

Perspectives of Rural Women with Breast Cancer



The 2003 Nunavut Run for the Cure team

**CANADIAN BREAST CANCER NETWORK
FOCUS GROUP PROJECT
2001**

Report Submitted by the The Ontario Breast Cancer Community Research Initiative

ISBN 978-0-9920288-6-2

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PERSPECTIVES OF RURAL WOMEN WITH BREAST CANCER

INTRODUCTION

In 2001, the Canadian Breast Cancer Network (CBCN), the national network of breast cancer survivors, embarked on a unique and ambitious project. Funded by the Community Capacity Building component of the Canadian Breast Cancer Initiative of Health Canada and the Canadian Rural Partnership – Pilot Projects Initiative of Agriculture and Agri-Food Canada, the project was designed to elicit the perspectives of rural women living with breast cancer about their illness experiences. The perspectives of these rural women are presented in this report. The report offers an important opportunity to increase awareness about the experiences of women living in often isolated and remote communities while struggling with a breast cancer diagnosis.

It is important to consider briefly what we mean by “rural,” as the term has been used to refer to individuals living in a variety of living situations/locations. The CBCN did not assume any particular definition, nor does this report. CBCN took the position that, in the absence of any agreed-upon definition, women could judge for themselves whether they fit the criteria for living in a “rural setting.” Some women who participated in this project lived on farms, but others lived in, or on the outskirts of villages or hamlets, while yet others lived in towns or small cities.

Background

A diagnosis of breast cancer is difficult regardless of where a woman lives. Within urban centres, a wealth of resources, programs and services have been created to help women meet their information and support needs. For many women these services are lifelines, helping them navigate through the complex

health care system from initial diagnosis through to the end of their treatments.

There is a paucity of research on the general health care needs and experiences of rural women and even less on the experiences specific to living with breast cancer in a rural community. Rural breast cancer survivors have important experiences and insights to offer and are positioned to make relevant recommendations about rural health care issues.

Most studies previously conducted with rural women with cancer have focused on issues of access. Canadian studies (Bryant et al. 1993; Bryant & Mah, 1992) reveal serious problems for women seeking access to screening. In Alberta, 40% of women accessing screening live at least 50 kilometers away from major centres, and women who live one to three hours from screening centres are half as likely to have had a mammogram (Bryant et al., 1993; Bryant & Mah, 1992). Other Canadian studies have reported differences in women’s access to surgery and other treatments (Goel et al., 1997; Iscoe et al., 1994; Elward et al., 1998; Nattingers et al., 1992). Breast-conserving surgery is more readily available in teaching hospitals in urban settings than in smaller centres where rural women are likely to receive mastectomies. Also, a choice of breast-conserving surgery has implications for rural women having to travel to an urban centre for radiation treatment.

Few studies have looked at the broader range of issues perceived by women with breast cancer who live in rural areas. White et al. (1996) highlighted the information needs of rural Michigan women with breast cancer in the months following diagnosis. Family physicians, oncologists and nurse practitioners were often the only resources for women, as

many did not have access to libraries and other resources. Studies conducted in Australia by McGrath et al. (1998) highlight additional social difficulties that women experience as a result of living in a rural community. They reported that rural women had significant financial burdens related to travel, childcare responsibilities and changes to work. Australian rural women expressed concerns about being a financial and emotional burden on their partners. When women worked on farms, or were self-employed, financial concerns tended to be exacerbated.

To date, there have been no Canadian studies about the needs of rural women with breast cancer. Lack of data has made it difficult to 1) clearly identify support needs; 2) assess whether these needs are being met; and 3) decide how best to improve the circumstances of rural women with breast cancer. The recommendations provided by women participating in the CBCN consultation are intended to help fill this gap, and to contribute to the development of a National Strategy focusing on the development and extension of programs for rural women with breast cancer.

METHODS

Participants

Seventeen focus groups were conducted across Canada, with a total of 276 women attending these meetings. Participants were accrued from breast cancer support groups, and through referrals from breast screening clinics, oncologists, nurses, allied health professionals, Canadian Cancer Society branches, provincial breast cancer networks, and members of the CBCN Board of Directors. Focus groups were hosted in Newfoundland – two meetings (Corner Brook and Deer Lake); New Brunswick – one meeting (Sussex); PEI – one meeting (Charlottetown); Nova Scotia – one meeting (Halifax); Quebec – two meetings (Quebec

City x two); Ontario – three meetings (Stratford, Toronto, Sharbot Lake); Manitoba – two meetings (Gimli, Winnipeg); Saskatchewan – two meetings (Saskatoon, Swift Current); Alberta – one meeting (Edmonton); British Columbia – one meeting (Prince George); and Yukon – one meeting (Whitehorse). A local consultant facilitated the majority of groups, with support from a CBCN staff person, who assisted with organization and recording. CBCN staff was not involved with the running of two groups.

