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## The Impact of Breast Cancer-Related Lymphedema on Rural and Small-town Survivors' Return-to-Work and Quality of Life: A Multiple-Case Study

Allison B. Anbari, PhD, RN, CLT<sup>a</sup> [Assistant Research Professor], Yuanlu Sun, PhD, RN, CLT<sup>b</sup> [Assistant Professor], Sarah McCaffrey, PhD (c)RN, ANP-BC, AOCNP<sup>a</sup> [PhD Graduate Student], Jamie Morton, MSN, RN PhD<sup>a</sup> [Graduate Student], Jane M. Armer, PhD, RN, FAAN, CLT<sup>a</sup> [Professor Emerita]

<sup>a</sup>Sinclair School of Nursing, University of Missouri, Columbia, MO 65211

<sup>b</sup>College of Nursing, University of Missouri – St. Louis, St. Louis, MO 63121

### Abstract

**Background:** Breast cancer-related lymphedema (BCRL) is a lifelong condition. Millions who develop breast cancer are younger than retirement age and at a lifetime risk for developing BCRL. Rural and small-town survivors may face unique challenges in terms of access to health care and BCRL/survivorship resources. This multiple-case study describes how BCRL influences the work experiences and quality of life (QoL) of survivors living in rural and small towns in Missouri.

**Methods and Materials:** Thirteen survivors from rural and small towns in Missouri completed semi-structured interviews and a standardized QoL instrument. Cases were analyzed using in-vivo and open-coding techniques and constant cross-case comparative methods. Twelve of the 13 participants' data are synthesized into themes to represent an illustrative case. The 13<sup>th</sup> case is presented as a contradictory (rival) case.

**Results:** Four themes are represented within the illustrative case – multiple medical encounters; the development of self-care routines; the reciprocity of work/live activities, triggers, and adjustments; and rural/small-town cultural impact. Upon BCRL diagnosis, survivors received intensive treatments, eventually establishing self-care routines. Survivors identified strategies for working around their BCRL when completing work and home responsibilities. The contradictory (rival) case was more recently diagnosed and, as such, had not established self-care and coping mechanisms in the same way.

**Conclusions and implications:** Survivors alleviate BCRL symptoms and improve their QoL by establishing self-care strategies. This provides guidance for client-centered survivorship care-planning and occupational rehabilitation of rural survivors with BCRL. This study provides the foundation for developing information for rural survivors that supports mental preparation and coping skills for BCRL self-management.

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corresponding author Phone: 4173438604, anbaria@missouri.edu.

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**Ethical Approval:** This study was approved by the Institutional Review Board of the University of Missouri (IRB#2003958)

## Keywords

breast cancer survivorship; breast cancer-related lymphedema; rural health; return-to-work; qualitative methods

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## Introduction

Breast cancer-related lymphedema (BCRL) is a condition in which fluid and protein accumulate in the extravascular interstitial spaces that occurs after treatment for breast cancer (BC). BCRL is associated with swelling, feelings of discomfort and heaviness, functional limitation, disfigurement, psychological distress, and an elevated risk of recurrent infection.<sup>1,2</sup> In the Western world, 20 to 40 percent of the women who receive BC treatment may experience BCRL in their lifetimes.<sup>3,4</sup> There are approximately 3.8 million female BC survivors (survivors) in the United States (U.S.),<sup>1</sup> with a median age at the time of BC diagnosis of 63,<sup>5</sup> meaning millions of women who developed BC remain at the age for gainful employment. Women with BCRL who are working have a significantly higher incidence of cellulitis or lymphangitis and increased medical costs compared to those who did not develop BCRL.<sup>6,7</sup> Thus, for working survivors, BCRL is a chronic condition that influences their working life and socioeconomic status.

Twenty percent of the U.S. population lives in non-metropolitan counties.<sup>8</sup> Some 33% of Missouri residents live in rural counties and 99 of Missouri's 115 counties are rural.<sup>9</sup> Survivors living in rural areas have concerns that are similar to those living in non-rural areas.<sup>10</sup> However, rural survivors may also face additional difficulties regarding access to care, role adjustment, and mental health.<sup>11,12</sup> Furthermore, this is an underserved population at risk for developing complications from BCRL. Higher rates of obesity, later stages of BC diagnosis, and potentially limited access to surveillance for BCRL in rural areas all potentiate BCRL symptom burden.<sup>2,9</sup>

