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Adult limb and breast amputees' experience and descriptions of phantom phenomena—A qualitative study

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ABSTRACT

Background: Phantom phenomena – pain or other sensations appearing to come from amputated body parts – are frequent consequences of amputation and can cause considerable suffering. Also, stump pain, located in the residual limb, is in the literature often related to the phantom phenomena. The condition is not specific to amputated limbs and has, to a lesser extent, been reported to be present after radical surgery in other body parts such as breast, rectum and teeth.

Multi-causal theories are used when trying to understand these phenomena, which are recognized as the result of complex interaction among various parts of the central nervous system confirmed in studies using functional brain imaging techniques.

Functional brain imaging has yielded important results, but without certainty being related to phantom pain as a subjective clinical experience.

There is a wide range of treatment methods for the condition but no documented treatment of choice.

Aims: In this study a qualitative, explorative and prospective design was selected, in the aim to understand the patients' personal experience of phantom phenomena.

The research questions focused at how patients affected by phantom pain and or phantom sensations describe, understand, and live with these phenomena in their daily life.

This study expanded 'phantom phenomena' to also encompass phantom breast phenomenon. Since the latter phenomenon is not as well investigated as the phantom limb, there is clinical concern that this is an underestimated problem for women who have had breasts removed.

Methods: The present study forms the first part of a larger, longitudinal study. Only results associated with data from the first interviews with patients, one month after an amputation, are presented here. At this occasion, 28 patients who had undergone limb amputation (20) or mastectomy (8) were interviewed. The focused, semi-structured interviews were recorded, transcribed, and then analyzed using discourse-narrative analysis.

Results: The interviewees had no conceptual problems in talking about the phenomena or distinguishing between various types of discomfort and discomfort episodes. Their experience originated from a vivid, functioning body that had lost one of its parts. Further, the interviewees reported the importance of rehabilitation and advances in prosthetic technology. Loss of mobility struck older amputees as loss of social functioning, which distressed them more than it did younger amputees. Phantom sensations, kinetic and kinesthetic perceptions, constituted a greater problem than phantom pain experienced from the amputated body parts. The descriptions by patients who had had mastectomies differed from those by patients who had lost limbs in that the phantom breast could be difficult to describe and position spatially.

The clinical implication of this study is that when phantom phenomena are described as everyday experience, they become a psychosocial reality that supplements the definition of phantom phenomena in scientific literature and clinical documentation.

Conclusions: There is a need for clinical dialogues with patients, which besides, providing necessary information about the phenomena to the patients creates possibilities for health professionals to carefully listen to the patients' own descriptions of which functional losses or life changes patients fear the most. There is a need for more qualitative studies in order to capture the extreme complexity of the pain–control system will be highlighted.

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1. Introduction

In line with the bio-psychosocial model (Engel, 1977) characterizing the view on health and disease within the Western countries, pain is presently seen as a function of the entire person rather than just a signal (Kugelmann, 1997). Individuals' thoughts and fears influence the perceived quality and intensity of pain as well as the meanings they assign to its consequences (Hill, 1999). Several studies have addressed this influence as being especially important when trying to understand intriguing phenomena such as post-amputation condition with phantom sensations and pain (Hill, 1999; Calvino and Grilo, 2006; Melzack, 1992; Weinstein, 1998).

Phantom pain is perceived as being exclusively present in amputated body parts. It is the most frequently studied phantom phenomenon with a reported incidence of 60–80% among limb-amputated adults (Hill, 1999; Kooijman et al., 2000; Nikolajsen and Jensen, 2001; Richardson et al., 2006). Prospective studies have reported the presence of phantom pain two years after limb amputation in 60–75% of cases (Jensen et al., 1985; Manchikanti and Singh, 2004). Residual phantom pain reportedly causes considerable suffering (Calvino and Grilo, 2006; Melzack, 1992; Kooijman et al., 2000) though the degree of associated distress and disability has seldom been formally assessed (Weinstein, 1998; Fraser et al., 2001; Horgan and MacLachlan, 2007).