Each focus group meeting was audiotaped and notes were also taken. Facilitators were asked to follow a pre-designed interview guide (see Appendix A) to focus the discussion within the following broad domains: 1) pre-diagnosis and diagnosis; 2) post-diagnosis and treatment; and 3) post-treatment and supportive care. In practice, facilitators varied in how closely they followed the interview process suggested in the guide. Participants were encouraged to complete a brief demographic form (including age, geographic location, and diagnosis/treatment information), as well as an evaluation form about the focus group process (see Appendix B).

Following each focus group meeting, facilitators were asked to write a report to document the most notable themes and quotes from the discussions, and to also provide their own reflections. A suggested reporting structure for this report was created by CBCN, but facilitators varied in how closely they adhered to the structure.

A wealth of information was generated during the focus groups about the experiences and needs of women with breast cancer. However, this report will be limited to those issues that women perceived as being specifically related to living in a rural setting.

Analysis

The CBCN, with assistance from a team of researchers from the Ontario Breast Cancer Community Research Initiative (OBCCRI), have utilized data from various sources (i.e., demographic forms, facilitator reports, evaluation forms and focus group audio-tapes) to investigate the perspectives of women who participated in the focus groups across Canada. Analysis of demographic materials and evaluation forms proceeded utilizing Microsoft Excel. A database was created to allow description of demographic variance in the focus group attendees. NVivo (a qualitative data software program) was utilized to help analyze the facilitators' notes and transcribed texts from selected focus groups.

Thematic analysis was conducted using the facilitators' reports and minutes, as well as selected focus group transcripts. Issues and concerns were coded initially in terms of content and proceeded through identification of larger theme categories. To ensure reliability, audiotapes of focus group were reviewed to ensure that quotes and themes appearing in the facilitators' reports and minutes correlated with verbatim material.

The initial round of analysis resulted in two types of data, one related to the issues faced by women with breast cancer across the continuum of care and the other related to needs and issues that were distinct to the rural setting. The information provided about issues across the care continuum, while rich and important, was similar to information provided in studies of other breast cancer populations. It reflected and confirmed previous findings about the information/education and support needs of women with breast cancer (Mills et al., 1999;

Bilodeau & Degner, 1996; Northouse, 1989). Rather than repeat these familiar findings in this report, the study team decided to focus additional analysis and the presentation of results exclusively on aspects specific to the rural context.

RESULTS

Selected Demographic Characteristics

One hundred and fifty-seven (57%) of the focus group participants filled in a demographics form (see Appendix C). Most (73%) participants who responded to an item about age were 50 years or older at the time of the focus group, although far fewer (40%) were over 50 when they were diagnosed. Most (73%) were either married or living common-law. The vast majority (86%) of those responding to an item about ethnicity specified that they were Caucasian. A minority of women (36 %) classified their residence as a farm, country home, or village, while 63% classified their residence as a town or small city.

Distance to Treatment Sites and Services

Travel information was reported by women involved with the CBCN project in a variety of ways. In an attempt to provide a uniform method of describing travel we translated all reports into number of hours to arrive at destination (where it was assumed that one hour of travel would equal 60 kilometers).

Surgery: Almost half (47%) of the women had to travel less than an hour for surgery, with 25% traveling more than 3 hours. Some of the women who traveled these longer distances had access to local surgical services, but chose to travel to cities where they hoped to receive a better quality of service.

Table 1 ~ Breakdown of hours traveled to corresponding site (1 hr = 60 km)

DISTANCE IN KMS	SURGERY LOCATION		CHEMOTHERAPY LOCATION		RADIATION LOCATION	
	#	%	#	%	#	%
Less than 1 hour	74	47%	66	51%	17	13%
1 – 3 hours	37	24%	28	22%	27	21%
3-10 hours	24	25%	17	13%	40	32%
10+ hours	15	10%	10	8 %	37	29%
	N=157		N=129 *		N=126 *	

* Variations in sample size are due to women’s differing treatment regimes

Chemotherapy: Half (51%) of the women who required chemotherapy in this project had less than one hour travel time to receive treatment, with a minority (21%) having to commute more than three hours. Some women commented that they had to travel to different settings, depending on where they were in the treatment cycle. During initial treatment they might have to travel to regional centres, whereas further along in their course of treatment they were able to receive care closer to home. Many women commented that their oncologists did try to arrange to have local hospitals provide chemotherapy whenever possible.