A limited number of studies have examined the effect of BCRL on survivors' work.<sup>13</sup> Results showed the detrimental effects of BCRL on women's work and career beyond the initial impact of BC in the long-term.<sup>13-15</sup> Previously, we also conducted an initial study investigating the work-related limitations created by BCRL.<sup>16</sup> We found that BCRL negatively influenced survivors' physical, emotional, and interpersonal functions and, in turn, had an impact on their work lives. However, the majority of participants reported living in more urban settings; most of the participants were highly educated, with education being a proxy for socioeconomic status; and most participants (11/13) reported adequate financial resources and having high levels of social support<sup>16</sup>. There might be disparity among socioeconomic groups with regard to work-return and quality of life (QoL) in the larger population than we were able to identify. As individual and environmental factors play important roles in returning to work and BCRL management, the survivors may face unique and additional barriers to successful work-return and BCRL self-management.<sup>17</sup> To understand these pervasive concerns in a more holistic way, we continued this project to study an additional population living and working with BCRL in a highly rural state.

The purpose of this multiple-case study was to describe how BCRL influences the work and life experiences of BC survivors living in rural counties in Missouri. How does living with BCRL in a rural county impact work-related activities and QoL in daily living? This project is one of the first to focus the underlying evidence that potentially connects BCRL and rural survivors' work-life experiences, QoL, and mental health.

## Material and Methods

### Design

A multiple-case study methodology was used to explore BCRL impact on rural and small-town survivors' QoL and ability to return to work. We employed a qualitative multiple case study method to examine how BCRL influences rural survivors' return-to-work and quality of life.<sup>19</sup> The multiple cases in the context of living and working with BCRL while residing in a rural or small town, are analogous to multiple experiments where each case consists of a "whole study" and each case's conclusions indicate how and why a particular proposition was demonstrated (or not). The findings from comparing and contrasting across subgroups provided evidence on what factors contribute to the positive and negative adjustments made by survivors.

### Conceptual Framework

Our interview protocol was guided by the International Classification of Functioning, Disability, and Health (ICF) provided by the World Health Organization.<sup>18</sup> ICF is a framework that explains how disease and disability are related. The ICF model delineates three levels of human function: 1) the body, 2) the whole person, and 3) the whole environment. The ICF model considers the influence of disease or disorders on an individual's participation in society and QoL. Our employment of ICF focuses on asking survivors to share their perspectives on how their environment, QoL, and work experiences have been influenced by their BCRL diagnosis, treatments, and ongoing self-management. After reviewing the relevant literature,<sup>13</sup> systematically and synthesizing our preliminary findings,<sup>14,16</sup> we structured interview questions based on each concept and the relationships of concepts represented in ICF (See Appendix).

### Data Collection

Approval was obtained from the University of Missouri Institutional Review Board prior to conducting the study. The inclusion criteria were: 1) women diagnosed with BCRL; 2) diagnosed with BC at least 12 months ago; and 3) residents of rural counties in Missouri as defined by the Missouri Department of Health and Senior Service Rural Health report.<sup>9</sup> Current employment was not an inclusion criteria because we anticipated rural survivors having varying perspectives on what work is and entails. Rural survivors responded to flyers and email/telephone solicitations from the research team and each was given a \$30 gift card in appreciation of their participation. Data collection included the use of an investigator-developed demographic and clinical background information survey; the Short-form 36 Survey (SF-36) and a semi-structured, digitally-audio-recorded interview.

The SF-36 is a widely-used and publicly-available QoL assessment used to measure and monitor adult patient care outcomes.<sup>20</sup> It includes 36 items that are scored to measure QoL within eight health concepts: 1) limitations in physical activities; 2) limitations in social activities; 3) limitations in usual role activities; 4) pain; 5) mental health; 6) limitations in role activities related to emotional well-being; 7) social functioning; and 8) general health perceptions.<sup>21</sup> The SF-36 has been used successfully with BC survivors and has reliable psychometric properties.<sup>22,23</sup>

The interview guide included semi-structured questions, using probes to gain details and obtain meaningful information from open-ended questions. Questions in the guide addressed the following categories: 1) work demographics: work content, demands, and meaning to individual; 2) BCRL-related changes: structural changes, physical functional impairment, and emotional and interpersonal changes; 3) work-related outcomes: engagement, retention, work ability, performance, and interrelationship; and 4) environmental characteristics: micro- to macro-level: family/friends support; workplace support; and society-policy-system support. The interview guide also allowed for final reflections on the experience of living with BCRL and what has been learned in the process. The interview protocol was a revised and advanced version of the one used for previous work completed by Sun et al. (2020), which was developed based on the framework of ICF,<sup>18</sup> our preliminary literature review,<sup>13</sup> and reflections on earlier interviews.

