Title: “How do we make it happen”? Expanding breast cancer networks to meet the needs of women with cervical, ovarian, and uterine cancer.

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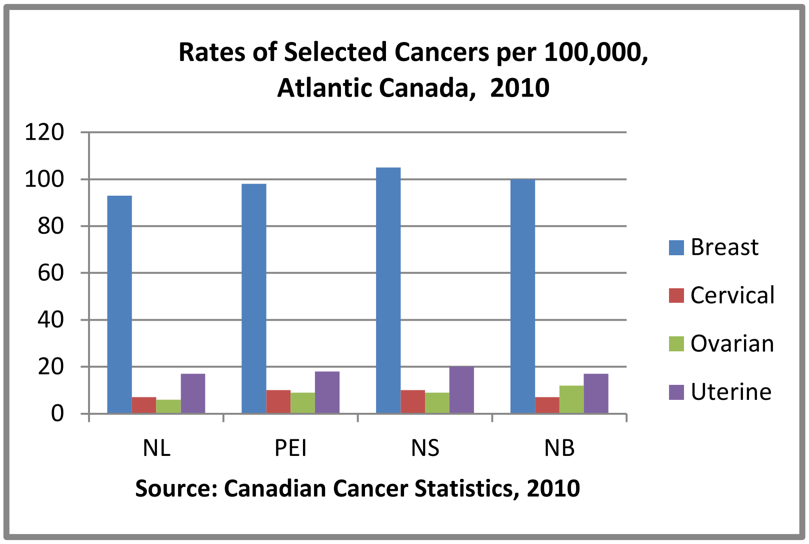
Introduction

Support services for women faced with a diagnosis of breast cancer have been growing steadily in number and scope since the 1970s and they are now, in much of the developed world, well-established and abundant (Gardner, 2006; Lerner, 2003). In Canada, national organizations, such as the Canadian Breast Cancer Foundation and Canadian Breast Cancer Network, provide specialized support for women living with breast cancer. By comparison, women living with a diagnosis of other forms of cancer, particularly gynaecological cancers, are not as fortunate to have specialized support services. Women with cancers other than breast cancer are typically supported by generic cancer support services, such as the Canadian Cancer Society. These organizations are structured to help all cancer patients, which means they do not necessarily include resources or programs geared specifically towards the needs of people with cervical, ovarian and uterine cancers.

A recent comparison scan of support services for women with breast and gynaecological cancers in Atlantic Canada catalogued dozens of services for women with breast cancer, but uncovered only a few programs for women with ovarian or cervical cancer and none geared specifically to those with uterine cancer (Clow, Hemmens & Mason, 2008; Ovarian Cancer Canada, n.d.). This gap in services is linked, in part, to differences in the rates of breast and gynaecological cancers. In 2010, an estimated 23,700 women in Canada will be diagnosed with breast cancer as compared to 1,300 with cervical cancer, 2,600 with ovarian cancer, and 4,500


Rates of Selected Cancers per 100,000, Atlantic Canada, 2010

Source: Canadian Cancer Statistics, 2010

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[1] The authors would like to thank Patsy Beattie Huggan, who conducted the interviews and wrote the initial report upon which this article is based. Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

with uterine cancer (Canadian Cancer Society Steering Committee, 2010). In the Atlantic provinces, the rates of gynaecological cancers are likewise much lower than the rates of breast cancer.

At the same time, the attention paid to breast cancer – and the resources committed to research, treatment and care – is also a product of the work of several generations of breast cancer survivors, who not only designed and delivered programs themselves, but also convinced policy makers, researchers and clinicians to promote and back their efforts (Gardner, 2006; Lerner 2003). Because the survival rates as well as the incidence of gynaecological cancers are generally lower than those of breast cancer, the same critical mass of survivors does not exist to undertake the work of raising awareness and advocating for better programs and services for women affected by these cancers (Canadian Cancer Society Steering Committee, 2009). As a result, only a single organization in Canada, Ovarian Cancer Canada, has taken up the gauntlet of addressing the needs of women with gynaecological cancers (Ovarian Cancer Canada , n.d.). There is no comparable provincial or national organization for women faced with a diagnosis of cervical or uterine cancer (Clow, Hemmens & Mason, 2008).