Phantom sensations are often described as kinesthetic (size, shape and proprioception) and kinetic (movement), thus confirming the existence of the amputated body part, and/or exteroceptive such as tingling, itching and numbness (Weinstein, 1998; Richardson et al., 2006). The prevalence of phantom sensations among limb amputees is reportedly almost in 100% of the cases but fades over time (Hill, 1999; Kooijman et al., 2000; Nikolajsen and Jensen, 2001).

Stump pain is reported by about half of the amputees (Hill, 1999; Manchikanti and Singh, 2004; Fraser et al., 2001).

Despite the need for more knowledge of different physiological mechanisms underlying different qualities of phantom phenomena (Hill, 1999), few studies (Richardson et al., 2006; Jensen et al., 1984, 1985; Wilkins et al., 2004) differentiate among the three categories mentioned above and conceptual as well as methodological shortcomings in the evaluation of phantom phenomena have been identified (Hill, 1999; Richardson et al., 2006; Horgan and MacLachlan, 2007; Desmond and MacLachlan, 2006; Hanley et al., 2004; Katz and Melzack, 1990). For instance, both researchers and study participants may find it hard to discriminate between the two categories of phantom phenomena and or stump pain: these often coexist and are mutually interrelated (Hill, 1999; Nikolajsen and Jensen, 2001; Richardson et al., 2006).

Some studies with a bio-psychosocial perspective have, besides standard assessments of location, quality, and intensity, incorporated criterion assessments of depressive symptoms, pain interferences in daily activities, and psychological distress (Hanley et al., 2004; Jensen et al., 2002; Whyte and Niven, 2001a). These studies have also included assessment instruments with the aim to find psychosocial predictors for good and/or inadequate adjustments to phantom pain and those results further supported the use of a bio-psychosocial model to assess adjustment to amputation and phantom pain (Hanley et al., 2004; Jensen et al., 2002; Whyte and Niven, 2001a). Horgan and MacLachlan (Horgan and MacLachlan, 2007) emphasize the need for more longitudinal research into how individuals experience and cope with social changes and limitations they must face from the immediate post-amputation phase to the rehabilitation phase.

Yet, while instruments constructed with predefined variables can be useful as screening instruments, they have limited clinical applications (Hill, 1999; Richardson et al., 2006; Horgan and MacLachlan, 2007; Desmond and MacLachlan, 2006; Hanley et al., 2004; Katz and Melzack, 1990). The reason for the limitation is that they constitute group-level estimation, with no scope for explaining the individual variations that exist in pain experience (Lund, 2006; Dijkstra et al., 2007).

Only a few recent studies are based on amputees' own descriptions of phantom experience (Richardson et al., 2006; Fraser et al., 2001; Wilkins et al., 2004; Hill et al., 1996; Whyte and Niven, 2001b). There is also a lack of systematic studies of patients' own evaluation of the distress and discomfort caused and of how they give their phantom phenomena meaning (Manchikanti and Singh, 2004; Fraser et al., 2001; Horgan and MacLachlan, 2007).

Thus, methodological innovations are needed to understand the ways patients experience and understand their phantom sensations and pain. The purpose of the present study was to explore the ways patients describe and evaluate their phantom pain/phantom sensations when they attempt to give meaning to their experiences.

2. Methods

2.1. Study design

Qualitative research methods are useful for studying human experience, how individuals attach meaning to their experience, and how they manage what they experience (Malterud, 2001a,b; Silverman, 2006).

Interviews using focused, open-ended questions with small samples constitute one possible qualitative method—as opposed to survey research where mainly multiple-choice questions are used with random samples (Silverman, 2006). The former small-sample, focused interview is suitable when studying "variations in perceptions and responses of individuals who were exposed to the same event or involved in the same situation" (Mishler, 1995, p. 99).

Because pain is always a subjective experience (Kugelmann, 1997; Lund, 2006), afflicted people often find it hard to communicate and share their experience. They must use language in a special way, that is, they must invent and use metaphors, similes, and analogies (Hydén, 1997; Schott, 2004).

