

Title: Effect of upper limb lymphoedema on the psychosocial well-being of breast cancer survivors.

Introduction:

The Sydney Lymphoedema Assessment Tool (LAT) is an assessment designed to capture the multidimensional sequelae of lymphoedema. Examination of the tool revealed that the psychosocial domains and functional sequelae were not captured in a way that enabled full understanding. This study aimed to identify whether other psychosocial factors should be included within the Sydney LAT.

Methods:

Twenty two women living with lymphoedema participated in one of 4 focus groups to identify psychosocial issues that arose from having lymphoedema. The focus groups comprised women aged 34 to 86 years, secondary to treatment of breast cancer, with mild to severe lymphoedema for 10 months to 11 years duration. The focus groups were audio-taped and the recordings transcribed and qualitatively analyzed using thematic analysis procedures.

Results:

Analysis of transcripts identified a number of themes. The 5 most common psychosocial themes were i) fear and anxiety; 2) loss of empowerment and control; 3) decreased self esteem and embarrassment; 4) decrease in participation in everyday activities; and 5) frustration. Time since breast cancer diagnosis and onset of developing lymphoedema as well as age and lifestage of the woman appeared to have an impact on their psychosocial well-being.

Conclusion:

Findings from the focus groups signify that psychosocial issues are important for women living with lymphoedema and there appears to be an evolving coping cycle for women over time. Inclusion of new psychosocial items into the LAT will require further reliability and validity testing to determine whether these items improve the usefulness of this clinical tool.