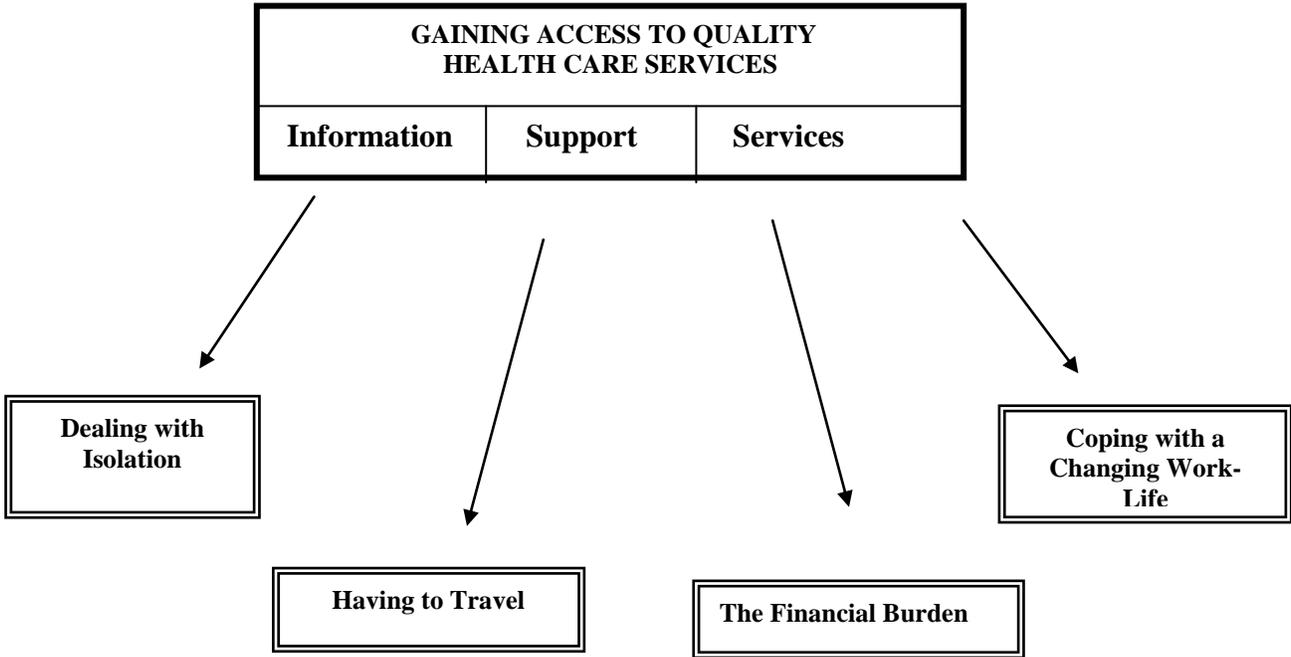
Radiation Treatment: Most (61%) of the women who required radiation treatment had to travel more than three hours to receive it. As a result of the extensive distances between women’s homes and their radiation treatment

site, many women were required to stay in urban centres for the duration of their treatment regime.

QUALITATIVE FINDINGS AND DISCUSSION

While focus groups varied in terms of the depth and breadth of discussion concerning rural issues, most of the focus groups provided detailed descriptions of specific rural issues confronting women dealing with a breast cancer diagnosis. The major theme identified through the analysis was “becoming aware of and/or gaining access to health care information, support and services.” Results directly related to this overarching theme will be presented first, followed by other themes, including: 1) dealing with isolation; 2) having to travel; 3) feeling the financial burden; and 4) coping with changing work.

Figure I~ A conceptual framework of distinct rural themes



Becoming Aware of and/or Gaining Access to Information, Support, and Services

Issues of access to information, support, and services were discussed openly and repeatedly in all of the focus groups, with women describing their experiences in trying to find appropriate programs and services. Too often, information about resources and/or services was nonexistent, outdated, or unhelpful. The process of becoming aware of programs and services seemed a gradual process for most women, involving extensive, time-consuming and stressful searching. Women were often disappointed about the types and levels of services offered locally or regionally, and they often compared their situations negatively to urban women.

Information: Across all of the focus groups, women discussed concerns about difficulties accessing information locally. As a result, rural women relied especially on physicians for whatever information they could get.

“We live so far away from information.”
“There’s no information in small towns.”
“Libraries are not well stocked or current.”

Support: Many of the women in the focus group project discussed struggles they had in finding the support they needed for themselves and their families. Consistent with what women with breast cancer have said in other studies, many of the rural women in this project highlighted the importance of being able to talk about what they were going through with caring others. Most often they found this type of support among family and friends. Some, although certainly not all, felt that the rural setting increased the possibility of support.

“Friends and family play a significant information sharing and support role in the rural area.”

“Tightly knit communities can be a source of support.”

While breast cancer support groups are less likely to be available in rural settings, many of those participating in the focus groups had nevertheless attended one (this being a function of the sampling strategy). Most had found it helpful. However, there was considerable discussion about the difficulties in establishing groups that are convenient for rural women.

“Support groups are necessary, but in small towns/cities and rural areas they are hard to organize and keep going.”

“The problem with organized, community based support groups is that there are so few of them, and so few people wanting to join such a group at any particular time. Another problem is having a suitable facility.”

Women perceived that facilitators for rural support groups often did not have the type of training they needed and they wondered if urban groups had more skilled leadership. Dealing with cancer-related issues was seen as too difficult for untrained women.