Because any illness constitutes a disruption of ongoing life (Hydén, 1997), it is common for interviewees in such contexts to report their experience in narrative form to re-create meaning (Hydén, 1997; Hydén, 2005; Riessman, 1993). Several varying approaches to the study of narrative exist and use of narratives in health-care research has increased (Hydén, 1997; Kleinman, 1988) to allow the study of patients' articulation of their pain experience (Carr et al., 2005; Thomsen et al., 2007).

Like most narrative studies, the present study treats narrative as a discrete entity with a clear beginning, middle, and end, and as distinguishable from the surrounding discourse (Silverman, 2006; Hydén, 1997; Riessman, 1993). By using methods from narrative analysis (Hydén and Brockmeier, 2008; Riessman, 2008) the present study focused on what communicative tools the study participants selected when, in the context of an interview, they were free to describe phantom phenomena.

The interviews were totally detached from a medical context and from standard medical check-ups. Based on personal preference, they took place in the first author's office or in participants' homes.

This present study forms the first part of a 2-year follow-up study. Only results associated with data from interviews with patients, one month after an amputation, are presented.

The Regional Ethics Committee of Karolinska Institutet approved this study. Potential interviewees received documentation on the study's objectives, an outline of the type of information being sought, details of measures used to ensure anonymity, and a clear statement regarding the voluntary nature of participation. All the interviewees who agreed to participate in the study gave their verbal, informed consent.

2.2. Study participants

Between September 2002 and October 2003 potential study interviewees were recruited at a tertiary university hospital in an urban area. Their circumstances were categorized as follows: (i) amputation related to complications of diabetes mellitus and vascular diseases (endocrinology clinic), (ii) amputation after cancer surgery (general orthopaedics, orthopaedic oncology, breast surgery), and (iii) amputation necessitated by trauma (general surgery, orthopaedics, anaesthesiology, and intensive care). The participants were selected consecutively—in cooperation with various coordinators from the medical units involved. Inclusion criteria were: (i) Swedish-speaking men and women, (ii) aged 18–80, and (iii) first amputation. The purpose of including different causes of amputation, interviewees of both gender and with a wide range of age was to get as much information as possible of how the interviewees described and experienced various types of phantom phenomena—not to seek, with causal analysis, statistical connection between these "three background-factors" and phantom experiences.

The prospective design of this study called for a first contact with amputees as soon as possible after amputation. As to the causes of amputation and the procedures current within participating medical units, some variations emerged regarding the *time* when interviewees were contacted by the coordinators. The interviewees were invited to participate when the decision about amputation was made (where surgery was related to complications of diabetes, vascular diseases, and orthopaedic oncology). Ten days after mastectomy – at their first medical check-up – a coordinator contacted the women. Interviewees with a traumatic amputation were asked a few days after waking up from surgery. Some difficulties in recruiting post-trauma-amputated patients for the study were noted, and the recruiting area was thus expanded to include three other hospitals in the same region; one included a hand surgery clinic. In addition, the recruitment period was extended by three months.

Participants who were assessed as medically or mentally unstable and who participated in other studies were excluded. Of 34 potential participants approached, five declined, three were too fatigued and two did not want to participate. One young woman with a traumatic amputation and complications was excluded. The remaining 28 participated in the study.

To avoid preconceptions about the participants the interviewer did not check their medical records before the interviews or during the analyses. Participants' age and clinical characteristics were gathered during the interviews (see Table 1).

2.3. Data collection

The first author conducted each interview, which took about 1 h. The interviews focused on four general areas: amputation as a life event, living with a lost body part, possible phantom sensations and/or phantom pain and other pain. The areas constituted the structure of the interview within which the interviewer could pose additional questions when an area was not dealt with satisfactorily or when descriptions were insufficient. The first author recorded and transcribed (verbatim) the interviews, omitting non-verbal communication such as sighs and pauses.

2.4. Data analysis

The transcribed interviews were used as the main data source and were analyzed using a method combining discourse analysis (Silverman, 2006; Schiffrin, 1994) and narrative analysis (Hydén, 1997; Riessman, 1993). Discourse analysis is an umbrella term for theories and methods used for studying the organization of talk and text (Silverman, 2006). Such an analysis seeks to understand how language is used when conveying "information about the world, ourselves, and our social relationships" (Schiffrin, 1994).