Growing awareness of this significant gap in services for women with cancer has spawned interest in the possibility of expanding well-developed breast cancer networks to include services for women with gynaecological cancers (Clow, Hemmens & Mason, 2008). The province of Manitoba has already extended the breast cancer network to include women living with cervical, ovarian and uterine cancers, which are referred to as "women's cancers" (Cancer Care Manitoba, n.d.). In the Atlantic Region, discussions among the non-governmental breast cancer networks and partnerships in recent years have led to expansion in two provinces: New Brunswick and Newfoundland and Labrador (Cyr, 2010). Meanwhile, the other two Atlantic provinces, Nova Scotia and Prince Edward Island, have decided to maintain their focus solely on breast cancer for the time being.

As the provincial breast cancer networks in Atlantic Canada are evolving differently, the current study was designed to shed light on the factors that have made or are making expansion desirable and/or feasible. In particular, we were interested in identifying barriers to and opportunities for expansion, both of which may affect perceptions of desirability and feasibility. Most of the people we spoke with acknowledged the desirability of expanding the breast cancer networks to include women with gynaecological cancers, but many also described the challenges of extending services. While expansion might be desirable in most contexts, its feasibility is dependent on capacity, confidence, leadership, and adequate resources.

This paper is divided into three main sections. It begins with a brief overview of the methods and analytical framework of the project. The second section deals with the desirability of expansion, both the pros and the cons, and the third section addresses the feasibility of expansion, again considering the opportunities and barriers. The paper closes with a summary of recommendations offered by key informants.

Methods

This study used qualitative methods, consisting of an organizational questionnaire and in-depth interviews with representatives of the breast cancer networks and partnerships in the four Atlantic provinces, and other key informants from government and/or other non-governmental organizations. Potential participants were identified during consultations with the provincial breast cancer networks during a national meeting organized by the Canadian Breast Cancer Network in 2008. In total, eight people were interviewed. All key informants had significant experience with the breast cancer networks, being involved or working with them for a minimum of five years. This timeframe was deemed sufficient to give participants an idea of the opportunities and challenges associated with expanding existing networks for breast cancer survivors to include women with cervical, ovarian, and uterine cancers.

The questionnaire allowed us to gather information about the networks and partnerships, including sources of funding, staff complement, volunteer base, service provision, etc. The questionnaire enabled us to gauge the relative strengths of and demands upon the breast cancer networks in Altantic Canada. Interviews were open-ended and semi- structured, with questions designed to elicit the informants' views on how desirable and feasible it would be to expand their own breast cancer networks to include services for women with gynaecological cancers. The interview questions were as follows:

1) Should the breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers? Why or why not?

2) Can the breast cancer networks be expanded to include services for women living with cervical, ovarian and uterine cancers? Why or why not?

3) If the breast cancer network in your province were to be expanded in this way, what resources would be needed?

All interviews were conducted over the telephone. The duration of the interviews was approximately 60 minutes. With the permission of all informants, the interviews were audio-recorded and written notes were taken. The interviews were later transcribed verbatim and then validated by the participants. A technical issue resulted in one of the interviews not being recordings with the result that only the field notes for this particular interview could be used for analysis. These were also validated by the interviewee.

Grounded theory methodology provided the framework for the data analysis (Charmaz, 2000; Glaser & Strauss, 1967). The transcripts were manually coded. The coding process involved analyzing sections of the text in relation to the research questions. The data was clustered into themes about feasibility and desirability of expanding the breast cancer networks to include gynaecological cancers. In many cases, participants' views on the desirability of expansion were closely tied to their perceptions of the feasibility of expansion for their own organization and context. We have focused on analyzing responses as they relate to the themes rather than grouping responses to each of the questions.

Desirability: Should breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers?

All those interviewed recognized the need for support services tailored for women with cervical, ovarian and uterine cancers and all acknowledged that creating and providing those services was imperative. As one participant remarked about her network, "T*here was consensus and total agreement that we should move forward because it was the right thing to do.*" As on previous occasions, many of those in the breast cancer networks remarked that there was a good deal of cross-over between the needs of women with breast and gynaecological cancers because they would face many of the same challenges with body image, intimacy, caregiving roles, etc. (Clow, Hemmens & Mason, 2008). But not all of the participants in this study believed that the breast cancer networks should be tasked with designing support services for women with gynaecological cancers nor that they should become the mechanism for delivering those services.

