



**Karolinska
Institutet**

Institutionen för Fysiologi och Farmakologi

Sektionen för Anestesi och Intensivvård

Amputees' experience and descriptions of phantom phenomena – a qualitative study.

AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Karolinska
Institutet offentlig försvaras i Nanna Swartz Auditorium,
Karolinska Universitetssjukhuset Solna

Fredagen den 8 juni 2012, kl 09.00

av

Berit Björkman

Socionom

Huvudhandledare:

Professor Lars-Christer Hydén
Linköpings Universitet
Institutionen för Medicin och Hälsa

Bihandledare:

Medicine doktor Iréne Lund
Karolinska Institutet
Institutionen för Fysiologi och Farmakologi

Docent Staffan Arnér
Karolinska Institutet
Institutionen för Fysiologi och Farmakologi

Fakultetsopponent:

Docent Mads Werner
Köpenhamns Universitet
Institutionen för Anestesiologi

Betygsnämnd:

Docent Mariann Olsson
Karolinska Institutet
Institutionen för neurobiologi, vårdvetenskap
och samhälle

Professor Pär Salander
Umeå Universitet
Institutionen för Socialt Arbete

Professor Claes Frostell
Karolinska Institutet
Institutionen för Fysiologi och Farmakologi

Stockholm 2012

ABSTRACT

In phantom phenomena, pain and/ or other sensations appear to be experienced from amputated body parts. The phenomena have long been the object of research and their underlying mechanisms have been discussed over the years. The condition is not specific to amputated limbs, having to a lesser extent been reported after radical surgery in other amputated body parts such as the breast. The phantom limb phenomenon is a well-documented, post-operative pain condition, but phantom breast phenomena are less documented. Multi-causal theories are used when trying to understand these phenomena, recognising them as the result of complex interaction among various parts of the central nervous system. This has been confirmed through studies using functional brain-imaging techniques. There is a wide range of treatment methods but no documented treatment of choice. In particular, there is a lack of knowledge about how amputees experience the meaning and consequences of their phantom phenomena.

The overall aim of the work presented in this thesis was thus to elicit and understand how amputees describe their phantom experience in everyday words, and how far their descriptions are influenced by different sociocultural factors. The approach adopted complements existing, predominantly neurobiological, knowledge.

The work is based on a two-year, prospective, explorative interview study with 28 women and men who had undergone limb amputation or mastectomy. The focused, narrative-oriented interviews were transcribed verbatim and the scripts were analysed with a combination of narrative and discourse analysis (Studies I and II). Content analysis was used for Studies III and IV. The approach in Study II was longitudinal, since all the four interviews with the eight women (out of the 28 sample) who had undergone mastectomy were analysed. In Studies I, III and IV only the interviews collected one month after the amputation/mastectomy were used. One month after the amputation 22 out of the 28 interviewees described and related their phantom pain and or phantom sensations in sensory-discriminative, motivational-affective and cognitive-evaluative dimensions. The phantom sensations were experienced mainly as more agonizing than the phantom pain, while the phantom breast phenomena differed from classic phantom extremity phenomena, not seeming to cause much distress. 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. Thus, when phantom phenomena were described as everyday experience, they become a psychosocial reality, which made it possible to find out *what* in the interviewees' phantom experience constituted suffering. The findings supplement the definition of phantom phenomena in scientific literature and clinical documentation.

In conclusion these findings highlight the importance of approaching the phenomena on an individual basis as a process of evaluation and selection. In addition, experience and understanding of the phantoms have sociocultural aspects. There follows the need for individualized communication and information from the clinician, and for incorporating a meaning-centred approach in future studies. The present insights may also be of value in other iatrogenic pain conditions.

ISBN 978-91-7457-783-9