Status of Benghazi women's experiences with Breast cancer–related lymph oedema

Dhandapani Premkumar,* Momen Abdou Alkhir,* Premkumar Remya,**
Mahmoud H. Milad,***

Abstract:

Objective: One distressing health problem facing breast cancer patients is breast cancer–related lymph oedema (**BCRL**). This incurable condition can occur many years after treatment is completed and often causes pain and disability and interferes with work and activities of daily living.

Design: A focus group and 15 individual in-depth interviews.

Setting: Hawari Radiology Centre and Shifa Rehabilitation Centre.

Participants: A diverse sample of 22 women with BCRL was obtained using age, location, time after breast cancer diagnosis, and onset of BCRL symptoms as selection criteria.

Method: The focus group discussion guided development of a semi structured interview guide that was used for 15 individual interviews exploring women's experiences with BCRL.

Main Findings: Four themes emerged from the interviews. First, participants thought they were poorly informed about the possibility of developing BCRL. Eleven women reported receiving very little or no information about BCRL. Second, triggers and symptoms varied. They reported a variety of both aggravating and alleviating factors for their symptoms.

Conclusion: Participants were unaware of the risk factors and treatment options for BCRL. Family physicians should discuss BCRL with their breast cancer patients routinely. They should be vigilant for the possible onset of BCRL and, if it is diagnosed, should manage it aggressively to minimize the severe effect it has on the lives of breast cancer patients.

Introduction:

Breast cancer is the most common malignancy in women, with around 259 new cases diagnosed in the Benghazi Hawari Radiology Centre (Libya) from November 2006 to May 2007.[1] One of the most distressing of the long-term health problems facing breast cancer patients is breast cancer–related lymphedema (BCRL). This incurable condition can occur many years after breast cancer treatment has been completed.[1]

Breast cancer–related lymphedema is a serious condition that often causes pain and disability and can predispose patients to life-threatening complications, such as cellulites and, very rarely, lymphangio sarcoma.[3,4,39]

Patients at risk of BCRL are those who have received radiation therapy or axillary node dissection; higher incidence is reported among patients who have received both radiation and dissection, particularly if either treatment was extensive (Table 1).[8,9]

Some additional risk factors for BCRL include poor nutritional status, obesity, delayed wound closure, and postoperative infections.[3,8,10,39]

Diagnosis:

Diagnostic criteria for BCRL vary, as do recommended treatments and their efficacy.[3,11,39] The lack of consensus on the diagnostic criteria and appearance of BCRL, even 30 years after cancer treatment, have led to an estimated incidence of 6% to 70%.[4,12] A review of the literature suggests that prevalence rates of 15% to 30% are reasonable.[9]

Table 1: Treatment-related risk factors for breast cancer-related lymphadenopathy.

Surgery, Radiation therapy, Extensive axillary node dissection
Nodal status, Radiation therapy plus axillary node dissection (markedly increase risk)

*) Teaching staff, Faculty of Public Health, Al-Arab Medical Sciences University, Benghazi, Libya.
**) Physiotherapist, Private Practice, Benghazi, Libya.
***) Teaching staff, Faculty of Medicine, Sebha University, Radiology department, Sebha, Libya.

Treatment:
Treatment of BCRL is controversial, and various treatment options have been proposed including manual and sequential pneumatic lymph drainage, compression garments, prescribed exercises, ultrasound therapy, and more recently, liposuction, selenium, and laser treatment.[4,12-14,39]
The authors found that primary health care professionals were not aware of important issues associated with prevention and management of this condition.[21]

Table 2: Advice for patients at risk of breast cancer-related lymphedema.

Avoid blood pressure measurements, venipunctures, or injection in the ipsilateral arm, Avoid trauma (e.g.; Scratches, burns) Maintain scrupulous hygiene, Treat skin infections immediately Maintain ideal body weight, Be careful in hot environments Be cautious about air travel

Our study was designed to document, from the perspective of BCRL patients, the effect of BCRL on Benghazi women's lives in terms of physical and psychosocial health and patients' perspectives on availability of information and access to treatment. We believe they would be similar to findings in other largely rural areas with limited medical resources across the country.

Method:
Setting:
There are 22 Patients participated in this study. We conduct our Questionnaire Interview in Hawari Radiology Centre and Shifa Rehabilitation centre .During our interview sessions we followed all our human ethics and privacy.

Data collection:
We recruited 22 Benghazi regional women to take part in the study. Women with recurrent disease were excluded. A diverse sample was obtained using age, location (urban or rural), time after breast cancer diagnosis, and time elapsed since onset of BCRL symptoms as selection criteria (Table 3).

Table 3: Age of woman, years since diagnosis of breast cancer, and years since onset of breast cancer-related lymphedema (BCRL).

