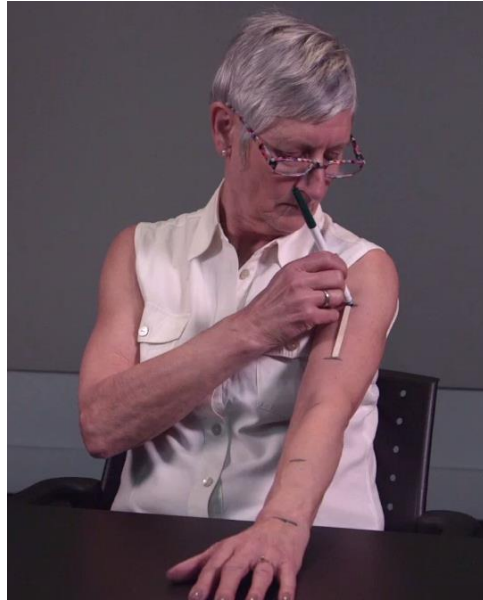


Can we deliver care differently?

Developing a patient-led surveillance program for breast cancer related lymphedema

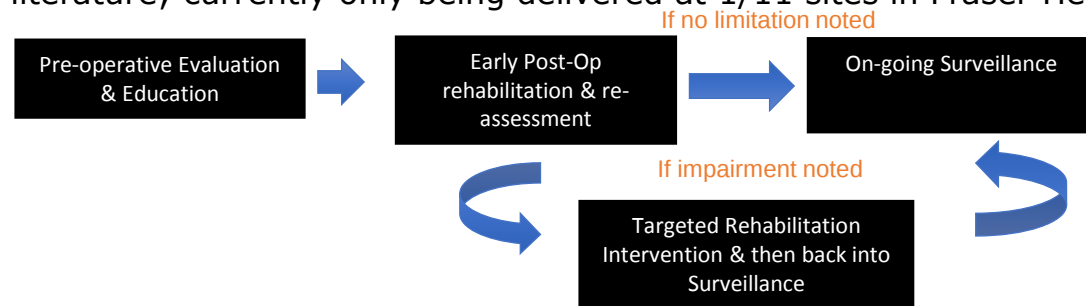


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Prospective Surveillance Model of Rehabilitation for Women with Breast Cancer (Stout et al Cancer 2012; 118 (Suppl 8): 2191-200)

- Gold standard model in the literature; currently only being delivered at 1/11 sites in Fraser Health = large gap in service delivery



Province-wide (BC) focus groups (B. Rafn et al)

- To identify ideal modes of delivery for rehabilitation services that can extend reach and access of care
- To explore the perspectives of women with breast cancer and rehabilitation professionals on a self-management approach to early detection and rehabilitation for upper-body issues

Results

- 100% of breast cancer survivors reported currently experiencing upper-body issues, and all reported a lack of support in the publicly-funded healthcare system for early detection and management of upper-body issues.

Patient: *"I was given a handout with diagrams of post-surgery exercises. As far as I recall in terms of rehabilitation that was it. Just a handout, maybe it was 4 pages double-sided"*

Patient: *"They say after you have a surgery not to sign any documents for at least 24 hours. So, let's not tell patients important information. Like how dare you come in when I'm half coked out of my tree and lay all this information on me and now I'm responsible for it?!"*

Rehab professionals and breast cancer survivors want enhanced services but how can we provide them with limited resources? **"Can we deliver care differently?" Is a patient-led surveillance program possible?**

University based study (UBC) on self-measurement of arm girth

Can women measure their own arm? Self-managed surveillance for lymphedema (*Rafn et al. PTJ in press*)

- Developed a short video (2 min) on self-measurement with written guide (in English) and then tested the resources
- Participants did self-measures at home and at the lab (UBC) and these were compared with therapist measures and with perometer measures

Participants:

- Women with BCRL n=20
- Women at-risk of BCRL n=21

Psychometric properties:

- Intra-rater reliability $ICC \geq 0.86$, $p < 0.001$
- Inter-rater reliability $ICC \geq 0.88$, $p < 0.001$
- Validity $r \geq 0.95$, $p < 0.001$: MDC 4 to 7%

Participants reported:

- Self measurement was easy to perform
- Strong **intention**, **self-efficacy** and **positive attitude** towards self-managed surveillance for lymphedema.

These findings indicated that **self-measurement was a possibility but could the results be replicated in a clinical setting with women who were undergoing breast cancer surgery and active treatment?** (all the women in the UBC study had completed treatment)



Step 1: Self-measures at home

Step 2: Self-measures at lab



Step 3: Therapist measures

Step 4: Perometer measures



Clinical Self Measurement-Partnership between Surrey Memorial Hospital Clinicians and UBC Researchers

Can women measure their own arm (in a clinical setting)?

- Before the study started, we identified a need for resources in Punjabi
- Self measurement for shoulder AROM was added

Participants:

- Women scheduled for surgery for breast cancer n=33
- Recruited at pre-admission clinic

Design:

- Prospective, single-group feasibility and reliability study

Self-management resources: Video guides + written material in English and Punjabi

Psychometric properties:

- Intra-rater reliability ICC .90-1.00 $p < 0.001$
- Validity $r \geq 0.95$, $p < 0.001$: MDC 4 to 7%
- Ease of measurement (0-10 numeric rating scale, 0 “very difficult” to 10 “very easy”)
 - Pre-surgery: 8.3 ± 2.2 Post-surgery : 8.0 ± 2.0



These findings were as good (and in some cases better) than the agreement found at the research lab at UBC

Conclusions, Implications and Next Steps

- Self-managed prospective surveillance for breast cancer-related lymphedema:
 - Feasible and reliable
 - Detects small changes → potential to diagnose early onset of breast cancer-related lymphedema
 - Has high clinical utility:
 - Self measurement is easy to understand, learn, and perform
 - Instructions do not require in-person teaching
 - Inexpensive, accessible, and easy to interpret

Impact on our patients

- Ability to self-identify concerns and seek targeted physiotherapy
- Reduced need for in-person appointments
 - Time
 - Travel
 - Cost associated with travel and parking



Next Steps

- Test effect in large-scale randomized control trial-CIHR Project Grant proposal has been submitted
 - Enhancing Access to Physiotherapy Services After Breast Cancer Surgery (EASE BC) Trial
- **Develop a case for standardized service delivery across Fraser Health with self-managed surveillance**