“Support group leaders should be trained in grief and loss.”

Some of the support that women sought, and had difficulty finding, had to do with meeting their family’s needs. The additional strain of running a home and parenting while coping with breast cancer diagnosis and treatment was often commented upon in the focus groups. Again, this concern was emphasized as being particularly difficult within a rural context, where services were rare and/or difficult to access. When women were away getting treatment for extended periods, these issues were gravely exacerbated.

“I needed day care for my kids. There was a total lack of help.”

“There’s a need for practical support, bringing food, taking children to activities, getting costumes/uniforms for kids activities, taking (me) out, providing transportation, etc.”

“I needed home support during my treatments. It wasn’t possible.”

Many of the women participating in this project spoke of the pressures put on their families by their illness, and on their perception that family members also needed support. They argued for the importance of having professional services available to family members at cancer treatment centres.

“I was oblivious to my family’s needs. They needed support.”

Women often commented that they wished they had access to supportive care programs run by health professionals or trained peers.

“I was jealous when I heard what Wellspring [urban psychosocial resource program] has to offer, nutritional support, exercise groups...we don’t have anything remotely like that.”

Services: Women in all the focus groups spoke about issues of access to necessary services, including family doctors, cancer specialists, screening centres, and treatment centres.

“Some women have no family doctor. No choice of doctors, and doctors with very large caseloads.”

“There aren’t enough doctors to go around. They are overbooked. You have to have a referral. An oncologist flies in from Vancouver once every two months for 1 day. It’s a different oncologist every time.”

“Difficulty in accessing even local doctors. Closest doctor ...is 400 kilometers from where I live.”

“It is worse when the tests are analyzed at an outside location. They cannot perform the analysis in the rural areas...it is much longer for us to wait.”

“Around here there’s a lack of options, re reconstruction, prosthetics, new drugs, etc.”

The issue of access to local physicians was seen as particularly critical in the rural context, as women rely more heavily on their physicians in the absence of other informational and professional options.

“Those living in rural communities rely heavily on their local health care providers for assistance with decision-making and support.”

Even when women had the access they wanted to local family physicians, poor communication from cancer treatment centres and specialists to family physicians often meant that the women could not get the informed help they needed.

“My GP was left out of the loop by the specialist.”

“Once rural women are back home, they are out of the system. Oncologists are leaving and women are getting dropped.”

There were some complaints from women that certain treatments might be offered more often in local centres than was occurring.

“Doctors seem to send patients to bigger hospitals, even if treatment is available locally. Small hospitals that could take chemo orders, don’t get them.”

Strong concerns were voiced across all the focus groups about issues of timing within the medical system. Women talked about long waits for tests followed by rushed decision-making.

“The system either moves too slow or too fast for rural women. There are issues regarding access to appointments, waiting

time for, and travel time to, appointments. Things go more slowly from rural areas. However once diagnosed, appointment time and treatment choices are scheduled quickly and women do not have enough time to make decision about surgeries/treatments.”

Treatment decisions were frequently influenced by the women’s rural context. Consistent with other studies (Iscoe et al., 1994; Elward et al., 1998), findings from this project showed that a higher proportion of women chose mastectomy over lumpectomy. Their reason for pursuing mastectomy most often related to the distance involved in traveling for radiation treatment, with associated impacts on childcare/family responsibilities, finances and work.

“I chose mastectomy over lumpectomy and radiation because I didn’t want to disrupt the family.”

“When I was offered lumpectomy or mastectomy I elected mastectomy given the higher costs of being away from my family.”

“I couldn’t afford lumpectomy and radiation.”

“Had mastectomy because of the threat of losing my job.”

Women’s experiences with hospital stay and post-treatment follow-up varied across the country. Many felt they were sent home too soon, given the distance they needed to travel home and the relative lack of medical/nursing supports available once they arrived home.

“Brevity of the stay following a complete mastectomy is completely unacceptable. Having to travel 5-6 hours after a mastectomy is simply inhumane.”

“I had a mastectomy at 1 p.m. and was sent home by 6 p.m., and was in emergency at midnight, with complications.”

“There was no one locally available to remove tubes/bandages/stitches/drains.”

Other Themes

Dealing with Isolation: Many of the women who participated in focus group discussions described having struggled with a sense of isolation, both in their home setting and in the urban setting where they received treatment. This was particularly pronounced for women who had to stay in an urban setting for extended periods in order to receive treatment. The initial experience was often one of feeling displaced from all the usual supports and contexts.

“It was devastating to come to an unknown city. No friends, nothing to do.”

“The worst part of all was the radiation. It was a living hell. I spoke to my kids on the phone every night to tuck them in. My parents took care of them and I was all alone with nothing to do.”

Often, over time, women made connections with other cancer patients in the cities where they were staying. But then when they returned home, it could feel like they were losing their hard-won support network.

“It was scary to be on my own [after completion of treatments]. I thought, ‘Now what do I do?’”