Participants who favoured expansion focused primarily on the need for support services for women with gynaecological cancers, which had become more and more evident as had the gap in services. While the networks were doing a first-rate job of supporting women with breast cancer, many women with gynaecological cancers could not find the kinds of services and supports they needed through existing cancer networks and organizations, or could not find them close enough to home. As one participant said, *"The need has been identified through that experience with the [patient] navigators... many of the navigators knew of other survivors of the other cancers and the need became very apparent."* Interviewees told us that, in the absence of tailored services, women with gynaecological cancers were already approaching the breast cancer networks for assistance, and staff members were frequently providing them with support. Many working with the networks recognized the need to fill this gap and wanted to extend support to women with cervical, ovarian, and uterine cancers. As one participant observed, "W*e would like to see women going through gynaecological cancers being as supported as we are..."*

Participants from the two provincial networks that had expanded their services at the time of the study identified a sense of ethical responsibility as a motivating force for their decision. According to one participant, "B*reast cancer has many, many resources. It has very sophisticated support services set up and we have a moral responsibility to share that with others*." Given the success of the breast cancer networks and the strong foundation they had built, there was a resounding feeling that it "*made sense*" for them to be the group to provide support to women living with gynaecological cancers. Information distribution channels, support links, and relationships with the health system were already well established and the networks had been highly successful in improving access to information, support, and delivery of services. Many believed that others could benefit from these accomplishments and build on the success of the breast cancer networks. As one participant concluded about her breast cancer network:

I think broadly that it makes a lot of sense for it to be expanded to include cervical, ovarian, and uterine. I think that women with breast cancer have benefitted tremendously from such projects as the [name of project] and similar projects around Atlantic Canada. That project was well received. It was well thought out, and the linkages with the lab, surgeons, family physicians, and other healthcare providers were well considered, and background information collected to make sure it was successful.

At the same time, many participants supported the idea of expanding existing breast cancer networks because they believed that developing new networks for women with gynaecological cancers would be an unnecessary and wasteful duplication of services and infrastructure. As one participant remarked, *"It really just makes sense to sort of piggyback on what has already happened and what is already going well to serve more women*." This was especially true for supports and services that would likely be of help to most women, regardless of the site or type of cancer. As one woman said, "Y*ou don't have to recreate the wheel... the emotions that I experience [as a woman with breast cancer], the fear, the uncertainty, the where does this take me? All of those types of things are the same types of emotions. And where do I go looking for the kind of support that I need to deal with that? Those again are all the same."* These informants concluded that expanding breast cancer networks to include women with gynaecological cancers would not only be more efficient than working to create new networks, it would also establish a specific, reliable resource for women to turn to when they needed information and/or support.

While many of the participants felt that expansion of the networks was an ethical responsibility as well as a logical step, some were uncertain about the desirability of expansion. One participant expressed reservations about trying to meet the needs of women with different cancers through a single organization. As she said, "*How does someone who has just been diagnosed with stage one breast cancer, whose prognosis is probably excellent, talk with somebody who has just been diagnosed with stage three or four ovarian, whose prognosis is five years at best?"* Along the same line, some participants worried that volunteers with the networks, many of whom are breast cancer survivors, would not be as well-informed about gynaecological cancers and therefore would find it difficult to support women with these cancers. As one participant said, "*How do we expand when our heads have been around breast cancer for so long and all we know is breast cancer?*" Some participants likewise were concerned that women with gynaecological cancers may feel marginalized in the breast cancer networks. This very issue had already been raised in one of the networks that had undergone expansion: "*We had people complaining to us from the ovarian side, and rightly so, that it was too much about breast cancer. Well, yes, it was, because 90% of the women in the room were affected by breast cancer. So, I am just wondering, I'm not sure this is a mix*."

Finally, participants who had reservations about expansion were concerned about the potential threat to the identity and credibility of the networks. They worried other cancer organizations might have less confidence in the networks and that expansion might diminish the effectiveness of the networks by diluting their focus. Some participants also feared that creating and delivering supports for women with cervical, ovarian and uterine cancers might jeopardize funding, which is drawn largely from organizations focused on breast cancer.

Feasibility: Can the breast cancer networks be expanded to include services for women living with cervical, ovarian, and uterine cancers?

