Living With Breast Cancer–Related Lymphedema: A Synthesis of Qualitative Research

Marion Burckhardt, MSc, RN, Marion Belzner, MSc, RN, Almuth Berg, MSc, RN, and Steffen Fleischer, PhD, RN

Lymphedema of the arm is one of the most common symptoms following breast cancer treatment (Pinto & de Azambuja, 2011), affecting every area of women’s lives. Lymphedema is mainly caused by procedures such as axillary lymph node dissection or axillary radiation (Shah & Vicini, 2011), which are associated with an accumulation of high-protein lymph fluid in body tissue that leads to swelling, chronic skin alterations, fibrosis, and functional impairment in the arm or upper body.

The incidence of breast cancer–related lymphedema (BCRL) varies depending on the kind of treatment received. The risk is estimated at around 2% when lumpectomy has been carried out in isolation and increases to as much as 65% when more extensive surgical techniques or radiation therapy are required (Shah & Vicini, 2011). The routine use of sentinel lymph node biopsy and modified treatment options has reduced the occurrence of BCRL (Morrell et al., 2005), but for the women concerned, it still means a considerable loss of quality of life (Pusic et al., 2013).

Women with breast cancer are at risk of developing lymphedema for the rest of their lives, and a distinct possibility remains that it may occur beyond the first year of treatment (Armer & Stewart, 2010), a time when the woman will have overcome an exhausting period of her life and, if no symptoms of cancer are apparent, may view life more optimistically. Specific research findings reveal many problems associated with BCRL, including pain, depression, and anxiety (McWayne & Heiney, 2005; Ridner, Bonner, Deng, & Sinclair, 2012). In comparison to who did not go on to develop lymphedema, women who did so experienced a much poorer quality of life (Ridner, 2005). Although a systematic search in relevant databases (e.g., the Joanna Briggs Institute, MEDLINE®, CINAHL®) included reviews focusing on the health-related outcomes of women with breast cancer, no systematic review of qualitative research exploring the particular experience of living with lymphedema after breast cancer treatment was found. Bringing together these perceptions of the women’s experience, by adhering to the nature of the qualitative approach, could benefit healthcare practitioners by offering a greater understanding of the phenomena and its complexities.

Therefore, the aim of this synthesis is to gain comprehensive insight into the experience of living with BCRL by aggregating the findings of available qualitative research in this field. In line with a pragmatic approach, could benefit healthcare practitioners by offering a greater understanding of the phenomena and its complexities.

Purpose/Objectives: To describe the experience of female patients living with breast cancer–related lymphedema (BCRL) to gain a comprehensive understanding of this experience. The review is designed as a qualitative meta-synthesis.

Data Sources: Electronic searches were conducted in MEDLINE®, CINAHL®, EMBASE, PsycINFO, and Social Sciences Citation Index. Articles were included where researchers used qualitative research methods and when a comprehensive description of methods and the study’s findings were provided.

Data Synthesis: From 2,185 references, 13 articles were included. A total of 94 author and participant aggregations were extracted, qualitatively assessed, and assigned to one of 14 categories. Four themes relating to the experience of living with BCRL were identified: experience of everyday life, energy sapping, personal empowerment, and contribution of others.

Conclusions: Requirements of living with BCRL may only be influenced to a limited extent by the women themselves. They struggle with their situation, appearance, and the concomitant uncertainties. They feel strengthened where they succeed in developing a helpful view of their situation and where support structures are available to them.

Implications for Nursing: Professionals can employ this meta-synthesis by contextualizing it as part of a process of critical reflection on their own endeavors to meet the requirements of women living with BCRL.

Key Words: systematic review; lymphedema; breast cancer; quality of life; nursing research; qualitative