“I was lonely, especially when I returned home, as I left my supports behind in the city where I had my treatment.”

Isolation continued for some of the women unable to find support locally. Sometimes this was because of a perceived lack-of-interest from others, while in other situations women decided to isolate themselves in order to avoid being the topic of gossip.

There are problems with lack of anonymity and confidentiality in rural areas. *“Nurses in town would often tell everyone.”*

“A common misunderstanding about rural life is the assumed connection among people.”

“It’s just me and my husband. I have nobody else.”

“Just because I live in a rural area, does not mean I am close to my neighbours. I don’t want them to know about me, and that I have breast cancer.”

Having to Travel: As already noted, many of the women participating in the focus groups reported having to travel to cancer centres in order to access treatment. For many this involved extensive distances, by car, plane, train and/or bus.

“I traveled 400 kilometers (one way) for chemo, and 300 kilometers (one way) to see my surgeon and for surgery and for follow-up appointments.”

“My husband and I have put on 12,000 kilometers coming into the city for appointments and treatments.”

“Travelling to the city on the late night bus for an early morning appointment (10 hours bus ride) is time-consuming, exhausting, and then being booked in a day room and expected to travel back on the same day...”

Many women talked about difficulties related to driving, including bad weather conditions, driving at night, and the fear of driving in an unknown city. Many felt that cancer centre staff gave little attention to patients’ travel challenges when appointments were being booked.

“Winter driving makes travelling impossible.”

“I’m afraid to travel into the city.”

“I’m reluctant to drive at night, but I had to.”

Women also talked about problems involved in arranging transportation,

especially those women who didn't have their own vehicles.

"I didn't have a vehicle, so I had to arrange drivers."

"If you don't drive, you won't get there. There is no other transportation."

"I couldn't participate in activities at the clinic because my volunteer driver was waiting outside."

While accommodation was usually arranged for patients in the city where they went for treatment, things did not always work out.

"There was not enough room at the lodge so I had to stay at a motel. I didn't know how much it would cost, or how long I would have to stay."

Feeling the Financial Burden: Concerns about finances were discussed in all of the focus groups. While this is not unusual among cancer patients, the economic realities of rural life added extra urgency to the concerns voiced by women in this project.

"All this financial stress on top of the disease. 'Will I be able to afford the rent?' is a common question I asked."

"Extreme poverty, 15 weeks of unemployment, and then nothing."

A common frustration linked with finances related to reimbursement. Many women referred to financial inequities (compared to urban patients) and to limited/scarce assistance.

"Living 3 hours away was not considered remote enough to warrant lodging or travel reimbursement."

"I come from a small, isolated community where resources are scarce for everyone."

"I was angry when I found out that [southern city] women were being sent to Sudbury for treatment, all expenses paid

(food/lodging/transportation) when I only get a certain amount reimbursed from my travel expenses."

"There are subsidies available but they are not advertised."

"No access to subsidies for travel to treatment, or anti-nauseant medication if your income is over \$15,000."

Other non-reimbursable costs that often came as a surprise to the women included phone calls from urban treatment centres, required side-effect medications, and prosthetics.

"Cost of phone calls and prescriptions was high."

"I couldn't afford the only anti-nauseant that would work for me."

"Women shouldn't be held hostage regarding medical supplies for post-mastectomy patients. Costs are higher because of rural location and purchasing outside the Yukon isn't always possible."

There were hidden costs involved for those who had to stay in the city for treatment.

"I had no money for childcare. The kids had to go away for two week periods with my mother-in-law, and the youngest child had to go to a different kindergarten during those periods."

Coping with a Changing Work-Life: Many women who participated in the focus groups expressed needs and issues associated with employment. The women emphasized the uniqueness of employment practices in rural communities where work options rarely include a full-time salary with a single organization. Many women were working multiple part-time jobs, all without benefits and/or job security. Others were self-employed. These women were left without options when they needed time off for sickness or to travel for treatments.

“Many jobs in the north are part-time, or involve people who are working for small businesses, or are self-employed without benefits.”

“Employers want to be rid of women with breast cancer since they think you won’t be reliable or you will get sick again.”

RECOMMENDATIONS

Women attending focus group were encouraged to make suggestions on how best to meet the needs of rural women with breast cancer. The women expressed strong determination to change the nature of the breast cancer experience for women diagnosed in the future.

“I hope our recommendations are listened to, and followed up on!”

“We want things changed, if not for us, then for our daughters, our friends’ daughters, our granddaughters.”

Each focus group participant was asked to list their personal top three recommendations, based on what they heard discussed during the group. Recommendations fell into four main categories: Information, Support, Medical Services, and Finances. These will be reported on below, while a complete listing of specific recommendations can be found in Appendix D.

Information

A frequent recommendation related to information was to encourage doctors to make a standardized information package available to women at the point of diagnosis. Such an information package would be sensitive to the rural context and might include: medical resources, contact information about breast cancer survivors, support group information, information about professional psychosocial support personnel, books, websites, and information on treatment and treatment side-effects.

