

Title:

Lymphoedema: Women's lived experiences following breast cancer treatment

Abstract:

Introduction: The purpose of this qualitative research study was to explore the lived experiences of those with lymphoedema secondary to breast cancer and to explore the impact of lymphoedema on daily life and physical activity.

Methods: Two focus groups, each involving four women, recruited using purposive sampling techniques, have been conducted, with an additional two focus groups scheduled. A phenomenological approach is being applied to this work and data analysis will be conducted using the program NVivo. However, results presented here represent preliminary findings of the first two focus groups.

Results: Participants were aged 28-67 years and were experiencing mild to severe lymphoedema. Women expressed significant frustration with their lymphoedema, in particular were "frustrated" at its chronic nature and 'frustrated' that "you can always see it, feel it and need to consider it in everything you do". Adherence to lymphoedema prevention guidelines prior to lymphoedema was varied, however, the majority were currently aware of the recommended 'dos and don'ts', with some women making significant lifestyle changes to adhere to the guidelines. Women explained physical activity as any activity undertaken throughout their day as well as planned activity (exercise). The impact of lymphoedema on daily lives ranged from 'mild' to 'profound' (with one woman being told she needed to change her profession) and was considered a barrier towards engaging in regular physical activity for some but not others.

Conclusions: More public education about the relationship between exercise and lymphoedema prevention and management will help women to overcome the exercise barrier of 'fear of lymphoedema progression'.