The interviewer (BB) repeatedly read the transcripts—often while listening to the recorded interviews (Riessman, 1993). With another researcher (LCH), the interviewer (BB) performed a three-phase analysis. Phase I involved getting an overview of all data and extracting descriptions and narratives in which interviewees focused on amputated body parts, phantom pain and phantom sensations, and other pain. Phase II focused on identifying and extracting communication devices used by the interviewees (Thomsen et al., 2007; Björkman et al., 2008; Kugelmann, 1999; Peolsson et al., 2000a,b). The interviewees primarily used descriptions and metaphors—communication devices that produced animated images of how something felt (Schott, 2004). Sometimes descriptions were short and concise and sometimes turned into extensive narrations. Phase III involved compiling all the interviewees' descriptions, metaphors, and narratives into one analysis, which revealed that interviewees used the communication devices to compare, to draw parallels, and to demonstrate individual knowledge about various factors related to the phantom experience and how they understood the phantom phenomena. These factors were – in one way or another and at one time or another – present in all the interviews and were important for understanding the experience of phantom pain and phantom sensations in an everyday context.

3. Results

The findings are based on how the interviewees chose to describe their experience in the four areas (amputation as a life event, living with a lost body part, possible phantom sensations and/or phantom pain, and other pain problems), and are aligned in a structure which correspond with significant factors associated

Table 1
Age and clinical characteristics of the participants in the study.

Age	Diagnosis								
	Cancer		Vascular-diabetes		Trauma		Total		
	Men	Women	Men	Women	Men	Women	Men	Women	Total
18–45	2	1	1	0	2	0	5	1	6
45–65	1	8(6)[a]	2	2	1	0	4	10(6)[a]	14(6)[a]
65–	3	3(2)[a]	0	2	0	0	3	5(2)[a]	8(2)[a]
Total	6	12	3	4	3	0	12	16	28

[a] The figures in brackets indicate the number of women with breast cancer within the cancer diagnosis and the different ages.

with phantom phenomena and revealed in the interviews. Examples of interviewees' narrated experience are given in quotation marks, and represent the most typical experience.

3.1. The awareness of a missing body part

With one exception there were no conceptual problems in talking about perceptions of phantom phenomena. One woman was certain that she did not know and could not understand what phantom pain was. Two others claimed that the phenomenon was completely unknown to them before they entered the study.

The interviewees started talking about phantom experience by using their vivid, functioning body as a reference, continuing primarily in this way when describing actual physical experience as compared to the period before amputation:

> "No I'm not woken up by the phantom pain. But I wake up every time I want to turn over in bed. Generally you use two arms to turn over, so it becomes a complicated process when I want to turn over." (IP 17)

The interviewees described how a spectrum of phantom phenomena changed in intensity and manifestation during the weeks after amputation; and the phenomena could vary. Some interviewees said their experiences were fading and others said they were increasing. The interviewees were not just reporting something that had happened (i.e., remembering or reminding themselves about the past); they were also describing something that existed in the here and now and in comparison with an earlier situation.

One month after amputation, all the interviewees were aware that they were missing a body part, although they reported that they might have doubted that the amputation had really occurred during the days right after surgery. This gradual adaptation to reality is even more clearly illustrated in the case of an interviewee who remained uninformed and unaware of a leg amputation for a few days after waking up from the amputation. Recalling those days he said that while he was in hyperbaric oxygen therapy, he had pain in the amputated leg and had thought that "it must somehow be squeezed" (IP 29). After being informed of the amputation he realized that there had been no leg to be squeezed and this led on his part to a redefinition of the sensation as phantom pain. Phantom phenomena did not appear to any of the interviewees to be imaginary. With their varied wealth of vivid detail, they gave a convincing picture of the phenomena as an integral part of themselves. One interviewee gave exact details of how, with her amputated leg, she could feel: ". . . all the wrinkles in the sheet under my leg" (IP 29). Moreover, she could visualize her shortened – or rather, telescoped – limb by "measuring" a reduction of 1–1.5 dm.

