

Symptom reporting as a useful tool to detect lymphedema

For breast cancer survivors and healthcare providers

Self-reporting provides preliminary understanding of lymphedema symptoms. A cost effective way to diagnose lymphedema.

By Mei R. Fu

Breast cancer-related lymphedema (hereafter, lymphedema) is an omnipresent concern for breast cancer survivors, who face a lifetime risk of lymphedema¹. Lymphedema is a syndrome of abnormal swelling coupled with multiple symptoms resulting from obstruction or disruption of the lymphatic system associated with cancer treatment^{2-7, 1}.

Many breast cancer survivors suffer from daily distressing symptoms related to lymphedema (hereafter, lymphedema symptoms), including arm swelling, breast swelling, chest wall swelling, heaviness, firmness, tightness, stiffness, pain, aching, soreness, tenderness, numbness, burning, stabbing, tingling, arm fatigue, arm weakness, and limited movement in shoulder, arm, elbow, wrist/fingers^{4,7}. The experience of lymphedema symptoms has been linked to clinically relevant and detrimental outcomes, such as disability and psychological distress, both of which are known risk factors for breast cancer survivors' poor quality of life (QOL)^{4,7}. More importantly, lymphedema symptoms may indicate an early stage of

lymphedema in which changes cannot be detected by current objective measures of limb volume or lymph fluid level^{4,9}. Without timely intervention in this early disease stage, lymphedema can progress into a chronic condition that no surgical or medical interventions at present can cure¹⁰. Symptom report using a reliable and valid instrument may play an important role in detecting lymphedema during clinical visits at the hospital or by patient's self-assessment at home^{9, 11-13}. Previous research suggests that an increased number of patient-reported lymphedema symptoms indicate an increased limb volume in the affected limb⁷. A new study led by researchers at New York University examines the validity, sensitivity, and specificity of symptoms for detecting lymphedema among breast cancer survivors who are at risk for lymphedema. The study, published in *Breast Cancer: Targets and Therapy*, also determines the best clinical cut-off point for the count of symptoms. This article is a summary of the study to help breast cancer survivors and healthcare

providers to better understand the role of symptom reporting in detecting lymphedema.

The researchers recruited 250 adult female participants with lymphedema from a metropolitan cancer center and communities in the New York City area. The study examined the validity (the ability of symptom-report to

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distinguish patients with lymphedema and without it), sensitivity (rate of true positive cases), and specificity (rate of true negative cases) of symptoms for detecting lymphedema defined by >200 mL limb volume in the affected limb using a sequential circumferential tape measurement. The study also aimed to determine the best clinical cut-off point for symptom count that maximized the sensitivity and specificity for detecting lymphedema as defined by >200 mL limb volume.

Participants were divided into three groups: healthy female adults, breast cancer survivors at risk for lymphedema, and those with lymphedema. Sixty healthy female adults, without a history of breast cancer



Dr. Mei R. Fu (PhD, RN, FAAN) is a Tenured Associate Professor of Nursing at New York University. Her research informs effective ways of performing symptom assessment and implementing risk reduction behaviours, which has profound sustained effect on national and international clinical practice for lymphedema care. She has completed award-winning research to demonstrate the effects of provision of lymphedema information on cancer survivors' cognitive, behavioural, and symptom outcomes.

Jeanna M. Qiu, Research Intern; Kavita Rampertaap, RN, BSN; Nardin El-Shammaa, BA are co-authors and are also from New York University.



or lymphedema, served as the comparison group. The dominant arm of the healthy women was considered the “affected arm”. One hundred and forty-eight breast cancer survivors were in the at-risk group. These women had completed surgical treatment within five years prior to study enrolment and had never been diagnosed with lymphedema. Forty-two breast cancer survivors with lymphedema served as the known lymphedema group, and their self-reported lymphedema was confirmed by the review of medical records and sequential circumferential arm measurements of >200 mL difference in limb volume between the affected and non-affected arms.

A self-report instrument, *Breast Cancer and Lymphedema Symptom Experience Index*, was used to measure the presence of lymphedema symptoms and distress from the lymphedema symptoms¹²⁻¹³. This instrument had a high internal consistency with a Cronbach’s alpha coefficient of 0.92, indicating that it is reliable to measure symptoms related to lymphedema,^{14, 11-13}. The instrument was also valid, with convergent validity ($r=0.35-0.93$), indicating that the instrument is able to differentiate breast cancer survivors with and without lymphedema based on the lymphedema symptom occurrences and distress ($P<0.05$)¹²⁻¹³. The instrument assesses

24 lymphedema symptoms listed in Table 1 (see page 8). All three groups were similar in education and marital status. However, significantly more women in the lymphedema group were unemployed and non-white, and had a significantly higher body mass index than women in the healthy or at-risk groups. More women in the lymphedema group had undergone clinical procedures such as mastectomy, chemotherapy, and axillary lymph nodes dissection. The healthy adults were significantly younger than the participants in the at-risk and lymphedema groups. Breast cancer survivors with lymphedema had significantly more lymphedema symptoms in comparison with the healthy adults and at-risk survivors. The most commonly reported lymphedema symptoms by breast cancer survivors with lymphedema were arm swelling (100%), tightness (71.4%), heaviness (71.4%), firmness (69%), aching (61.9%), tingling (59.5%), limited arm movement (57.1%), and tenderness (52.4%).

