Final Report

A Novel Approach to Teaching Women How to Reduce Their Breast Cancer Risk:

The Breast Cancer Prevention & Risk Assessment Clinic

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Executive Summary

It is estimated that as many as 40% of breast cancers could be prevented by modifying lifestyle risk factors, yet this fact is not well-known in the population. In 2011, the Breast Cancer Prevention & Risk Assessment Clinic launched in BC, providing women with objective risk assessments and evidence-based counseling about how to reduce their risks. Between 2011 and 2016, the Clinic revised its approaches and procedures to maximize potential reach in the province. In 2016, the grant providing financial support for the Clinic ended, and a new cost-recovery model was adopted. This report describes this novel Clinic’s changing service models, activities, and accomplishments.
The Burden of Breast Cancer

Cancer has now surpassed cardiovascular disease as the leading cause of death in Canada, and accounts for 30% of Canadian deaths [1]. As the most common invasive female cancer in Canada, breast cancer represents a significant burden for women and society. Approximately 1 in 8 Canadian women will develop breast cancer in her lifetime, and 1 in 31 women will die from the disease [1]. In British Columbia in 2017, it is estimated that 3,500 women will be diagnosed with breast cancer, and 610 will die from the disease [1].

Breast Cancer Prevention

While there have been advances in breast cancer control, including reduced mortality due to earlier diagnosis and more effective treatments, this disease continues to pose an enormous societal and personal burden, which calls for an evidence-based prevention effort.

Increasing research indicates that up to 40% of breast cancers are potentially preventable. When mutated, breast cancer genes, such as BRCA1 and BRCA2, confer considerable increased non-modifiable risk. However, these gene mutations account for only 5% to 10% of all breast cancers, and even for this population, risks can be reduced [2]. Other factors including sociodemographics (e.g., higher income), reproductive history (e.g., parity, older age at first birth, breastfeeding history), and personal health history (e.g., exposure to ionizing radiation) are also linked with increased breast cancer risk [3]. Some of these factors (e.g., age at first birth) are possible in theory to modify, but are not likely to be the target of public health interventions.

However, convincing epidemiological evidence also points to a number of modifiable lifestyle risk factors that may account for considerable numbers of breast cancers. Specifically, the World Cancer Research Fund states that 38% to 42% of breast cancers in developed countries are caused by obesity,
physical inactivity, and/or alcoholic beverage consumption. In fact, obesity may become the biggest attributable cause of cancer in women in the next decade [4].

Despite the potential to prevent breast cancer through modifying risk factors, this information remains unknown to many women. A large body of research has demonstrated that women’s perceptions of their breast cancer risk are not correlated with actual risk. One BC-based study of 761 women found that on average, women’s ratings of their own breast cancer risk were 19% higher than their objective risk calculated by a standard risk assessment tool [5]. Another BC-based study, based on data from 93 attendees at our Clinic, found that women overestimated their risk three-fold [6]. A study based on a large sample of 1,700 women at both increased and average objective risk expanded on these findings, indicating that women at average risk overestimated their risk, whereas women at high risk underestimated their risk [7]. Given that a recent meta-analysis [8] showed that women’s acceptance of chemoprevention for breast cancer prevention was associated with perceived risk, ensuring that women are provided with accurate risk information is an important driver of risk reduction. This priority, as well as counseling about how to reduce risk, has not been systematically incorporated in medical care on a wide-scale basis [9, 10].

The Breast Cancer Prevention & Risk Assessment Clinic

The Evolution of the Clinic

Initial model. The Breast Cancer Prevention & Risk Assessment Clinic was launched in 2011 to provide women with objective risk assessments, information, and counseling about how to reduce their breast cancer risk [11]. The Clinic’s initial model was based in a hospital setting and involved two-on-one sessions with individual women who were identified as being at an increased medical risk for breast cancer (e.g., previous breast biopsies). The Clinic sessions were provided by a medical oncologist and a
lifestyle counselor, an experienced clinician professionally licensed in physical activity and/or nutrition who received specialized training for this program. An initial trial period demonstrated that while this model was greatly valued by the women, it required lengthy and intensive clinic visits, was not feasible for a brief one or two session intervention, and did not provide service to a broader group of women who could benefit.