Behind the interviewees' descriptions of their daily experience lay an urgent need to understand the mysterious phenomena and to give them an acceptable explanation. In describing their experience, about two-thirds used popular concepts and definitions of phantom phenomena (borrowed from health professionals, family and/or the media), in a way that indicated, they were knowledgeable about the significance of the complex interactions among nervous system, spinal cord and brain – thus enabling them to give meaning to their phantom phenomena. One amputee commented:

> ". . . they have. . . you know cut away nerves and so on . . . and you think your brain's going to understand that there's nothing . . . no; but the nerves are still sending signals." (IP 34)

3.2. Descriptions of phantom phenomena

None of the interviewees, who experienced phantom phenomena (including a man ignorant of the phenomenon before amputation) found it difficult to distinguish among phantom sensations, phantom pain, and/or pain and discomfort from the stump. Most reported perceptions of phantom pain and phantom sensations (16 of 28, including a woman with breast cancer). Five reported only phantom sensation (among them two women with breast cancer). One, a woman with breast cancer, reported only phantom pain; while six interviewees, including four women with mastectomies, perceived no phantom sensation. Interviewees mentioning post-surgical problems with stumps most often spoke of them as natural consequences of surgery that probably would go away when the body healed.

The most frequent description and narrative regarding phantom sensations was the observation that an active body leads to an active phantom experience.

Interviewees were trying to understand their many varying and somewhat bizarre expressions for their phantom sensations, (e.g., a body part detached from the unit they viewed as their body). The detached body parts (now phantoms) still behaved like the missing limbs would have behaved had they been still attached. These experiences were often described in relatively detailed narratives:

> "Lying in bed the other day I thought 'I'm moving my toes'. But I didn't move anything because nothing's left. But I actually experienced it. It was strange . . ." (IP 15)

The reported experience appeared to uncover three separate types of expression regarding phantom sensations: (1) kinaesthetic sensations – perceptions associated with size, shape, and proprioception, (2) kinetic sensations – perceptions of movement and (3) exteroceptive sensations such as itching and prickling. Kinaesthetic sensations may be described as positions or states that lead to very stressful consequences. Sweating from skin that sticks to skin is incomprehensible and tiresome when in fact there is nothing there to cause the sensation. Not being able to bend two fingers that stick straight out or toes that are plaited to each other could be fascinating, but such the sensations were mostly described as "like, really nasty". Kinetic sensations were frequently described as uncontrollable behaviour, often very frustrating. The arm, hand or leg with a will of its own became a burden that affected the temper:

> "... it is almost like you want to shake him . . . I would really like to shake him." (IP 6)

Some super-added sensations were described via metaphors such as "a tight-fitting skate" around the missing foot and "a seat belt pressing . . ." against the missing arm. A few descriptions of a conscious ability to move the phantom limb were also presented.

Yet, descriptors of phantom pain common in the literature – smarting, burning and stabbing – were mentioned, a few interviewees reported that phantom pain could be difficult to describe.

The most frequent description and narrative regarding phantom pain contained metaphors used to capture daily action or experience, to interviewer and interviewee obviously be painful such as:

> ". . . what we as children called 'tight nails' – when in the winter you'd been outside too long and your hands were frostbitten." (IP 6)

These ordinary expressions describe characteristic phantom pain as striking in sudden, unpredictable attacks:

> ". . . it (the pain) is sort of like boiling water, when you're going to boil water it just happens, you don't see it . . . suddenly it's just happening". (IP 28)

Many interviewees used knife metaphors, although they had never been stabbed with a knife. There were also descriptions as if violent excesses were caused by something or somebody from another world:

"... sometimes it stabs, you can feel that someone is digging into your Achilles tendon or someone is thrusting fire into the arch of your foot". (IP 34)

3.3. Mastectomies

Women who had had mastectomies described phantom phenomena differently from limb amputees. Like other interviewees, these women could distinguish between different kinds of phantom phenomenon, but it was more difficult for them to be sure about where they were experiencing phantom pain and or phantom sensations. Two women had difficulties in determining whether the sensation was located inside or outside their breastbone or ribs. Only one woman expressed herself in a manner similar to limb-amputated interviewees, and her phantom sensations were given a specified body space to be in. The other women had to strain to express their descriptions of their phantom sensations as correctly as possible.