All of the interviewees agreed that it was feasible, in theory, to expand the breast cancer networks, but many described significant challenges to expansion. Lack of o*rganizational readiness* was identified as a major obstacle. In other words, some of the networks were simply not in a position to take on the demands of extending services to include women with cervical, ovarian, and uterine cancers. One of the networks had recently experienced a change in leadership after the loss of their Chair to cancer and needed time to adjust and regroup before they could even consider expanding their network. As one participant observed about a specific provincial network:

I don't think they are ready yet. I think they have a desire [to expand their services], but I don't think they are ready until they get their own clear mandate once again and know the direction they are going into... you really have to do your own housework before you invite somebody else in.

At the same time, several participants noted that the lack of *organizational capacity* made it difficult, if not impossible to consider expansion of the breast cancer networks to include women with gynaecological cancers. For one thing, the lack of paid staff made expansion unrealistic. As one informant remarked, "*We really don't have the resources to put into it [expansion] at this point and that primarily means people-power."* The networks also relied heavily on volunteers and expansion without an infusion of new volunteers would create strain and possibly endanger existing programs. As one participant said, "*How do we make it happen without taxing people who already have a heavy workload?*"

Many who were interviewed also believed that expanding services to include cervical, ovarian, and uterine cancers would place a strain on financial resources, which were already unstable and/or unpredictable. The breast cancer networks relied on project-based funding from two major funding bodies, but had to secure additional resources through fundraising events, private donations, partnerships with corporations, and applying for grants and contracts. Not only would expansion require additional financial resources, it would also require more human resources to write grant proposals, organize fundraising activities, and to solicit donations.

Participants also concluded that considerable effort would be required to establish and maintain new relationships that would be crucial to expansion. Because cancer care services are diverse and involve many different disciplines and sectors, the breast cancer networks would need to reach out to new partners to develop and deliver programs for women with gynaecological cancers. As one woman said, *"To build the partnership with pathology and all of those things we already have within the breast cancer partnership [network] would take energy because that creates more work for other people."* Although expansion of the breast cancer networks would be undertaken, in part, to avoid duplication of services, it would nonetheless involve the duplication of efforts to reach out to relevant stakeholders and providers.

Considering the many obstacles to expansion, some participants stressed the importance of being realistic and doing the ground work necessary for a smooth transition. As one woman said:

I think we really have to think about the practical aspects of it [expansion]. Pies in the sky. Yes, it would be great for all this to happen, but there really has to be a process in place to make it happen. I think there will be lots of bumps in the road. And as long as we are prepared for that, because resources themselves are an issue and it takes time and money... And you need community input in the sense that you need survivor input as well as those within the system and organizations... In my opinion, it has much more body, much more clout and it has much more everything if it has good community representation – if it is coming from everyone.

Participants identified a variety of conditions and resources that would be needed to support expansion of the breast cancer networks to include women with cervical, ovarian and uterine cancers.

- Secure funding (partnership with a funder; flexibility)
- Time, energy, passion, and commitment to move forward
- Stable leadership and personnel (paid coordinator and staff)
- Volunteer commitment, support, training
- Clarity and transparency of identity, mandate, and process – including terms of reference and guidelines for partner decision-making; clear guidelines and expectations for volunteers; clear identity and purpose for the public (i.e., branding and logo)
- Strategic plan, including development of a logic model, team building processes, and evaluation, for integration, accountability, and sustainability of expanded networks
- Stakeholder buy-in/communications and strong survivor-base from each of the other cancers
- Support and collaboration from the relevant sectors of the health care system, including provision of credible, reliable sources of information and communication networks
- Collaboration across provinces and regions to share resources, avoid duplication, collaborate on tools, contribute to sustainability
- Increased visibility for expanded networks, including political engagement, public awareness, media interest

Conclusions

According to the participants in this study, there are compelling reasons for working to expand the breast cancer partnerships and networks to meet the needs of women living with cervical, ovarian and uterine cancers. The need for support services for women with gynaecological cancers is great and the breast cancer networks have the experience, the expertise and the connections that would enable them to rise to the challenge of expansion. At the same time, there are many obstacles to expansion, ranging from the limits of organizational capacity and resources to concerns about shifting the identity of the networks and losing credibility and sustainability. As all of the participants saw the merits and potential of expansion, it remains to be seen whether the barriers to expansion can be overcome in each of the Atlantic provinces.

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