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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.