3.4. Overall distress from a missing body part and phantom phenomena

The interviewees' utterances revealed two interesting variations in their evaluations of phantom experience. First, the degree of experienced incapacitation varied between age groups. Secondly, the intensity of phantom sensations differed from that of phantom pain in the evaluation of distress.

(1) Descriptions of, or narratives about, the *missing body part* mostly originated in comparisons between what the active body could do when it was still whole and what it could no longer do now that it had lost one of its parts. This ran through all the narratives—irrespective of age or activity level:

> "... after the operation I felt like just being a half. I won't be able to manage on my own; I'm going to be dependent on others. But I've found out that I actually *can* manage on my own". (IP 15, age 55)

But, for the older interviewees, the narratives often revealed that this loss of function was enormous and sad.

> "For instance when I lost my leg I became very sad. I'm alone and how will I be able to cope when I've lost my leg. I'm very sad." (IP 20, age 72)

Yet the interviewees also described how they try to compensate creatively for lost function, trying for example to overcome experienced distress through other types of distraction. Opportunities to understand seemed to be primary and necessary for this task. It became apparent here that rehabilitation and advances in prosthetic technology were very important for them, as offering a possibility to recapture former capacity. Here, there was a difference between the older and the younger interviewees' narratives. Again, for the older interviewees, extensive anxiety and big problems of lost mobility dominated at several levels.

For younger interviewees, there was more hope for the future. The hope was based on greater confidence in their physical capabilities, such as better balance, sight, and strength. These had been challenged, confirmed and developed in the advanced rehabilitation program. Thus a 22-year-old interviewee was totally convinced that he would be able to ride a motorcycle and go slalom skiing again very soon. The same good spin-off effects were absent from the older interviewees' descriptions.

(2) There was also an obvious difference in how interviewees communicated the distress they felt in connection with *phantom sensations* and the distress of *phantom pain*. It was very apparent that the experience of a body part that had been lost from the functioning unity – and was thus out of control – became a discomfort: this occurred mostly with phantom sensations. It was easier for interviewees to find descriptions and metaphors for distress associated with phantom pain and stump pain than to do so for phantom sensations. Regarding pain, even if the characteristics and intensity were unfamiliar to the interviewer, the descriptions and metaphors were often based on daily-life situations and actions familiar to interviewer and interviewees alike, as illustrated in this example:

> "A few times every day it hurt so bad that I almost cried. Now it's like that just a few times every week. And it often happens when you're standing and waiting for something or waiting to pay in a shop." (IP 17)

When interviewees tried to communicate the distress-related burden of phantom sensations, it became apparent that temporality was a problem. The sensation was often described as being present all the time, with a never-ending dimension, and this was very frustrating to experience, making sensations (as they put it) a real torment:

> "The phantom is there from early morning when you wake up until you go to bed. It's not like having an ordinary arm because you don't feel that arm all the time, like I feel my phantom arm." (IP 26)

Itching, prickling, and numbness were not painful, but if they did not stop, the interviewees reached a point in which persistence had to be described in metaphors that would be almost as strong as those used to express very intense pain. But because such metaphors were not available in the same experiential way, irritation and disgust came through in the narration.

In contrast, phantom pain – despite sometimes being very intense – was often described (as was stump pain) with confidence that it would disappear or at least be rendered liveable-with medical assistance. For example, many interviewees emphasized that the pain as a whole decreased although for the past few days it had broken through again. One interviewee said that the phantom pain had helped him slowly but surely to deal with his feelings concerning the loss of his leg (IP 31).

4. Discussion

4.1. The subjective experiences of the interviewees

This study examined how persons with phantom pain and phantom sensations experience, understand, and live from day to day with these phenomena. It has sought to expand knowledge about the phenomena and reveal ways in which amputees communicate their experience. When attempting to understand and describe their unique, extraordinary phantom experience, their former experience of a vivid body, perceived as functioning wholeness, an instrument for actions, constituted important support. All the interviewees (except those who had had mastectomies) had received information from health-care professionals about possible phantom phenomena, and they were not reluctant to discuss this with their physicians.