Some women reported that information packages were becoming available in their regions, but that the information was often not standardized, and that dissemination tended to be erratic.

Specific recommendations were made for better information about all of the following:

- Breast Health
- Breast Cancer Risk
- Treatment Options
- Treatment side-effects
- Post-treatment issues such as menopause and lymphodema

Some women talked about wanting information in various formats (video, pamphlets, books). Others spoke of the need for information written especially for their spouses and/or children.

Many women saw the need for better information/education as extending beyond breast cancer survivors and their families to include women who were well. Concerns about future generations of women were expressed through comments that younger women need to be properly educated about breast cancer. Many focus group participants recommended that education about breast health start in adolescence, and that young women learn about the need for breast self-exam and mammography.

Support

The most common support-related recommendation was to find ways to facilitate access of newly diagnosed women to another breast cancer survivor. Women noted that this peer support is critical for helping to minimize fears, normalize experiences, and offer a “survivorship” perspective.

“I immediately thought death, when I heard the word cancer. If I would have spoken to a survivor, I would have seen someone who continued to live and thrive after a diagnosis.”

Other support recommendations made by the women related to access to services and programs. Women recommended more programs for rural areas.

“Support needs to be an automatic part of the process, from the moment that an abnormality is detected.”

“All women and their families should get the support they need, regardless of where they live.”

Medical Services

Many women participating in the focus groups strongly recommended improvements to the current system, so as to allow breast cancer survivors better access to high quality medical/nursing services, in a coordinated, patient-sensitive manner. Women noted that the health care system is disjointed, with little communication between health professionals and organizations.

A specific recommendation supported by a substantial number of women was to have nurses specializing in oncology available within rural regions. Such nurses would be able to meet with patients to address health issues, thereby lowering costs and lightening the load for oncologists.

Another specific recommendation was to create networks of “patient navigators” who could guide newly diagnosed women through the cancer care system. Many women thought that a patient navigator would make it more likely that any given woman would access available services in a timely way, thereby reducing unnecessary stress and anxiety.

Finances

Women in all of the focus groups were angry and upset about costs incurred during breast cancer treatment. Women recommended that all expenses incurred be covered and that lower income women get special consideration, such as free prosthetics (replaced when appropriate).

Women also recommended overwhelmingly that travel-related expenses be provided up-front, so that they wouldn't be out-of-pocket and have to be reimbursed.

FINAL COMMENTS

Rural women have considerable unmet needs, including many issues related to access. Focus group participants strongly voiced their displeasure that urban women with breast cancer seem to be receiving better care and support than they are. They argued for practical help that would make the treatment process more feasible. Daily living concerns such as travel, time away from work, home and childcare, need to be better addressed if there is to be hope for equitable care for women in rural communities.

The recommendations that were generated through the seventeen focus groups organized by CBCN across Canada offer a variety of important ideas and suggestions. Some of these recommendations have already been implemented in selected regions – such as providing information packages for newly diagnosed women or linking them with patient navigators. An important next step is to extend such innovative initiatives beyond urban centres. We hope for a future Canada in which all women will have equal access to high quality breast cancer care.

FEEDBACK ON THIS REPORT

The preceding report, together with a feedback form and covering letter, were sent to 266 breast cancer stakeholders across Canada. Stakeholders were asked to read the report and provide input. A total of 67 feedback forms were returned – for a 25% response rate. The forms included 11 scaled items, for which stakeholders were asked to indicate levels of agreement or disagreement. For the purposes of reporting findings, ratings were organized into categories of “agree,” “uncertain/neutral” or “disagree.” (See Appendix E for more information).

At least two-thirds of stakeholders agreed with each of the following 11 items. The specific percentage of those agreeing with each item appears in front of the item.

- 74% - Rural women with breast cancer have difficulties accessing high quality information in a timely manner.
- 84% - Rural women with breast cancer have difficulties accessing peer and professional support in a timely manner.
- 68% - Rural women with breast cancer have difficulties accessing appropriate medical and nursing services.
- 85% - Rural women with breast cancer have more difficulties than do urban women accessing high quality information, peer and professional support, and medical and nursing services.
- 81% - Dealing with social isolation is a major problem for rural women with breast cancer.
- 97% - Having to travel for treatment is a major problem for rural women with breast cancer.
- 89% - Inadequate financial programs create a major burden for rural women with breast cancer.
- 83% - Coping with a changed work life if a major problem for rural women with breast cancer.
- 98% - Standardized, and locally sensitive, information packages should be made consistently available to women with breast cancer in all regions of Canada.
- 98% - Systems need to be developed to better help newly diagnosed breast cancer patients living in rural areas navigate the health care system.

93% - Systems need to be put into place to ease the financial burden for rural women with breast cancer.