**Move to group risk assessment model.** In 2012, based on input from the Clinic Advisory Board (including leading breast cancer and breast cancer prevention experts from the BC Cancer Agency and Research Centre; members of UBC Departments of Surgery, Physical Therapy, and Radiology; and community organization representatives), we developed a new group session model to deliver education and risk assessment sessions in the community. Participants could be self-referred or referred by a physician.

Prior to the risk assessment session, participants completed a brief online survey assessing family history of breast cancer and lifestyle habits, (e.g., physical activity, nutrition, weight management, smoking, alcohol use, environmental exposures), and perceived risk of breast cancer, as well as two validated breast cancer risk assessment tools: the Breast Cancer Risk Assessment Tool (Gail Model) [12] and the Your Disease Risk Tool (Siteman Cancer Center) [13]. Together, these two tools determined the basis for personalized and evidence-based recommendations about lifestyle changes to achieve maximum possible breast cancer risk reduction.

A lifestyle counselor delivered the risk assessment sessions, which included a standardized 60-minute presentation on breast cancer prevention, followed by discussion. The session included a review of strategies for achieving behaviour changes, including concrete and realistic advice for attendees. Information about chemoprevention (e.g., tamoxifen and raloxifene) was also provided. The lifestyle counselor recommended that the women discuss any questions or concerns with their physicians.
Participants were provided with an individualized letter summarizing lifestyle recommendations (regarding physical activity, weight management, nutrition, breastfeeding, hormone replacement therapy, tobacco use and exposure, and alcohol consumption). With the participant’s permission, a summary of this information was sent to her family doctor.

**Addition of group educational sessions.** Over time, as the Clinic became known in various communities, we received requests to deliver Clinics to ad hoc groups and events, such as church groups, employee health and wellness, community health fairs, and “lunch and learn sessions.” These provided excellent opportunities to reach large numbers of women. However, they did not allow the pre-session data collection and risk assessments. In response, we provided educational sessions that included the same content as the risk assessment format, but without questionnaires and risk assessments, and did not provide individualized letters to participants or their physicians. However, attendees were provided with a session summary that included links to the online risk assessment tools.

**Addition of online sessions.** In order to accommodate requests to provide outreach beyond the lower Mainland catchment area, and based on resources, we could not reach all interested women using an in-person format. In 2013, a new approach using internet-assisted technologies was implemented, in addition to the face-to-face community group sessions. Incorporating a telehealth model allowed the Clinic to expand into a service with province-wide and national reach. These sessions incorporated the questionnaires and physician letters when possible, and used the same content as in-person individual and group sessions.

**Addition of clinics targeted at specific populations.** In response to requests from particular groups, we developed evidence-based and culturally-appropriate content for specific populations of women, including the South Asian, Filipino, Aboriginal, Chinese, and Ismaili communities, as well as women with a history of chemical dependency and breast cancer survivors. The tailored sessions included, for example, statistics relevant to the attendees and culturally-specific foods in our discussion.
of nutrition and culturally preferred activities in the physical activity discussions. For Aboriginal sessions, we worked with the First Nations Health Authority to develop a protocol that was culturally-sensitive and informed.

We also designed an initiative for high school students in Metro Vancouver. The curriculum included most of the same information provided to adult women, except the style of presentation was tailored to this audience, and specific information pertaining to younger audiences was added (such as the importance of physical activity across the life-course for reducing breast cancer risk, and the significance of reducing environmental tobacco smoke exposure for cancer in younger women). More than 1,500 students in 12 secondary schools attended and learned how to reduce their risk of breast cancer, and how their lifestyle choices (e.g., tobacco use) may affect the breast cancer risk of friends and family.

Presenting this information to this audience was novel, in that it was open to all students, and 35% of the attendees were males. Attendees were asked, “What is one thing you will do differently after hearing this presentation?” Responses were open-ended and coded by category. Fifty-three percent said that they would eat a healthier diet, and 36% said that they would increase their level of physical activity.

