



Exploring patient perception of success and benefit in self-management of breast cancer-related arm lymphoedema



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ABSTRACT

Purpose: The aim of this study was to identify factors influencing patient perception of success and benefit with self-management of breast cancer-related lymphoedema (BCRL) and explore how patients decide whether their swollen limb has improved or deteriorated.

Methods: This qualitative study used a Grounded Theory approach. Twenty-one women in the BCRL self-management phase participated in one in-depth interview exploring their experience and perspective on self-managing their BCRL.

Findings: Seven enablers and blocks to self-management were identified: routine, recognising benefit of self-management and consequences of non-treatment, owning treatment, knowledge and understanding, problem-solving, time required for treatment and aesthetics of hosiery.

Women determined treatment outcome by monitoring size, appearance, texture and internal sensations within the affected arm.

Conclusions: Women who participated in this study showed varying degrees of acceptance and adjustment to life with lymphoedema. This appears to directly impact their ability to self-manage lymphoedema. Lymphoedema practitioners and oncology nurses have a valuable role providing knowledge and support to patients transitioning to independent self-care. A better understanding of factors facilitating patients to become experts in their condition may improve longer term outcomes and reduce cost pressures on lymphoedema services.

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1. Introduction

Lymphoedema is a common consequence of breast cancer treatment. It is conservatively estimated that around 20% of women undergoing axillary node dissection, and 6% undergoing sentinel node biopsy, will develop arm swelling at some point (DiSipio et al., 2013). The impact on the survivor is significant as breast cancer-related lymphoedema (BCRL) is not merely a physical problem of increased arm size and symptoms such as ache and heaviness, but

has many associated practical challenges related to daily living (Carter, 1997; Ridner, 2005; Fu, 2008; Radina, 2009; Ridner, 2009; Burkhardt et al., 2014). BCRL also causes considerable psychological distress as it alters body image and acts as a visible reminder of breast cancer and its treatment (Tobin et al., 1993; Curtis, 2006; Vassard et al., 2010; Fu et al., 2013).

Lymphoedema treatment generally comprises skin care, exercise, compression and manual lymphatic drainage (MLD). The initial intensive decongestive phase is followed by a maintenance phase of self-management (Lymphoedema Framework, 2006; International Society of Lymphology (2013)). The aim of treatment is to return the limb to as near normal as possible and prevent deterioration and development of complications such as skin thickening, fibrotic tissue changes, cellulitis, increased skin folds and hyperpigmentation (Lymphoedema Framework, 2006; Oremus

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et al., 2012; International Society of Lymphology (2013)). Life-long self-management is necessary to control lymphoedema as the underlying problem of reduced lymph drainage capacity cannot be rectified (Foldi and Foldi, 2012; International Society of Lymphology (2013)). In the UK, the self-management phase comprises compression armsleeves worn daily with a glove or gauntlet as appropriate, skin care, self lymphatic drainage massage (SLD) and exercise to promote lymphatic and venous return (Lymphoedema Framework, 2006).

Adherence to lymphoedema self-management activities is essential for achieving and maintaining successful treatment outcomes (Fu, 2005; Foldi and Foldi, 2012). However, there is no agreement regarding what constitutes a good treatment outcome. Poor adherence to recommended self-management may include neglecting aspects of self-management, such as insufficient use of compression garments, and failure to attend booked appointments. The little published information regarding adherence to BCRL self-management reports variation in adherence and compliance rates (Ridner et al., 2011; Jeffs and Wiseman, 2013; Brown et al., 2014). A better understanding of the issues surrounding patient adherence to lymphoedema management is needed.

Fu (2005) found that intention to engage in BCRL self-management was related to how women perceived lymphoedema, its consequences, and their ability to prevent deterioration of swelling and to accept and integrate treatment into their daily life. However, it is not known which factors most contribute to individual perception of improvement or deterioration in symptoms, or how women decide whether their treatment is effective. With increasing emphasis on assisting patients to self-manage their health (Davies and Batehup, 2011), there is a need to identify how patients monitor and perceive changes to their swollen limb, and how these perceptions relate to adherence to prescribed BCRL self-management.