## Data Analysis

After reviewing the informed consent, data were collected during private one-on-one, semi-structured interviews conducted in-person by author AA (n=8) or via Zoom web-conferencing (n=5; authors AA and JM, n=3; JM n=2). Participants who participated by Zoom either emailed or mailed the paper forms to the research team. Each interview lasted between 40 and 70 minutes. Data collected from the demographic form and SF-36 survey were transcribed into a spreadsheet using only the participant identification numbers. The SF-36 scores for each subcategory were scored using the methods recommended by Rand Corporation.<sup>20</sup> We used the qualitative software Dedoose (Version 8.03.43, 2020) to analyze the interview transcripts and improve communication across our team. First-level coding was completed independently by author SM with cross-checking and input from author AA using in-vivo and open-coding techniques.<sup>19,24</sup> Second-level coding included the use of axial coding and explanation-building where the process by which outcomes occur was explored thoroughly. Authors AA, SM, and JM participated in the second-level coding and subsequent case descriptions. Each kept reflexive memos throughout the coding process. Finally, the entire author team used constant case synthesis methods per case study methodology to describe themes that represent an illustrative case, as well as a contradictory (rival) case.<sup>19,24</sup> Triangulation was achieved through monthly team meetings where coding strategies and conflicts or questions were addressed.

## Results

### Case Context

The demographic information was described using Excel and can be found in Table 1. Table 2 includes the SF-36 subcategory information. We interviewed 13 women living with BCRL in small town/rural areas of Missouri (median age = 65 years; median years living with BCRL = 9 years). At onset of the study, the sample size was anticipated to be from 6 to 15 participants. The total final sample size of 13 participants aligned with how informative and predictable the cases were becoming and with data saturation. Sample characteristics are described in Table 1. All participants were white and seven of the 13 (53.8%) had completed college or graduate degrees. All the participants lived in rural counties as defined by the Missouri Department of Health and Senior Services Rural Health Report.<sup>9,25</sup> SF-36 subcategory/health concept scores are presented in Table 2. Most subscale category scores averaged > 50, indicating an overall more positive health status which was supported by the qualitative interview data. To note, the subcategory of “role limitation due to physical health” averaged < 50 and lower than the other subcategory average scores. Participants answered according to their current QoL and were encouraged to complete the SF-36 keeping their entire health in mind (including co-morbidities). We attribute the lower subscale average for the subcategory “Role limitations related to physical health” to six of 13 participants reporting co-morbidities that could contribute to issues with role fulfillment.

### Illustrative Case (Cross-Case Synthesis)

To explore the phenomenon of having BCRL while living in a rural/small town and its impact on work and QoL, 12 of the 13 participants’ interview data were synthesized into four main themes: medical encounters, self-care routines, reciprocity of work /life activities, and rural town culture impact. The 13<sup>th</sup> case is presented as a contradictory/rival case.

**Medical encounters** —Participants experienced a flurry of medical encounters to be diagnosed with BCRL. They reported consistent symptoms such as swelling, redness, and pain which led them to seek medical attention. *“I kept going to the doctor and they’d just give me a treatment and nobody ever really said anything about it...And so, it was really in the 2010s when it (BCRL) was kind of identified by my primary doctor as, you know, a side effect ... of my initial breast cancer.”* Another participant shared that the swelling under her arm “felt like a balloon.” For one participant, the diagnosis process meant ruling out a blood clot and, for another, treatment of cellulitis. Participants reported not knowing exactly what their risk for developing BCRL and ended up seeing their primary care physicians or oncologists and then being referred for physical therapy. Initially, participants had more intense treatments, such as manual lymphatic drainage and compression wrapping carried out by lymphedema therapists. It was at this time they were educated about self-care practices. As one participant says, *“When I first found somebody that knew what I was talking about and treated it (BCRL) (laughs). She had people that worked for her and they did the actual massage and taught me how to do it. And I forget how long I went to that office, probably about two or three months.”*

