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The meaning and consequences of amputation and mastectomy from the perspective of pain and suffering

Berit Björkman [a], Iréne Lund [b,*], Staffan Arnér [a,1], Lars-Christer Hydén [c]

[a] Department of Physiology and Pharmacology, Section of Anesthesiology and Intensive Care, Karolinska Institutet, SE-171 77 Stockholm, Sweden
[b] Department of Physiology and Pharmacology, Karolinska Institutet, SE-171 77 Stockholm, Sweden
[c] Center for Dementia Research (CEDER) Department of Medical and Health Sciences, Linköping University, SE-581 83 Linköping, Sweden

HIGHLIGHTS

- Amputation and mastectomi can inflict consequences of severe suffering.
- The loss of the body part may entail loss of function and personal identity.
- Dialogue with the patients is necessary to verbalize the patients suffering.

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ABSTRACT

Background: The concepts 'pain' and 'suffering' are frequently treated as synonymous. However, they are clearly distinct phenomena. Phantom phenomena including pain and sensory disturbances are still recognized as long-lasting problems after limb amputation and after mastectomy. The complex nature of phantom phenomena makes the interpretation of its results ambiguous, regarding the prevalence of pain, sensory disturbances and the accompanying suffering. There is clinical experience that suffering is a great burden for the individual but there is a lack of systematic studies of patients' own evaluations of the suffering caused by their phantom phenomena.
Objectives: The overall aim of this study was to identify and describe patients' suffering related to, and as a part, of their post-amputation situation.
Methods: The present study constitutes a part of a prospective, two-year follow up project investigating interviews of 28 men and women in different ages and who have undergone a limb amputation or mastectomy. The reason for amputation or mastectomy varied among the patients and included vascular diseases, cancer (sarcoma and breast-cancer) and trauma. Our ambition was to extract as much variations as possible in different, individualized aspects of the actual pain and suffering producing situation. The participants were, here, invited to open-ended, narrative-oriented interviews one month after the surgery. The interviews were transcribed verbatim and analyzed within qualitative methodology: thematic content analysis.
Results: Twenty-two of 28 interviewees experienced phantom pain and phantom sensations. The two surgical processes amputation and mastectomy meant for a majority of the interviewees a critical event with threatening consequences for everyday life such as loss of function and personal integrity. Nine interviewees felt even stigmatized as a result of their lost body part. Numerous inter-related factors following the amputation/mastectomy, which can inflict severe suffering on the amputee, were uncovered. The context in which the interviewees were informed about the decision to amputate proved to be one such critical and important factor.
Conclusion: To understand potential suffering in relation to phantom phenomena, it will never be enough merely to have knowledge of the underlying physiological or neurological mechanisms and/or the intensity of phantom pain and phantom sensations. Rather, it is necessary to find out how the loss of the body part and its everyday consequences are experienced by patients.

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* Corresponding author.
E-mail address: irene.lund@ki.se (I. Lund).
[1] Deceased.

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Implications: It is important to create time for real dialogue with the patients both during pre-operative preparation and post-operative rehabilitation in order to clarify and verbalize elements that constitute the patients individual suffering. Hopefully this strategy can alleviate future chronic pain problems, severe psycho-social distress and suffering. Such an approach ought to have impact also for perceived suffering after other types of surgery or different invasive treatments.

1. Introduction

In line with the bio-psychosocial model [1] pain is presently seen as a function of the entire person rather than just a signal [2–4]. Individuals' thoughts and fears influence the perceived quality and intensity of pain as well as the meanings they assign to its consequences [5,6]. Within this knowledge base about pain, there has been a serious and lively discussion centering on the concept *suffering* and its relation to the concept *pain* [7–10].

Frequently, the concept of pain and suffering are used as if they were synonymous [9–11]. However, it is important both in science and in clinical meetings to elucidate that they are distinct phenomena [10–15]. Suffering can include perceived pain, but consists of other and broader states than just physical and psychological distress [10–12,16–21]. Suffering is a personal matter that afflicts the person when the psychological and social intactness of the person's integrity is threatened [10,22]. In the context of perceived pain, suffering is often described when pain is: (i) overwhelming; (ii) its source is unknown; and (iii) chronic. Thus, the meaning of pain influences suffering [10–13].

