

Precautionary practices for lymphedema

One size does not fit all

Current lymphedema risk reduction and education strategies for breast cancer survivors should be reconsidered

By Maria Asdourian, Melissa Skolny, Cheryl Brunelle and Alphonse Taghian



There is limited high-level evidence supporting the current lymphedema risk reduction recommendations that are provided to breast cancer patients. We discuss the results of our recent prospective study examining the impact of various risk exposures on the development of lymphedema and advocate for a shift towards individualization when it comes to patient education.

Introduction

Paradigm shifts over the last several decades, including the advent of multimodality therapy, have allowed for unprecedented rates of survival in breast cancer patients. Yet, these survivors are faced with a whole new set of challenges and potential complications resulting from treatment. One of the most feared is lymphedema. The physical and psychological distress resulting from this condition cannot be understated—as there are limited prophylactic interventions available. Women usually seek care only after they

begin to experience symptoms and are left to bear a lifetime of compression and various other treatments, with limited curative hope.

Research has sought to identify strategies aimed at reducing the risk of developing this distressing condition. The National Lymphedema Network (NLN) has published a comprehensive list of lifestyle modifications and precautionary behaviours that patients having breast and axillary surgery can adopt to minimize excessive strain to their at-risk arm(s) and prevent the onset or exacerbation of lymphedema symptoms. These include the use of compression garments during air travel, the avoidance of ipsilateral skin and venous puncture, limb

constriction, skin infections, extremes of hot and cold, and more. Although supported by clinical reasoning and a common sense approach, the putative beneficial outcomes of abiding by these guidelines remain without definitive scientific backing and may

contribute to a patient's worry about developing lymphedema, significantly impacting quality of life^{5,6}.



Massachusetts General Hospital
Perometer Room.

Lymphedema studies at Massachusetts General Hospital

Establishing a high-level evidence base is key for adjusting existing

guidelines and shifting our approach to patient education. Our Lymphedema Studies Program at Massachusetts General Hospital (MGH) is one of the research groups that have looked into this issue prospectively. Since 2009, through an IRB approved protocol titled “Prospective Analysis of Symptoms, Functionality, and Quality of Life Questionnaires to Evaluate Lymphedema in Patients Following Treatment for Breast Cancer,” we have been using a Perometer to prospectively screen women having breast cancer treatment at MGH for lymphedema, measuring patients at regular follow-up intervals up to several years after surgery. Determining the etiologic factors contributing



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to lymphedema development has been of much interest to the medical and scientific communities, as with our research group. Thus, as a component of the lymphedema screening program, patients complete a risk assessment survey at the time of every follow-up arm measurement, where they report the number of blood draws, injections, blood pressure readings, trauma to the at risk arm(s), number and length of flights since their last measurement, as well as the use of compression sleeves while flying. Using this data gathered over the years, a prospective analysis was recently published by our group² to determine whether these non-precautionary incidents conferred a risk for the development of lymphedema.

Six hundred and thirty two patients with unilateral or bilateral surgery were included in the analysis, each with a pre-operative baseline measurement and an overall median follow up of 24 months. Patients were measured with the perometer and reported their risk exposures at regular follow-up intervals of three to seven months. Arm volume changes of patients having unilateral breast surgery are calculated using the Relative Volume Change (RVC) formula, incorporating arm volumes of the at-risk arm at pre-operative baseline and follow-up, as well as arm volumes of the unaffected control arm at the corresponding

time points. The weight-adjusted arm volume change (WAC) equation is used for patients who undergo bilateral breast surgery and thereby lack a contralateral control arm. The WAC equation takes into account pre- and post-operative at-risk arm volumes and the patient's weight corresponding to these time points^{3,4}. Univariate analysis demonstrated that having a BMI ≥ 25 lb/in² at the time of diagnosis, axillary lymph node dissection (ALND), regional lymph node radiation (RLNR), blood pressure readings on the ipsilateral arm, and cellulitis were significantly associated with arm volume increases (Figure 1). By multivariate analysis, none of the lifestyle risk factors examined, including the number of ipsilateral blood pressure readings, blood draws, injections, and number or duration of flights were associated with an increase in arm volume (Figure 2). The only factors found to be significantly associated included a BMI ≥ 25 lb/in², ALND, RLNR, and cellulitis, which are commonly cited risk factors in the literature.