**Self-Care Routines**—Participants shared about the process of developing self-care routines, including wearing compression garments and manual lymphatic massage, to stabilize the burden of their symptoms. As one participant told us, “*Every morning from 6 to 7, I do what I call my treatments. I have an (intermittent pneumatic compression device) that I got from my massage therapist.*” These routines eventually balanced with their work and life roles and responsibilities to become sustainable. Self-care routines also acclimated or plateaued to a tolerable level. “*Mostly I do it (self-massage) every day in the shower and that seems to work really well for me.*” Access to care was not an issue as much as hypothesized, given that the majority of our sample lived outside of a metropolitan area, but commuted daily to work or were accustomed to driving. The commute for BCRL treatment was not fleshed out as a barrier or deterrent to BCRL care. “*There’s lots of travel involved, but we live in (small town) so we know we’re going to have those travel issues.*”

**Reciprocity of Work/Life Activities, Triggers, and Adjustments**—Participants were cognizant of the work and life activities that would trigger their BCRL symptoms. So much so, that they were able to adjust or increase their self-care accordingly. “*So, like moving Christmas boxes down...from the attic down, and then the next day I would notice that I’d be a little swollen and I would do my exercises or wear my sleeve.*” Another example of adjusting self-care was told to us by the same participant who used her compression device before work every day. After a long vacation, she increased her sessions to twice-daily because she preferred not to use the compression pump on vacation.

The reciprocal relationship between work/life activities and BCRL symptoms was also true. Work/task adjustments were made, so as not to exacerbate BCRL symptoms. Only two of our participants discussed switching job titles altogether. Other work/task adjustments for the rest of our participants were more subtle or nuanced, such as one participant who simply stated, “*Just reaching for stuff, I always use my other arm.*” Another participant acknowledged that she “*write(s) right-handed, so I’m using the phone left-handed. You know, I do a lot of typing and there’s... no way around it (using arm with BCRL; BCRL exacerbation) ...*”

**Rural/Small Town Cultural Impact**—There were components of a rural/small-town culture that facilitated reaching a balance of BCRL symptom burden and self-care. Fortunately, the rural characteristic of self-reliance was seen in our sample as an advantage to BCRL self-management. The symptom burden of BCRL was more understated and couched in phrases like, “*It’s (BCRL) not that bad*” and, “*Life just goes on*” and “*Least of my worries.*” Participants frequently described their self-reliance and independence in conjunction with the way they coped with their BCRL. BCRL became something participants managed, but not something they dwelt upon. Example excerpts of the phenomenon are, “*Breast cancer doesn’t own me and neither does my lymphedema.*” Another participant also concluded, “*Some things I can’t control. How somebody’s going to react to my appearance is not anything I have control over.*”

### Contradictory (Rival) Case

Of the 13 participants, one participant, pseudonym Emily, presented as a contradictory case, or outlier, providing interview data that differed from the other 12. Emily's experience with BCRL was different enough to, first, be discussed/analyzed separately, and, second, to support the synthesis of the remaining 12. Emily was age 59 years at the time of the interview. She reported adequate finances and had Medicaid and private insurance. She lived with family and had good social support. Emily had seven lymph nodes removed during surgery and underwent chemotherapy and radiation treatments. Similar to the other 12 participants, Emily also experienced a flurry of medical activity to be diagnosed and treated for BCRL. Likewise, she did not know about her risk factors for developing BCRL. Emily was on disability because of knee pain at the time of her cancer diagnosis however she discussed role adjustments in a similar way to how other participants discussed theirs. She pointed out that her family roles as a wife and guardian of her three grandchildren were now more difficult, how she and her husband had been adjusting those roles, and the impact BCRL had on them (e.g. child care and grocery shopping are now much more difficult). However, she had not established the self-care balance and normalization that the other 12 participants had. Compared to other cases, Emily was more recently diagnosed with BCRL (less than 6 months with a BCRL diagnosis; BC diagnosis 2 years ago). Emily became tearful during the interview and was not as confident as the other participants in her ability to manage her arm swelling and pain. She was unsure of her ability to correctly don and doff her compression garments, even though she admitted to having been shown how by physical therapists. "Having to wear this thing (*compression garment*) for the rest of my life doesn't sound like a fun thing, to be honest, and it is a pain in the butt to put on." Emily's struggle with BCRL in these early stages contrasts the seemingly successful coping strategies demonstrated by the other 12 participants. Emily's discussion of BCRL is also testament to how burdensome a BCRL diagnosis can be initially, if not indefinitely.