Bivariate odds ratios, which measure the risk or odds of having lymphedema given each symptom, were calculated. Significant odds ratios were found to have strong associations with arm lymphedema and limb volume >200 mL, except for symptoms of breast and chest swelling. Thus, only 22 symptoms were used in the data analysis. Of the remaining 22 odds ratios, significant odds ratios ($P < 0.05$) were found for all symptoms except stabbing, arm soreness, and blistering. Certain symptoms indicated higher odds of having lymphedema. For example, women who reported arm heaviness, arm firmness, increased arm temperature, seroma formation, tightness, limited arm movement, tingling, and arm aching had more than five times the odds of lymphedema compared to women without these symptoms. Similarly, women who reported symptoms of limited finger movement, limited elbow movement, and limited wrist movement had more than four times the odds of lymphedema compared to women without these symptoms. Women who reported pain in the affected arm had about twice the odds of lymphedema compared to women who did not report that symptom.

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The researcher used Youden’s method, a statistical test that helps to determine the optimal cut-off point for a diagnostic test with numerical results (such as the number of symptoms), using a receiver operating characteristic (ROC) curve 15-16. The ROC curve was constructed with sensitivity and specificity data. According to this method, the best clinical cut off point was three symptoms, in order to differentiate healthy participants from survivors with lymphedema, and nine symptoms was the best cut-off point to differentiate at-risk survivors from survivors with lymphedema. A diagnostic cut-off of three symptoms discriminated

breast cancer survivors with lymphedema from healthy women with a sensitivity of 94% and a specificity of 97%, while a diagnostic cut-off of nine symptoms discriminated at-risk survivors from survivors with lymphedema with a sensitivity of 64% and a specificity of 80%.

Findings of this study suggest that, despite medical advances, lymphedema still has a large, negative impact on breast cancer survivors’ quality of life. Patients with lymphedema reported many symptoms with significantly higher frequencies compared to the at-risk group or healthy group. While more research needs to

be done to investigate the causes of lymphedema symptoms, this study may provide preliminary understanding. It is likely that the accumulation of lymph fluid in the affected limb leads to sensations of heaviness, tightness, and firmness, as well as aching and tingling as a result of the pressure the fluid puts on the nerves. In addition, the accumulated lymph fluid may lead to stiffness and limited limb movement of the arm, shoulder, fingers, and elbow. Increased temperature in the affected limb may be because of inflammation in that limb.

The study bolsters the potential of using symptom report as a useful method to detect lymphedema. Since early intervention leads to better clinical results, patients with >9 symptoms should be evaluated immediately and treated in a timely manner, as >9 symptoms can differentiate at-risk patients from patients with lymphedema. This study provides evidence that patient self-reported symptoms actually have the ability to discriminate between patients with lymphedema and those without, with fairly high sensitivity and specificity. Typically, more objective tests are preferable to subjective symptom assessment by patients themselves; however, considering that patients with lymphedema and its symptoms have a poorer quality of life overall, the perception of lymphedema from the patient’s point of view may be of more importance than solely quantitative measures. Finally, symptom count is a very efficient and cost-effective method for screening patients at high risk of lymphedema.

The researchers of this study are also currently working on improving breast cancer survivors’ self-care abilities through mobile device applications. An electronic version and mobile version of the symptom assessment tool have been used by patients to report their symptoms during clinical visits and to evaluate their odds of developing lymphedema at home. Future research should focus on more prospective studies that track the development of lymphedema among patients at-risk to determine the predictive ability of symptom report in detecting lymphedema. [L4](#)

A comprehensive set of references can be found at www.lymphedemapathways.ca.

TABLE 1

Lymphedema symptoms and odds ratio for developing lymphedema

Symptom	Yes	No	Odds Ratio (higher odds ratio indicates a higher risk of having lymphedema given each symptom)
1. Arm swelling			561.00
2. Arm heaviness			17.46
3. Arm firmness			10.33
4. Increased arm temperature			9.07
5. Seroma formation			8.61
6. Arm tightness			7.78
7. Limited arm movement			5.86
8. Tingling in affected arm			5.54
9. Arm aching			5.14
10. Limited fingers movement			4.56
11. Limited elbow movement			4.39
12. Limited wrist movement			4.23
13. Limited shoulder movement			3.84
14. Stiffness in the affected arm			3.55
15. Burning in the affected arm			2.86
16. Arm redness			2.47
17. Numbness in the affected arm			2.40
18. Stabbing in the affected arm			2.12
19. Tenderness in the affected arm			2.07
20. Pain in the affected arm			1.99
21. Arm soreness			1.44
22. Blistering in the affected arm			0.97

As a patient who previously received surgical treatment for breast cancer, if you mark “Yes” for arm swelling alone or for nine or more of the above symptoms, please see your healthcare providers immediate for further evaluation of lymphedema. Remember, early diagnosis and early treatment often lead to better clinical outcomes.