Current risk reduction guidelines remain unsubstantiated

Many times in the clinic, patients who have been having their arms measured regularly over the last few years, ask me how our data analysis is going, and whether

there has been any new and interesting findings they ought to know about. Although I can tell them about the recent results described above, I always have to end with a particularly lackluster response—the jury is still out. Despite seeing a lack of a significant association between lymphedema and any of the lifestyle exposures examined in our study, this is not the norm in the literature base, with many past studies having demonstrated a relationship between these putative risk-increasing behaviours and lymphedema^{7,8,9,10,11}. However, many of these studies are restricted in scope, being either retrospective reports or anecdotal accounts, or are fraught with recall bias. Even in the prospective analysis by Clark and colleagues, which demonstrates a relationship between hospital skin puncture and lymphedema, there is no direct evidence linking the process of skin or venous puncture itself to the development of lymphedema.

The conflicting nature of existing studies makes it difficult to establish clarity when determining the possible predictive factors for lymphedema and the way in which health care practitioners should approach patient education about the adoption of these risk-reducing behaviours. For instance, although there are yet to be any high-level studies demonstrating a causative relationship between the use of blood pressure cuffs on the ipsilateral arm and the development of lymphedema, the NLN maintains that such measurements be taken on an unaffected limb whenever possible. Similar ambiguity surrounding other recommendations—extremes of temperature, venous puncture for the purpose of medical procedures, the risk of air travel, and more—places an additional burden on patients, that of picking and choosing which precautionary measures they ought to vigilantly adhere to, if not all of them, or run the risk of developing the condition. Women may be left frustrated and often seek out the reason as to why they developed lymphedema despite following the precautionary guidelines, even when they carry several risk factors and it may be the case that it was not preventable regardless of their actions. How can we help better educate patients about preventative guidelines, when even we do not wholly understand what those guidelines should be?

FIGURE 1

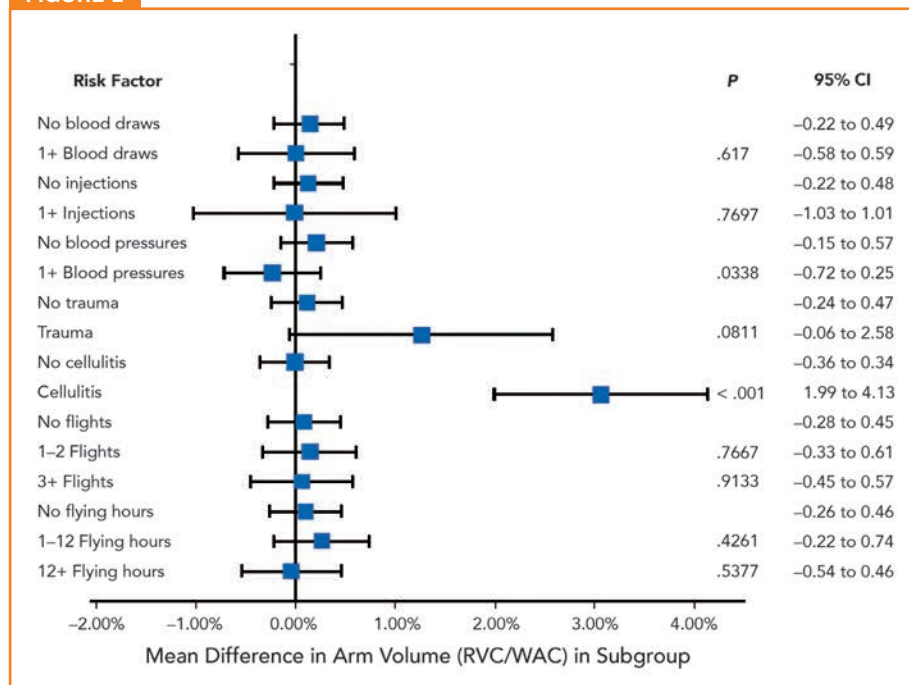
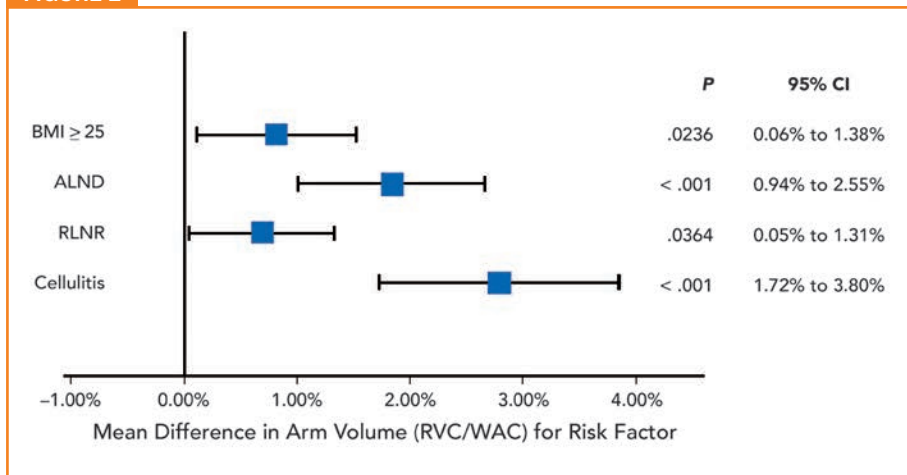