### Discussion

Our ability to delineate between explanatory cases (illustrative) and a contradictory (rival) case complements the findings from Sun et al. (2020) by adding additional contextual clues to BCRL management, work, and QoL. Sun et al. found that women with BCRL highlighted the loss of control found with a BCRL diagnosis. Furthermore, survivors with BCRL often express frustration and psychological burdens when managing the chronic condition of BCRL.<sup>26</sup> Participants in our explanatory cases focused more on what they could control and used that power/"gumption" to normalize and find balance. Loss of control was more subtle with these participants and work/life adjustments occurred over time without being dwelt upon. Our contradictory case spoke openly about the struggles and uncertainty she and her family were experiencing with the new BCRL diagnosis.

Study participants clearly spoke to the BCRL diagnosis as a burden that they navigated, mostly successfully. The burden could be more significant for some individuals adding on to their existing responsibilities, such as our contradictory case. Current recommendations highlight the importance of prospective surveillance for the signs and symptoms of early BCRL.<sup>27-29</sup> Early interventions such as compression and self-massage can be initiated

before BCRL signs and symptoms worsen to the point where BCRL negatively impacts work/life responsibilities and QoL. Likewise, early education and risk-reduction strategies are also recommended for survivors at risk for developing BCRL.<sup>27–29</sup> Our participants benefitted from seemingly directive education and self-management instructions. They adapted those instructions to meet their needs and to decrease the burden of BCRL.

The ICF model continues to be applicable to our work, especially the idea that health and disability do not exist in absolutes, but rather on a continuum.<sup>18</sup> The results of SF-36 showed role limitation associated with functioning impairment could be a more significant concern than physiological limitations, which is consistent with ICF model's illustration that chronic conditions effect the triad of “body structure and function,” “activities,” and “participation.” We also found the learning curve and coping strategies, as participants navigated their chronic condition, could extensively balance or normalize the limitations. Thus, it is important to implement client-centered survivorship care-planning and occupational rehabilitation of survivors with BCRL. Besides personal factors, ICF also describes that disability status depends on important environmental origins. Rural town resources and cultures serve as unique contextual factors to survivors' return-to-work journey with lymphedema care.

Our findings demonstrate that the rural small-town environment may have had two side effects on participants' journey with BCRL. The somewhat disjointed access to medical resources may have led to the flurry of medical encounters (e.g. oncology care in a metropolitan area nearby, coupled with primary care in their small town). In previous studies, limited awareness and knowledge of BCRL among clinicians was identified as one of the major barriers for adjustment to return to work while managing lymphedema.<sup>16</sup> The challenges in searching for information about BCRL and seeking diagnosis and treatment seems more evident in rural areas. On the other hand, the survivors in our study presented strong characteristics of self-reliance which is essential in developing self-care skills. This is similar to other work that has found that rural dwellers appear to have better diabetes self-care than their nonrural counterparts.<sup>30</sup> Our participants showed positive attitudes and high levels of resilience towards the chronic condition of BCRL. Fortunately, our sample benefitted from the behaviors/attitudes of independence and self-reliance. Admittedly, these characteristics could be detrimental if taken to the other extreme (e.g. denying that the condition is chronic and must be managed daily). Providers can perhaps harness the rural cultural components of independence and self-reliance in a positive way to benefit survivors' BCRL self-management, improve their QoL, and maintain their work/life roles and responsibilities.

## Limitations

The majority of our participants had been living with BCRL for a period of time, allowing them to develop coping mechanisms that seemed to offset the burden of BCRL. Results may have differed had we sampled more newly-diagnosed participants. There is also an element of self-selection to study participation, i.e., perhaps only those who were doing well agreed to talk about how they were doing. In our future studies, we plan to examine more about the time that survivors might take to adapt to their BCRL diagnosis and treatments; and the



time it takes to develop self-management strategies that are sustainable. We will continue investigating this process as it relates to medical support. An additional limitation of our work here is in the homogeneity of our sample. Our research team has conducted similar studies with Latina women and women living in Ghana. Findings from these studies will help to create a better understanding of work/life balances and QoL while living with BCRL.

## Conclusions

Through this multiple-case study we were able to add to what is known about BCRL and work/life experiences and perspectives, specifically those of survivors living in rural and small-towns. Our illustrative cases present a somewhat ideal scenario of survivors surviving and thriving with this chronic BCRL condition. Our rival case challenges that ideal and calls attention to how detrimental a diagnosis of BCRL can be. Both of these cases inform our future work in creating early and meaningful interventions for survivors at-risk for or diagnosed with BCRL. For example, developing tailored education programs to enhance the awareness and knowledge of BCRL among the public and improving health services to optimize the related medical access in the rural community are targets for further research and clinical practice.