Women's Age (Y)	Years since Diagnosis of Breast Cancer	Years since Onset of Bcrl
60	7	7
39	1	1
41	6	1
41	6	6
70	19	18
60	3	1
63	6	3
65	5	5
70	5	1
44	5	5
52	2	2
60	2	2
52	1	1
52	6	6
61	13	5

Findings:
Four substantive themes captured women's experiences with BCRL: lack of information, triggers and symptoms, access to treatment, and effect on daily life.

Table 4:

Activities that exacerbate symptoms
Overuse of arm (5), Heat (4)
Not wearing compression garment (2)
Repetitive actions related to hobbies (2)
Repetitive actions related to aerobics (2)
Cold (1), Massage (1)
Lifting at work (1)
Lack of exercise (1)
Conditions that reduce symptoms
Elevation (8),
Wearing compression garment (6)
Exercise (5), Rest (4)
Cold (2), Massage (2)
Heat (1), Deep breathing (1),
Weight loss (1)

Discussion:

Breast cancer incidence has not changed markedly in recent decades, yet survival rates have increased. This has led to a corresponding increase in the number of women with BCRL.[30-32]

Our study indicated a lack of awareness of BCRL among breast cancer patients and health care professionals, which supports the findings of two earlier studies on patient information and knowledge of BCRL in primary care.[20,21]

There are only few physiotherapists in the entire Benghazi who are trained in BCRL treatment, including proper measurement techniques for compression garments. These physiotherapists are located in main centres, which limit rural women's access to them.

Physicians might want to use the information in **Table 4** for patient education. Summarizes some clinical practice guidelines.[39] If patients live in areas where access to physiotherapists is difficult, physicians might want to increase their efforts at patient education.

Psychosocial effects of BCRL:

Along with the trauma associated with a diagnosis of breast cancer and subsequent surgery and ancillary treatments, women with BCRL are further confronted with the psychosocial effects of BCRL. Our study has documented the severity of these effects on their daily lives.

Limitations:

We acknowledge there might have been a self-selection bias because participants who had experienced difficulties might have been more likely to come forward. We believe this does not take away from the issues discussed.

Conclusion:

We conclude that most of participants suffering BCRL due to lack awareness. Although additional research on BCRL is needed, family physicians are in a position to improve the care of women who have it. They should strive to provide more patient education and increase awareness of BCRL symptoms. They should also try to ensure that BCRL patients are referred to physiotherapists for rehabilitation and treatment and are provided with supportive counselling, if necessary.

Resources for proper management of BCRL in Benghazi are inadequate to serve the needs of breast cancer survivors. Our findings suggest that further research into primary care physicians' knowledge of BCRL is warranted.

Acknowledgment:

The authors would like to thank **Dr. P. Amanula**, Medical staff of the Hawari Radiology Centre and the Physiotherapy and Nursing staff of the Shifa Rehabilitation Centre, Benghazi, Libya.
Special thanks to **Dr. Soma Sekaram Potli**, Associate Professor in Anaesthesiology, The Great River Hospital for Ophthalmology.

References:

1. Breast cancer statistics. Hawari Radiology Centre, Benghazi, Libya, 2007.
2. Smith RA. Introduction: American Cancer Society workshop on breast cancer treatment–related lymphedema. Cancer 1998;83(12 Suppl):2775.
3. Petrek JA, Pressman PI, Smith RA. Lymphedema: current issues in research and management. CA Cancer J Clin 2000; 50(5):292-307.
4. Marcks P. Lymphedema. Pathogenesis, prevention and treatment. Cancer Pract 1997;5(1):32-8.
5. Glanz K, Lerman C. Psychosocial impact of breast cancer: a critical review. Ann Behav Med 1992;14:202-12.