FIGURE 2



We can start by making sure patients understand that there is little definitive evidence behind some of these recommendations.

and similar skin infections have been found time and again to represent a significant risk factor for lymphedema development^{2,13,14,15} and patients of all risk-levels should be made aware of this. As for the rest, precautionary advice has and will continue to be an indispensable part of breast cancer treatment, yet should be communicated to patients with caution. Individualization in the advice we provide as well as the interventions we make available to patients—both prophylactic and palliative—is paramount for reducing the risk of developing lymphedema and ensuring that breast cancer survivors are not left to adopt restrictive lifestyle adjustments with no guarantee as to their efficacy. Although we are at present unable to definitively predict the risk of lymphedema in breast cancer survivors taking into account, for instance, underlying genetic factors, we are gaining a greater understanding of the surgical and treatment-related factors that are associated with its development. Nomograms have been developed using clinical factors to help estimate the individual risk of lymphedema in patients¹⁶, and we ought to make use of this and similar knowledge to change our approach to patient education. Along with further research into the risk factors contributing to lymphedema and the merit of current risk reduction guidelines, we hope that the results of our study continues the discussion regarding patient education and facilitates the shift to individualization we are all eagerly anticipating. [L2](#)

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

Figures 1 and 2 are originally published by the American Society of Clinical Oncology. [Ferguson, CM, Swaroop, MN, Horick N, Skolny MN, Miller CL, Jammallo LS, Brunelle C, O’Toole JA, Salama L, Specht MC , & Taghian, AG: 34. (7), 2016: 691-698].

Changing our approach to patient education

We can start by making sure patients understand that there is little definitive evidence behind some of these recommendations. Rather, they provide a framework that patients, upon careful discussion with their oncology health providers and lymphedema therapists, ought to be able to tailor, based on their own individual risk and the lifestyle they hope to maintain. Individualization is key, as many groups recognize^{5,12}, but how can we move away from a standardized approach to risk reduction advice while still ensuring that patients at the highest risk are given the right tools and knowledge to reduce their chances of developing this condition? We are asking many questions here—the dilemma lies in lowering the risk of potential morbidity while preventing unnecessary discomfort when patients are faced with a checklist of things to avoid which they must rigidly adhere to for the rest of their lives.

Although the risk for lymphedema is not eliminated, women having only sentinel lymph node biopsy (SLNB) may not need to be provided the same risk reduction advice as women who underwent ALND. In the same vein, those with a high BMI, those undergoing RLNR, those with established swelling versus women who are merely at-risk should be approached and instructed with a different level of urgency. Take, for example, patients who are at-risk and patients who have greater

than a 5 or 10% arm volume change. The NLN, although distinguishing between these two groups, provides essentially the same recommendations for them. We cannot say that they are wrong for aiming to be comprehensive in their guidelines, as we do not know whether patients at a low risk would be put at a disadvantage should practitioners advise them to move away from these precautionary guidelines. What we do propose is reminding patients of the nature of the research behind these guidelines and the controversy surrounding them. Must patients having SLNB avoid saunas and/or hot tubs for the rest of their lives? Should air travel be avoided whenever possible and compression garments worn when flying? Does the contralateral arm need to be used for all blood draws or injections after surgery? Patients ask us these and similar questions, and we respond with ambivalence—which is the last thing we ought to do.

In quest of individualization

Here is what we can say at the moment: as one of the most prevalent of the risk reduction practices, the importance of avoiding infection and maintaining proper skin integrity cannot be stressed enough. Cellulitis