The high agreement for the above items corresponded to stakeholders' responses to an open-ended question in which they were asked to comment about the overall report. Almost all of the 32 responses to this item reinforced and validated points that had been made in the report (see Appendix F for complete listing) or else offered suggestions about how rural women with breast cancer could be better served by the health care system. Only two responses addressed a perceived limitation of the report. One stakeholder thought that it was important to acknowledge that the issues raised for women with breast cancer were also relevant for women with other kinds of cancer. Another commented that it was important to note that services could be quite variable in quality from one rural region to the next.

The feedback received from stakeholders strengthens the validity of the findings developed from the initial focus group study. The relevance of the experiences and recommendations made by women in those groups was broadened by the agreement of a substantial number of breast cancer stakeholders across Canada.

Stakeholders were also asked to indicate existing programs or services that they were aware of that are helpful to rural women and that might serve as models for other parts of the country. Responses to this item did not reveal programs specific to rural women. Information kits and support groups were most often listed (see Appendix G for complete listing). In order to obtain a fuller understanding of existing "best practices" for rural women with breast cancer, a more targeted information-gathering approach seems warranted.

REFERENCES

- Bilodeau, BA.& Degner, L.F. (1996). Informational needs, sources of information and decisional roles in women with breast cancer. *Oncology Nursing Forum* 23: 691-696.
- Bryant, H.E., Desautels, JE., Castor, WR., Horeczko, N., Jackson, F., Mah, Z. (1993) "Quality assurance and cancer detection rates in a provincial screening mammography program. Work in progress." *Radiology* 188: 811-816.
- Bryant, HE., Mah, Z. (1992). Breast cancer screening attitudes and behaviors of rural and urban women. *Preventive Medicine* 21(4): 405-418.
- Elward KS, Penberthy LT, Bear H, Swartz DM, Boudreau RM, Cook SS. (1998). Variation in the use of breast-conserving therapy for Medicare beneficiaries in Virginia: clinical, geographic, and hospital characteristics. *Clinical Performance Qualitative Health Care* Apr;6(2):63-69
- Goel, V., Olivotto, I., Hislop, TG., Sawka, C., Coldman, A., Holowaty, EJ. (1997). Patterns of initial management on node-negative breast cancer in two Canadian provinces. *British Columbia/Ontario Working Group. Canadian Medical Association Journal*. 156(1): 25-35.
- Iscoe, NA., Goel, V., Wu, K., Fehringer, G., Holowaty, EJ., Naylor, CD. (1994). Variation in breast cancer surgery in Ontario. *Canadian Medical Association Journal*, 150(3): 345-352.
- Koopman, C., Angell, K., Turner-Cobb, J.M., Kreshka, MA., Donnelly, P et al. (2001). Distress, coping, and social support among rural women recently diagnosed with primary breast cancer. *The Breast Journal*, 7(1): 25-22.
- McGrath, P., Patterson, C., Yates, P., Treloar, S., P, Oldenburg, B., Loos, C. (1999) A study of postdiagnosis breast cancer concerns for women living in rural and remote Queensland. Part 1: Personal concerns. *Australian Journal of Rural Health*, 7:34-42.
- McGrath, P., Patterson, C., Yates, P., Treloar, S., P, Oldenburg, B., Loos, C. (1999) A study of postdiagnosis breast cancer concerns for women living in rural and remote Queensland. Part II: Support issues. *Australian Journal of Rural Health*, 7: 43-52.
- Mills, M.E.& Sullivan, K. (1999). The importance of information giving for patients newly diagnoses with cancer: a review of the literature. *Journal of Clinical Nursing* 8(6): 631-642.
- Muldoon, J.T, et al. (1996). Utilization of cancer early detection services among farm and rural non-farm adults in Iowa. *Journal of Rural Health*, 12 (4 suppl) 321-31.
- Northouse, L.L. (1989). The impact of breast cancer on patients and husbands. *Cancer Nursing* 12, 276-284.
- White, NJ., Given BA., Devoss, DN. (1996). The advanced practice nurse: meeting the information needs of the rural cancer patient. *Journal of Cancer Education* 11(4): 203-209.

APPENDIX A

Focus Group Guide

CBCN Consultation Facilitator's Copy

Focus Group I – Pre-diagnosis and Diagnosis Stages

Some of the following questions and probes may not need to be posed because the participants may get to the issues on their own as the discussion proceeds. However, these questions capture the essential points we wish the group to address. The more specific the recommendations at the end, the more useful they will be.