**Reflections and Current Status**

Between 2011 and mid-2016, the Clinic saw 4,175 participants, including 1,537 high school students. Of the total of 2,638 adult women who took part, 565 participated in the risk assessment sessions, with the remainder (n= 2,071) attending educational sessions.

**Lessons learned.** The impetus for the program was to improve broad public awareness of breast cancer’s preventability and for the adoption of risk-reducing behaviours. We demonstrated that there was sustained and wide interest in this program, both as a “general” session and one tailored to
interests of specific sub-populations. We came to understand that interest in breast cancer prevention and risk reduction wasn’t limited to middle aged and older women (the group at highest immediate risk), but it also extended to men (as both men and women attended a number of the community sessions) and young people. Also, modifying the sessions to tailor them to particular groups increased the personal relevance of the content for attendees, including translation where needed; for example, we translated our presentation into Chinese and Punjabi.

We found that we needed to change our approach in response to our resources. Our initial intensive 2-on-1 approach offered a high quality experience, but not one that could be supported by our budget, which came as a grant from the Canadian Breast Cancer Foundation, British Columbia Yukon. Women who require the expertise of a medical oncologist are better served through the health care system, its program and resources.

We also found that we needed to change our approach in response to the needs of the population. Our initial location at the BC Women’s Hospital provided an excellent and reputable location, but for many, travel to the hospital posed a considerable barrier. We had much greater success going to where the women were, rather than expecting them to come to us.

Finally, we found that we adapted our approach in response to requests from communities of women within the Province. With the increasing use of internet-based approaches to education and training, online sessions were a natural next step. We had one national online session that reached offices across Canada and another that reached First Nations Health Authority personnel BC-wide. In determining the impact on the attendees, we found that because this was a knowledge translation activity of limited duration, not a research project with decades of follow up, we did not have “hard data” to demonstrate that the project led to lower breast cancer rates, nor would we expect a brief educational experience to have such an impact. However, we do have some information to suggest that
attendees benefitted from their participation on variables we sought to impact, particularly understanding of breast cancer’s preventability with lifestyle changes.

**Impact.** Data were collected from the women who attended the risk assessment sessions, both before and after the session. We found that before the session, the mean estimate of one’s personal risk of breast cancer was 32.5% (standard deviation of 23.6), and after the session, it was 24.8% (SD=29.8), a statistically significant decrease (p < .0001, N=516). Although perceived risk was still higher than the population-based figure of 12.5%, it became more realistic. There was no difference in reports of being bothered by thoughts or worries about one’s chances of developing breast cancer pre- and post-session, with more than half of respondents saying they were “slightly” worried at both time points. But when it came to agreement with the statement “Breast cancer can be prevented,” after the session, 45% of women (N=158) said that they were “very” or “extremely” confident in this statement, compared to only 22% (N=520) who said the same before the session.

We were attentive to our interactions with physicians throughout the program. At midpoint, we surveyed all physicians who had received a report for one or more of their patients following the risk assessment session to ask if they wanted us to continue sending the reports. No physician asked us to stop sending the reports, and several spontaneously remarked that they found the reports useful. Also, upon physician request, we developed a chemoprevention info-sheet for breast cancer risk reduction to accompany the reports.

**Summary**

The Breast Cancer Prevention & Risk Assessment Clinic provided a novel model of cancer prevention in British Columbia, reaching more than 4,200 participants who learned about modifiable breast cancer risks, and increased community and organizational awareness of breast cancer. With the
end of funding, the Clinic has moved to operating on a cost-recovery basis, and continues to offer in-person and telehealth sessions to organizations, health care providers, and community groups. We are also open to collaborating with organizations that may want to take on this program as part of their health and wellness goals. Breast cancer continues to be the most common cancer diagnosis in Canadian women, and we have found the population of British Columbia is eager to learn more about how to reduce risks for this disease.
Reference List


Appendix 1—Selected Clinic Photos

Clinic Opening, October 2011
Filipina Community Session
Chinese Community Session
First Nations Health Authority Session
South Delta Senior Secondary Session
Telehealth Session