6. Ferrans CE. Quality of life through the eyes of survivors of breast cancer. Oncol Nurs Forum 1994;21(10):1645-51.
7. Thomas-MacLean R. Victims, patients, survivors, women: experiences of embodiment after breast cancer [PhD dissertation]. Fredericton, NB: University of New Brunswick; 2001.
8. Ververs JM, Roumen RM, Vingerhoets AJ, Vreugdenhil G, Coebergh JW, Crommelin MA, et al. Risk, severity and predictors of physical and psychological morbidity after axillary lymph node dissection for breast cancer. Eur J Cancer 2001;37(8):991-9.
9. Kwan W, Jackson J, Weir LM, Dingee C, McGreggor G, Olivotto IA. Chronic arm morbidity after curative breast cancer treatment: prevalence and impact on quality of life. J Clin Oncol 2002;20(20):4242-8.
10. Stanton AW, Svensson WE, Mellor RH, Peters AM, Levick JR, Mortimer PS. Differences in lymph drainage between swollen and non-swollen regions in arms with breast-cancer–related lymphedema. Clin Sci 2001;101(2):131-40.
11. Kosir MA., Rymal C., Koppolu P., Hryniuk L., Darga L., Du W., et al. Surgical outcomes after breast cancer surgery: measuring acute lymphedema. J Surg Res 2001;95(2):147-51.
12. Brennan MJ, DePompolo RW, Garden FH. Focused review: postmastectomy lymphedema. Arch Phys Med Rehabil 1996; 77 (Suppl 3):74-80S.
13. Brorson H. Liposuction gives complete reduction of chronic large arm lymphedema after breast cancer. Acta Oncol 2000;39(3): 407-20.
14. Micke O, Bruns F, Mücke R, Schäfer U, Glatzel M, DeVries AF, et al. Selenium in the treatment of radiation-associated secondary lymphedema. Int J Radiat Oncol Biol Phys 2003;56:40-9.
15. Brennan MJ, Miller LT. Overview of treatment options and review of the current role and use of compression garments, intermittent pumps, and exercise in the management of lymphedema. Cancer 1998;83(12 Suppl):2821
16. Chau N, Harris S. Practices and opinions of physiotherapists treating patients with breast cancer–related lymphedema. Physiotherapy Can 2002 Summer;156-63.
17. Davis S. Lymphedema following breast cancer treatment. Radiol Technol 1998; 70(1):42-60.
18. Pain SJ, Purushotham AD. Lymphoedema following surgery for breast cancer. Br J Surg 2000;87(9):1128-41.
19. Passick SD, McDonald MV. Psychosocial aspects of upper extremity lymphedema in women treated for breast carcinoma. Cancer 1998;83(12 Suppl):2817-20.
20. Bosompra K, Ashikaga T, O'Brien PJ, Nelson L, Skelly J. Swelling, numbness a disablement process model perspective. Breast J 2002;8(6):338
21. Logan V, Barclay S, Caan W, McCabe J, Reid M. Knowledge of lymphoedema a questionnaire survey. Br J Gen Pract 1996;46(411):607-8.
22. Martin SM, Hanson C. The differences in body image between patients with and without lymphedema following breast cancer treatment. Occup Ther Ment Health 2000;15(2):49-69.
23. Hare M. The lived experience of breast cancer–related lymphoedema. Nurs Stand 2000;15(7):35-9.
24. Carter BJ. Women's experiences of lymphedema. Oncol Nurs Forum 1997; 24(5) :875-82.
25. Miedema B, MacDonald I, Tatemichi S. Cancer follow-up care. Patients' perspectives. Can Fam Physician 2003; 49:890-5.
26. Canadian Cancer Society. Canadian Cancer Statistics 2003. Toronto, Ont: Canadian Cancer Society; 2003. Available at: Accessed 2004 November 1.
27. Morgan DL. Focus groups as qualitative research. 2nd ed. Newbury Park, Calif: Sage Publications Inc; 1997.
28. Munhall PL, Oiler-Boyd C. Nursing research: a qualitative perspective. New York, NY: National League of Nursing; 1993.
29. Van Manen M. Modalities of body experience in illness and health. Qual Health Res 1998;8(1):7-24.
30. Wyatt G, Kurtz ME, Liken M. Breast cancer survivors: an exploration of quality of life issues. Cancer Nurs 1993;16(6):440-8.
31. Pelusi J. The lived experience of surviving breast cancer. Oncol Nurs Forum 1997; 24(8):1343-53.
32. Beaulac SM, McNair LA, Scott TE, LaMorte WW, Kavanah MT. Lymphedema and quality of life in survivors of early-stage breast cancer. Arch Surg 2002; 137 (11):1253-7.

33. Gerber LH. A review of measures of lymphedema Cancer 1998;83 (12 Suppl): 2803-4.
34. Harris SR, Niesen-Vertommen SL. Challenging the myth of exercise-induced lymphedema following breast cancer: a series of case reports. J Surg Oncol 2000; 74(2):95-9.
35. McKenzie DC. Abreast in a boat - a race against breast cancer. CMAJ 1998;159(4) :376-8.
36. Mitchell T, Nielsen E. Living life to the limits: dragon boaters and breast cancer. Can Womens Studies 2002;21(3):50-7.
37. Mirolo BR., Bunce IH., Chapman M., Olsen T., Eliadis P., Hennessy JM., et al. Psychosocial benefits of postmastectomy lymphedema therapy. Cancer Nurs 1995; 18(3):197-205.
38. Ridner SH. Breast cancer lymphedema: pathophysiology and risk reduction guidelines. Oncol Nurs Forum 2002; 29(9): 1285-93.
39. Harris SR, Hugi MR, Olivotto IA, Levine M, Steering Committee for Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. II. Lymphedema. CMAJ 2001;164(2):191-9.