Phantom phenomena, including pain and sensory disturbances, are well recognized problems after limb amputation [5,23,24]. To a lesser extent, they have also been reported as being present after surgical removal of other body parts such as the breast [25–28]. Residual phantom pain is reported to cause considerable suffering [29–31], but it is also claimed that the degree of associated distress and disability has seldom been evidentially assessed [32–35].

One reason for these reported discrepancies is the limited access to scientific tools able to capture the multifaceted complex phenomena, especially their evaluative-cognitive dimensions [5,36], and to distinguish from their different sensory content [23]. Even bio-psychosocial studies within this field have proved to be limited in uncovering personal suffering and its individual variations [3,4,22,37]. Several such studies report that it appears difficult and sometimes even somewhat provocative for informants to capture their feelings of suffering this quality using traditional questionnaires [23,27,38,39]. A qualitative follow-up study about phantom breast phenomena [26] found that the women experienced and described the mastectomy as a life-disruption with an inherent threat to their identity. Another qualitative study [40] uncovered, as previously [41], that concepts of emotional and psychosociocultural character were connected more often to the amputation/mastectomy itself as a life-change event than to the phantom pain as such. During the last decades, there are several qualitative studies [16,33,42] which have corroborated Parkes' findings [43,44] that an amputation confronts the individuals with several types of losses including grief. Those psychological mental conditions have been neglected in research to date. Basic descriptive studies are therefore needed for a more profound understanding of what losses and challenges amputees have to face, and which can inflict suffering [16,33,42]. Melzack and Torgeson emphasized the importance of including the meaning of the pain-producing situation itself, when, holistically, trying to understand a patient in pain [45]. Limb amputation and mastectomy are universally known and well-documented pain-producing situations. Thus, to regarding these specific pain producing situations as life-change events could be an approach to clarify their consequences in the clinical context.

The aim of this study was to identify and describe patient's suffering related to, and as a part of, their post-amputation situation. It was also of interest to discuss what factors that could influence and determine the experience of suffering, and the potential relation of these factors to the experience of phantom pain and or/phantom sensations.

2. Methods and subjects

2.1. Study design

The current study constitutes a part of a prospective, explorative, two-year follow-up project investigating men and women who have undergone a limb amputation or mastectomy. This study-project used open-ended, narrative-oriented interviews which were performed at four occasions: one month, six months, one year, and two years after the surgery. The first author performed all interviews. The interviews explored how the study participants talked about their phantom experiences [26,40,46], and constituted the main data source for all studies.

2.2. Study participants

The potential study participants were recruited consecutively during a period of 16 months, among amputated patients at a tertiary university hospital in an urban area. The patients' circumstances were categorized as follows: (i) amputation related to complications of diabetes mellitus and vascular disease (from the endocrinology clinic); (ii) amputation related to cancer disease (from the orthopaedic, oncology and breast-surgery clinics); and (iii) amputation necessitated by trauma (from general-surgery, orthopaedic, anesthesiology and intensive-care clinics) (Table 1). The purpose of including patients with different causes of amputation in a wide range of age and with both genders represented was to extract as much variations as possible in different, individualized aspects of the actual pain-producing situation.

The patients were selected in cooperation with coordinators from the medical units involved. Inclusion criteria were: (i) Swedish-speaking adult men and women; (ii) aged 18–80 years; and (iii) undergoing their first amputation. Participants who were assessed as medically or mentally unstable and who were participating in other studies were excluded.

To avoid preconceptions, the interviewer did not check the present medical records prior to the interviews or during its analyses. Clinical characteristics were gathered during the interviews. Only results associated with data from the patients one month after an amputation/mastectomy were analyzed and presented in the current study.

The Regional Ethics Committee of Karolinska Institutet approved the study (Dnr 01-289). Potential study participants received documentation on the study's objectives, an outline of the type of information being sought, and details used to ensure anonymity. They also received a clear statement regarding the

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