughout rehabilitation. Our findings agreed with evidence that phantom pain is a common experience which frequently persists with variable degrees of severity for longer than 6 months after amputation (Sherman and Sherman 1983; Sherman et al., 1984; Jensen et al., 1985; Houghton et al., 1994; Hill et al., 1995; Nikolajsen et al., 1997a,b). Descriptions of phantom pain were similar to the categories defined in the literature of burning, cramping and shooting type, and somatosensory memories of past painful experiences (Sherman and Sherman 1983; Sherman et al., 1984; Jensen et al., 1985; Jensen and Rasmussen, 1994; Nikolajsen et al., 1997).

With a few exceptions, the information from professionals had failed to meet need in terms
of content, timing and mode of delivery. On a positive point there was little evidence of past misconceptions, which lead to people being told that phantom pain was just ‘in the head’. The findings of the current study reflect a lack of a standardized approach to educating patients about phantom pain. They also indicate that professionals may not be adequately equipped with an up-to-date knowledge and understanding of phantom pain and its management, and are possibly basing the information that they give to patients on often outdated and contradictory literature.

There was a strong feeling that people undergoing an amputation should be informed about the possibility of phantom pain either before or soon after amputation. The few instances where people recalled receiving detailed information, which had been helpful, illustrated the potential value to the patient of providing this type of information. Initial information should seek to reassure the patient that the sensations and pains that they experience are normal, are not imagined and do not necessarily signify the occurrence of any complicating conditions or re-emergence of a past disease (Portenoy, 1994; Sherman 1997). Our findings highlight the importance of informing patients about the different character, duration and intensity of phantom pain that they may experience. They also suggest that it is inappropriate to tell a patient that phantom pain will definitely reduce or disappear with time.

Education needs to continue throughout rehabilitation at later stages addressing the underlying cause and possible treatment strategies including pharmacological and non-pharmacological management. Harwood et al. stated that ‘phantom pain is a clinical event well suited to the ‘biopsychosocial’ model, with fundamental neurophysiological events manifesting themselves in multiple areas of the patient’s life’ (Harwood et al., 1992). Explanations of the underlying cause of persistent pain can form the foundation for pain management. This need not involve complex technical terminology. As an example, Sherman suggested that an appropriate way of discussing phantom sensation is by using the analogy of banging the ‘funny bone’ in the elbow which can result in tingling in the fingers (Sherman, 1997). Education should also discuss how a variety of physical, psychological, environmental and social factors can influence the pain experience to encourage the patient to develop self-management strategies through learning to recognize exacerbating and alleviating factors (Turner and Romano, 1990).

Professionals involved early on in rehabilitation were seen as the best source of initial information. Whilst changes in professional education are leading to a greater emphasis on pain it seems unlikely, from recommendations for medical and allied professional education, that phantom pain is specifically addressed in all professional groups (Berde, 1993, 1994; Fields, 1995). Clearly, to ensure consistency and to achieve reinforcement of information throughout rehabilitation, all professionals involved should have a good understanding of phantom pain and its management.

Informal peer support was identified as an integral part of rehabilitation. The strong feeling that only another person with an amputation could fully empathize with the experiences suggests that trained peers could be an alternative formal source of information on phantom pain. The identified reservations about peers misleading or overwhelming the patient would be minimized by training them to provide suitable support and information, and by careful consideration of the best time and most appropriate person to support an individual (Butler et al., 1992).

An unexpected finding of our study was the strong desire for initial information on phantom pain to be delivered verbally on a one-to-one basis rather than as written information. This reflected a fear that written information might replace contact with a professional when the need for reassurance was crucial. It has been suggested that the best way of educating elderly patients about pain is through simple written information in combination with verbal information focusing on reinforcement and allowing the patient time to ask questions (Pasero and McCaffery, 1996). This strategy may also be applicable to providing people undergoing amputation with information about phantom pain.
A recent report recommended that patients undergoing surgery be provided with appropriate information on their risk of post-operative pain and the strategies available to deal with it (Clinical Services Advisory Group, 2000). Our study has shown that there is a need for improvements and standardization of the information that patients are given about phantom pain. The inclusion of examples of patient information within national guidelines for the management of pain conditions, e.g. rheumatoid arthritis (Scottish Intercollegiate Guideline Network, 2000), is an attempt at developing consistency and quality in the provision of information. Our recommendations for providing patients with appropriate information about pain after amputation could be facilitated by the inclusion of protocols for patient education within future guidelines on phantom pain (Bond, 2000). Implementation of these guidelines should aim to equip professionals with the skills to adapt these protocols to the needs of the individual and deliver sensitive timely information.

The focus group discussion method is consistent with recent emphasis on ensuring that patients are informed about their care and involved in the development of information which meets their need (Department of Health, 2000; The Scottish Executive, 2000). Using focus groups to consult patients was an appropriate first step in developing patient information on phantom pain. This study was conducted within a tight geographical area, but because the sample details are consistent with descriptions of sufferers of phantom pain in the literature the results are likely to have relevance outside this boundary. In addition, the proposed development of guidelines suggests that there is a widespread need for improvements in phantom pain management, including patient education (Bond, 2000).

Our findings support the development of information and form the basis for recommendations for the desired content and mode of delivery of information. A continuation of this work is needed to develop and implement standardized procedures for providing patients undergoing amputation with information on phantom pain. Future studies need to explore whether providing information improves the management of phantom pain and determine what components are most successful and meet the needs of patients.

Conclusions

Our study has shown that the information provided to patients on phantom pain is failing to meet their need. Patients expect to receive information from a variety of professional and peer sources at different stages of rehabilitation, and, at present, the timing and content of the information is extremely variable. Arising from these findings we propose that a systematic incorporation of standardized information in the education of patients will be beneficial to their care. A potential way of standardizing information would be to develop, implement and evaluate protocols for the use of a minimum set of information that people undergoing amputation should receive on phantom pain at different stages of the rehabilitation process. Efforts to improve information need to be centred on ensuring that the multidisciplinary team involved throughout rehabilitation is equipped with the most up-to-date understanding of the occurrence, nature and management of phantom pain, and the skills necessary to tailor this information to the individual.

References


Heinemann, Oxford.


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