

Women's experiences of breast/truncal lymphoedema: a retrospective audit of case notes

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Introduction: A consistent increase in the number of women referred to one lymphoedema service, with symptoms of breast/truncal swelling following treatments for breast cancer (n= 2019 23.7% to 2022 n= 51.9%), led to a retrospective audit of case notes. Women attending the service reported similar negative experiences prior to referral. These included:

- A lack of information pre-treatment for breast cancer
- A lack of awareness post treatment
- Conflicting advice from health care professionals when symptoms of breast/truncal swelling develop.

There was often tremendous relief when symptoms were confirmed as breast/truncal swelling and not, for example, cancer recurrence.

Aims: To investigate women's experiences of breast/truncal swelling and highlight similarities. To understand what resulted in effective management of symptoms and reduced anxiety.

Method: A retrospective audit of the case notes of women with breast/truncal swelling were examined (2022 (n= 42), and January to March 2023 (n= 19)) to establish:

- Length of time from developing symptoms to referral to lymphoedema service
- Advice and information prior to referral
- Common themes reported.

Results: 42 case notes were inspected in 2022 and 19 in the first 3 months of 2023. More women had symptoms for weeks rather than months (41% compared to 34%) prior to referral to the lymphoedema service. 5 women (8%) had symptoms for more than a year before referral. Many of the women expressed anger and frustration at the lack of awareness of breast/truncal swelling amongst health care professionals and these emotions remained forefront in the women's minds. Treatments received at the lymphoedema service were, in almost every case Manual Lymphatic Drainage /Self Lymphatic Drainage, skin care and exercise. (Verbelen et al 2021). A small number were fitted with compression bras, but mostly women opted for comfortable bras as opposed to those with compression. In all cases the degree of breast/truncal swelling was maintained or improved, but the main outcome was the confidence to continue with self-management and improved coping strategies. There were no reports of the swelling worsening.

Conclusion: Anecdotal descriptions gleaned from case notes, served as a powerful reminder of the importance of acknowledging the potential emotional and psychological impacts of the side effects of breast conserving surgery, as much as the physical changes and symptoms. The findings of this audit confirm the need for further research into all aspects of the management of this type of swelling.