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## Appendix

### Example of Semi-Structured Interview Questions

How do you describe your overall health now?

Tell me a little bit about how you learned you had lymphedema. What happened? What do you believe caused it?

Describe the current work that you do – how long have you been in this field? How long is your commute? Talk to me about your typical work day. What hours do you work? What are the physical demands?

What type of work were you doing prior to your breast cancer diagnosis? Tell me about the hours you worked, the physical demands, etc.

What about your work after your diagnosis of lymphedema? What changed?

How does lymphedema affect your ability to carry out any physical tasks your work requires?

Tell me a little bit about how your lymphedema affects your confidence or self-esteem? What about your mood or emotional well-being?

Describe to me how you process or cope with your work place demands that might be affected by your lymphedema. Have you tried coping mechanisms that were more successful than others?

If you were to advise newly diagnosed women, what suggestions or advice would you give them?

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**Table 1.**

## Context of Cases

Context of cases	Description (N=13)
Demographic characteristics	
Age	52-78 (median 65), <65 years (38%, 5/13)
Ethnicity	White (13/13)
Education	college (7/13)
Number of persons living in household since LE diagnosis	1 (1/13), 2 (7/13), 3 (4/13), 4 (0), 5 (1/13)
Marital status	Married (11/13), Divorced (1/13), Never married (1/13)
Household financial status	Extremely adequate (9/13), Somewhat adequate (4/13)
Level of social support <sup>*</sup>	High (7/12), Above average (3/12), Average (1/12), No support (1/12)
Disease-related characteristics	
Breast cancer survival time	2 years - 25 years (median: 12 years)
Time with LE	5 months- 20 years (median: 9 years)
LE on the dominant side	5/13
Initial LE detection	Self-detection, sought medical diagnosis (6/13)
	Detected by nurse, physical therapist, occupational therapist, or other clinicians (7/13)
	Specialist follow-up (2/13)
	Primary care follow-up (1/13)
	Breast cancer study participation (1/13)
Cancer treatment types	Surgery (13/13): lymph node removal (11/13) <sup>**</sup> , mastectomy (10/13), lumpectomy (4/10) <sup>***</sup>
	Radiation (11/13)
	Chemotherapy (12/13)
Symptoms of LE	Swelling (13/13), heaviness (9/13), upper extremity weakness (7/13), sensation alteration (9/13: e.g., numbness, firmness, stiffness, aching) and cellulitis-related symptoms (5/13: e.g., redness, blistering, increased upper extremity temperature)
Employment characteristics	
Occupation type <sup>****</sup>	Professional/white-collar (11/13), Blue-collar (5/13), Retired (2/13)
Change of occupation <sup>***</sup>	Stayed the same (4/10), Changed to other (6/10)
Change of working hours after LE	Significant reduction of work hours (3/13)
Restriction to work duties	Restriction to some duties and needed workplace modification (3/13), No restriction (9/13), Not working due to disability (1/13)

LE: lymphedema; BC: breast cancer;

\* denominator = 12 as one participant did not provide an answer

\*\* 2 participants did not specify number of nodes; 3 participants answered this question by stating "all"

\*\*\* denominator = 10 as 3 participants did not provide an answer to this question

\*\*\*\* numerator total is 18 (i.e. greater than n of 13) as participants were allowed to select >1 response

**Table 2**

## SF-36 Quality of Life Subcategory Results

SF36 Subcategory	Participant Score Range	Group average	Group Median	Standard Deviation
Physical functioning	10 - 100	58.65	65.00	27.08
Role limitations due to physical health *	0 - 100	41.67	37.50	41.25
Role limitations due to emotional problems *	0 - 100	80.56	100.00	33.21
Energy/fatigue	15 - 85	60.38	60.00	17.13
Emotional well-being	64 - 100	80.85	80.00	11.13
Social functioning	50 - 100	79.81	75.00	18.78
Pain *	10 - 100	57.71	62.50	31.27
General Health	35 - 85	62.69	70.00	17.60

\* One participant did not provide answers to any questions in this subcategory, so was not included in group average. Median = 100 as 8 of 12 participants answering this subcategory scored exactly 100.

Note: SF-36 subcategory scores range from 0-100, with higher scores defining a more favorable health state