The aim of this study was to explore improvement and deterioration in arm BCRL from the perspective of those affected by it, and to understand how these perceptions and other factors influence decisions to perform recommended lymphoedema self-management.

2. Method

2.1. Study design

A qualitative research design following Grounded Theory methodology was used (Corbin and Strauss, 2008). This systematic qualitative approach to data collection and analysis used the knowledge gained about living with and managing BCRL to move from descriptors of experience to developing a conceptual understanding of how women undertake and develop their approach to recommended BCRL self-management. Data collection entailed one off in-depth interviews exploring the experience and perspectives of women self-managing arm BCRL. It was envisaged the research approach adopted would generate clinically relevant findings to guide professional practice. Fig. 1 shows the flow of participants through the study.

2.2. Selection of participants

Participants were recruited from three lymphoedema clinics in London: two hospital-based and one hospice-based lymphoedema service. A sample of 25 participants was sought as it was believed this would be sufficient to reach data saturation, the point at which no new information is obtained (Corbin and Strauss, 2008). In accordance with principles of Grounded Theory, criteria for sample selection were refined as the study progressed in order to explore

emerging strands of interest and check findings across particular groups, for example, parents of young children, individuals from Black and Minority Ethnic groups, and individuals known to be struggling with lymphoedema self-management or non-adherent to treatment.

People eligible to participate in the study were men and women aged 18 years or older with arm BCRL, who had been in the self-management phase of BCRL treatment for a minimum 6 months. They were excluded if unable to communicate verbally unaided in English. Individuals with active disease were eligible for the study; none chose to participate.

One hundred eligible people at participating sites were approached by lymphoedema practitioners and informed about the study; they were given a study invitation letter, participant information sheet with contact details for the Researcher (EJ), and a stamped addressed envelope to return a form registering their interest in participating. Thirty three women responded to the invitation letter and were screened by the Researcher (Fig. 1); no men chose to participate.

2.3. Data collection

Interviews were conducted in a quiet room at participating sites ($n = 16$) or at the Researcher's hospital ($n = 5$). Participants were interviewed once for approximately 1 hour. Interviews were guided by a supporting interview schedule comprising a series of prompts regarding the experience of lymphoedema self-management, changes in BCRL symptoms, and perceptions of arm swelling.

Interviews were digitally audio-recorded and field notes written immediately following interviews to aid analysis. Interviews were transcribed semi-verbatim by a transcription service, leaving out background noises but including filler sounds (um, er), repetitions and descriptors (e.g. laughingly, pauses). Completed transcripts were checked for accuracy against the original recording by the Researcher (EJ).

Demographic and clinical data regarding severity of swelling and prescribed lymphoedema self-management were collected from participants' lymphoedema clinic notes by the Researcher (hospice only) or clinic staff.

2.4. Data analysis

Data collection and analysis ran concurrently incorporating constant comparison, a key component of Grounded Theory (Corbin and Strauss, 2008). Initial, and then more focused, coding broke data down into named component parts. These codes were grouped into larger subcategories and categories to formulate concepts which were discussed in subsequent interviews. Analysis of early data helped determine ongoing lines of questioning and the optimal individuals to recruit. The interview schedule was modified over time.

The Researcher (EJ) analysed transcribed interviews. Another research team member with expertise in Grounded Theory (TW) undertook early open coding and exploration of findings and supervised the analysis process. Summaries of emerging findings were circulated by email to the research team for discussion, leading to more detailed questioning of the data and further refinement of the analysis.

2.5. Ethical approval

Approval was obtained prior to commencement of recruitment from the National Research Ethics Service (NRES Committee London—Surrey Borders, reference: 12/LO/0930) and the Research and Development departments at each participating site.

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