

The Experiences of Women with Lymphedema following Breast Cancer-related Treatment

Report of Funded Research Project
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Researchers:

Dr. M. Victoria (Vicki) Greenslade (PI) is a Nurse Educator at the Centre for Nursing Studies, St. John's, NL. She received her PhD in Higher Education from the Ontario Institute for Studies in Education of the University of Toronto (OISE/UT) where she studied under the mentorship of Professor Michael Skolnik who holds the William G. Davis Chair in Community College Leadership. Dr. Greenslade co-ordinates the Nursing Research Office at the Centre for Nursing Studies and is appointed to the Corporate Nursing Education/Research Council and the multi-disciplinary Evidenced-Based Practice Council at the St. John's Health Care Corporation. She also sits on the Nursing Research Unit at Memorial University School of Nursing. Dr. Greenslade has been involved with nursing education for more than twenty years, teaching in diploma-based schools of nursing as well as in the Baccalaureate (Collaborative) Program at the Centre for Nursing Studies. She has presented at numerous conferences over the years on a variety of nursing and nursing education topics.

Colleen J. House received a BN and M.Ed. from Memorial University. She has been involved in nursing education since 1988 and is presently a faculty member at the Centre for Nursing Studies in the Bachelor of Nursing (Collaborative) program in St. John's, NL. Colleen's practice background includes adult surgical nursing, cardiology nursing and gerontology. Her research interests include promotion of health for women with lymphedema following breast cancer treatment and women's experiences of breast cancer treatment. She is currently teaching courses in therapeutic communication and health promotion practices. Clinically she is working with first year students in a gerontology setting.

This study is co-sponsored and supported by the following grants:

General Hospital Health Foundation

Canadian Breast Cancer Foundation – Atlantic Chapter Research Grant

Canadian Nurses Foundation – Nursing Care Partnership Program grant from Canadian Health Services Research Foundation

This study originally intended to interview twenty-five (25) participants on the Avalon Peninsula of Newfoundland and Labrador about their experiences of living with lymphedema following breast cancer-related treatment. During data collection, it became evident that emerging themes were becoming repetitive and as a result, data collection ceased. At the same time, it was decided to expand this study by adding a second component that would include participants from

the remainder of the island and Labrador and complete a comparative analysis of the participants' experiences. Approval of the extension was granted by the Human Investigation Committee

Implementation of Part A: Participants living on the Avalon Peninsula

This study used a qualitative, descriptive approach to explore the experiences of women with lymphedema following breast cancer treatment. Data collection included taped, unstructured interviews of approximately 60-90 minutes duration.

This study used a purposive sample of thirteen (13) female participants. Acceptance into the study included: a) upper extremity lymphedema following breast cancer-related treatment, b) lymphedema for at least one year, and c) no current evidence of cancer disease or cancer recurrence.

Thematic analysis identified five major themes: 1. Always There; 2. Yearning for Normalcy; 3. Continually Searching; 4. Emotional Impact; and 5. Dismissed and Abandoned. Subsumed within each of these were sub-themes articulating various components of each theme. Participants described their lymphedema as a constant in their lives. They continuously searched for a return to normalcy. Participants expressed an array of emotions from frustration and anger at the health care system to helplessness, hopelessness, and resignation to their situation. They feared abandonment and the absence of or lack of continuity with follow-up care created increased stress and anxiety. The essence of Existential Aloneness was apparent in the true inner nature of the everyday existence of these women with Lymphedema.

Participants' dissatisfaction with the continuity of follow-up breast cancer care in this study clearly indicated the need for nurses to assume leadership roles in providing for continuity of immediate and long-term physical, psychological, and emotional follow-up care for women having breast cancer treatment. Participants suggested the need for accessibility to a breast cancer care expert and most participants suggested that a nurse would best provide this care.

The following recommendations were made:

- Nurse-led inter-disciplinary teams need to be established to provide care for women with lymphedema.
- Breast health nurse clinician/educator positions need to be established to provide long-term follow up care to women having breast cancer treatment and to be accessible to women and their physicians to provide more consistent information regarding the care of lymphedema.
- Nurses need to teach women how to assess and monitor themselves for developing signs of lymphedema following breast cancer treatment.
- Nurses need to assume a leadership role in the education of other members of the health care team to have lymphedema recognized as a serious long-term complication of breast cancer treatment.

- Nurses need to take an active role by working with communities to help develop and provide community resources to empower women with lymphedema.

Dissemination of the Study:

Memorial University of Newfoundland School of Nursing’s Nursing Research Day, October 5, 2002

Association of Registered Nurses of Newfoundland and Labrador, Annual Meeting, June 2003

McMaster University School of Nursing 10th Anniversary Nursing Research Day, October 16, 2003 (Won Best Poster Award)

Memorial University of Newfoundland Family Practice Department, October 21, 2003

Newfoundland Cancer Treatment and Research Foundation (NCTRF), November 6, 2003

Application of Research to Practice:

As a result of the dissemination to the NCTRF on November 6, 2003, a meeting was held to discuss the study’s recommendations. At the present time, a working committee has been struck to develop interdisciplinary practice guidelines for patients with lymphedema. Committee members are comprised of key stakeholders who are involved in cancer care.

Financial Update:

Data Collection and Transcriptions:	\$665.00
Literature Searches	\$860.00
Advertising	\$445.00
Professional Consulting	\$200.00
Poster Development	\$220.00 + another invoice to come
Conference Fees	\$250.00
Conference Costs/Travel	\$885.00

Total to Date: **\$3525.00**

Implementation of Part B – Participants Living in the remainder of Newfoundland and Labrador

To commence in January, 2004