The study showed that more recent evidence-based pain literature describing the brain's role in phantom limb experience (Melzack, 1992; Halligan, 2002; Rachmandrandran and Hirstein, 1998), has influenced the interviewees understanding of these phenomena. Irrespective of age and education level, most of them had learned about phantom phenomena from the media and pop-scientific literature, as well as from health-care professionals.

In agreement with Weinstein (Weinstein, 1998), Fraser et al. (Fraser et al., 2001), and Richardson et al. (Richardson et al., 2006), this study found that the interviewees had no trouble differentiating between phantom sensations, phantom pain, stump pain, and other possible pain conditions – although several suffered from multi-morbidity. It underscores the importance of clearly defining various categories when questioning patients and knowing how to question patients (in the clinic as well as in research). When describing their phantom sensations, the present interviewees, as those in other studies (Jensen et al., 1984; Halligan, 2002; Rachmandrandran and Hirstein, 1998), seldom talked about specific exteroceptive sensations but more often about the presence of the amputated body part. This phenomenon has been called "corporeal awareness" by Hunter et al. (Hunter et al., 2003, p. 580).

4.2. Clinical and scientific implications

Weinstein (Weinstein, 1998) and Halbert et al. (Halbert et al., 2002) have established that the effect of phantom pain on overall functioning is poorly assessed and that the degree of disability associated with post-amputation pain poorly determined. Knowledge of how people affectively and cognitively evaluate their phantom experience is evidently insufficient although the two present findings summarized below are of clinical interest.

(1) Interviewees' experience of adequate, individualized, post-operative pain treatment appeared to have generated trust and the assumption that the pain was alleviable, or could at least be made liveable (in the interviewees' descriptions, individual rehabilitation appeared to be more important than the need for more effective pain treatment). But for phantom sensations, some interviewees agonized over the possibility that there was something in their bodies which was out of control – almost overpowering – and that this state might continue. Time without end is a problem in the context of illness because absence of an ending makes it difficult to evaluate and understand symptoms and illness events; there is no temporal horizon to give them meaning (Hydén, 1997). This finding raises an important scientific question: can possible absence of control and unending experience (in a medical context) trigger pain, or even become painful? Perhaps the belief (among clinicians) that phantom sensations are a rare problem (Kooijman et al., 2000; Nikolajsen and Jensen, 2001) represents a far more complex problem that is being overlooked?
(2) Evaluating the consequences of amputation revealed variations between the age groups' responses. Thus the loss of a bodily function made older interviewees sad and more dependent on the social welfare system and thus more anxious about the future. Accordingly, the present findings further draw attention to older amputees' need for a rehabilitation that is adapted to their limited resources. The finding also supports the reservation about generalizing findings from studies where older persons represent the greater percentage of amputees studied (Hill, 1999; Desmond and MacLachlan, 2006).

4.3. Limitations

The study was explorative with a design based on a limited number of patients with no randomized selection. This precludes the possibility of generalizing the findings to the whole population of amputees.

And, the opportunity for the interviewees to discuss their phantom phenomena and other pain problems at the interviews might have influenced their experience positively, leading them to tone down the distress of the phantom pain.

However, the design allowed evaluation of the patients' individual ways of giving meaning both to their experience of phantom phenomena, co-existing pain conditions and sensory disturbances in the context of amputation. Such findings could further form a base for larger randomized studies of this kind of problem.

5. Conclusions

Since no evidence-based treatment of choice for phantom pain exists, there is a need for clinical dialogues with patients, not only for giving necessary information about the phenomena, but carefully listen to the patients' own descriptions and find out which functional losses or life changes patients fear the most. There should be a special focus on older patients.

Thus, the present results agree with those of other recent studies and highlight the need for more qualitative studies with semi-structured interviews to capture the extreme complexity of the pain–control system. Further research on specific mechanisms underlying phantom phenomena needs to assess carefully various types of non-painful sensation. Well-known metaphors used to describe phantom phenomena after limb amputation may not, for example, apply to amputation of other body parts.

Conflicts of interest

None.

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