

Understanding lymphedema self-care challenges for breast cancer survivors living in a resource-restricted community

Authors: Jane M Armer, Professor Emerita, University of Missouri Sinclair School of Nursing armer@missouri.edu; Nuha K. Wareg, PhD Candidate, University of Missouri Sinclair School of Nursing; Yuanlu Sun, Assistant Professor, University of Iowa College of Nursing; Natsayakarn Narkthong, PhD Candidate, University of Missouri Sinclair School of Nursing; Elizabeth A. Anderson, Assistant Professor, University of Missouri Sinclair School of Nursing; Allison B. Anbari, Assistant Professor, University of Missouri Sinclair School of Nursing; Miriam Sekyere, University of Missouri Sinclair School of Nursing

Introduction: Lymphedema, a frequent long-term effect of cancer treatment, is one of the major challenges for breast cancer survivors, especially in resource-restricted communities. Breast cancer-related lymphedema (BCRL)-associated chronic symptoms and related distress negatively impact functional ability, self-esteem, social activities, and overall health and well-being. Ghana has limited health resources, with only two certified lymphedema therapists in the entire nation at the time of this study. The International Classification of Functioning, Disability, and Health (ICF) framework considers the important contextual factors of environmental origins influencing individuals' functions. Within this framework, a person's self-care behaviours interact with attributes of the community. Thus, the survivor's BCRL self-care behaviours have a dynamic interaction with the environment.

Aims of Study: The purpose of this study was to examine the lymphedema self-care challenges in resource-restricted settings among breast cancer survivors living in Ghana.

Method: Semi-structured interviews were conducted with breast cancer survivors managing cancer treatment-related lymphedema in Ghana (N=9). Within-case and cross-case analyses were conducted with a constant comparative approach to generate themes and subthemes.

Results: Emerging themes from the data revealed both negative and positive aspects of BCRL. Negative aspects included: negative impact of BCRL on work; decreased quality of life; physical and emotional/psychological consequences of BCRL; and low level of BCRL awareness among clinicians and society. Positive aspects included: family and work support; believing in self-management; and emotional coping and acceptance. Overall findings included: (1) Breast cancer and lymphedema self-care challenged survivors financially through interrupting their work demands, productivity, and workability; (2) Long-term lymphedema self-care stressed survivors with limited workplace support; and (3) Lack of understanding of lymphedema from society impeded survivors from carrying out their daily self-care while functioning in social activities.

Conclusion: This study suggested significant challenges faced by breast cancer survivors living with lymphedema in Ghana, which could be attributed to several factors, including limited access to specialized care, workplace support, and societal understanding. There is a need for research and innovations that provide survivors with person-centered and culturally sensitive support for lymphedema self-management.