Would you think back to the time before you were diagnosed with breast cancer:

1. What did you know about breast cancer then and how did you get that information?
Probes: Ask for a show of hands: (*Recorder should count and record*)
Who paid attention to information from TV, radio, newspapers, magazines, and so on?
Who learned about breast cancer through talking with other women?
Who got information through friends or family members with breast cancer?
Who did something you thought might help protect you from breast cancer? If so, what?
2. What did you do about your own breast health?
Probes:
Who did regular Breast Self-examination?
Who went for an annual physical check-up during which the doctor did a breast exam?
Who had a mammogram every year?
Who had a mammogram every two years? If not, why?
Were you doing anything “preventative” (stop smoking, watch your diet, cut down on alcohol, etc)
3. How did you discover your lump? (mammogram, BSE, doctor's office, etc)
Probes: Ask for a show of hands: (*Recorder should count and record*)
How did you feel about your discovery?
What was the sequence of events after that?
Please describe the time after your initial discovery (pre-diagnosis):
Probes:
Were you given a series of tests? What were they?
Did you have to wait a long time for tests?
What were your fears? Did you feel uncertainty?
Did you get support at this time?
Did you consider whether it was a cyst, or malignant?
4. Diagnosis: Please describe how you were told about your diagnosis
Probes:
How did you feel about the way you got your diagnosis?
Did you ask for a second opinion?
What, if any, written information were you given?
Were you given the pathologist's report or told about your diagnosis (grade, stage)?
How soon did you receive information regarding your treatment options or recommendations?
How well coordinated did you think your medical team was?
(for example, did your General Practitioner, Surgeon and Oncologist seem to be communicating and recommending the same course of action?)
5. After your diagnosis, where did you get additional information about your disease?
Probes:
Were you given information (package, documents, etc)?
Were you told where to access information?
What information did you get from whom or from what organizations?
How did you feel about that help?

6. **Recommendations:**

Looking at the various aspects of life listed on the left side of your answer sheet, and with those aspects in mind, what would you wish for or recommend for changes in services and support during the **pre-diagnosis** and **diagnosis** stages of breast cancer?

Probes:

- First, what would you wish for **before** you knew you had breast cancer?
- Second, what would you wish for **during** the time **between** your **suspicions** and your actual **diagnosis**?
- Third, what would you wish for **when you were told** you had breast cancer?

If time and space permit, invite participants to rotate to the various flipcharts for each aspect of life and record their recommendations. Alternatively or in addition, they may use the spaces under each aspect of life on their own Issues sheets for this session.

7. Could we quickly go around the table and hear from each of you **one** thing you **celebrated** or **one** thing you **learned** through these stages?

CBCN Consultation Facilitator's Copy

Focus Group II – Post-diagnosis and Treatment Stages

Some of the following questions and probes may not need to be posed because the participants may get to the issues on their own as the discussion proceeds. However, these questions capture the essential points we wish the group to address.

Over the next hour and a half, we want you to think back to what it was like for you in the time between your diagnosis with breast cancer and your surgery; the time between surgery and your first treatment; and then what it was like to go through all the treatments you had. We realize this may be difficult for you—those must have been hard times. We will appreciate your efforts to help others through sharing your stories.

1. Where did you get information prior to surgery and treatment?
Probes:
Did you get information in making your decisions? Who/where from?
How satisfactory was that information in helping you understand your choices and make your decisions?
What determined your choice of treatments?
What, if any, opportunities for discussion or clarification were available to you?
How well did you understand your choices?
How did you feel about the choices and decisions you had to make?
If options were available to you, were you able to take advantage of them? If not, why not?

2. How involved were you in treatment options and decisions?
Probes:
How did you finally decide what treatment was best for you?
Who helped you in this decision making process?
Did you have all the information you needed, or was there something that would have been helpful?
What did you want to know that on one was able to help you with?

A - SURGERY

3. If you had to wait awhile for surgery, what help did you get and from whom?
Probes:

Were you told about support groups in your area?
How easy was it to access information and/or consultation with knowledgeable people?
How were any of your contacts helpful?
What, if any, help did your family need and/or seek? How helpful was that?

4. What was it like to go through your surgery and recover from that?
Probes:

How timely did you think your surgery was?
What troubled you most? Why?
Were there any big surprises—good or bad?
What and who helped you through the process?
What was the impact of your surgery on your body? On your emotions?
What was the impact of your surgery on your family?

B - TREATMENTS

5. What was it like to go through your treatments?
First, let's get a picture of the range of treatments this group experienced:
 - Who had chemotherapy?
 - Who had radiotherapy?
 - Bone marrow treatment?

- Who had both?
- Who had some other treatment? What treatment(s)?
(Facilitator should record—perhaps in columns—on flipchart)

Probes:

What were your greatest hardships?

Were there any big surprises—good or bad?

How did your treatments affect you physically?

How did your treatments affect you emotionally? Spiritually?

Who and what helped you most through the treatment process?

What was your experience like with the Cancer Clinic?

Were you asked to be part of any drug trials or other research-oriented treatments?

How did your treatment process affect your family? Other aspects of your life?

6. Recommendations:

Looking at the various aspects of life listed on the left side of your answer sheet, and with those aspects in mind, what would you wish for if you were going through the **post-diagnosis, surgery** and **treatment** stages again? What recommendations for changes in services and support would you make?

If time and space permit, invite participants to rotate to the various flipcharts for each aspect of life and record their recommendations. Alternatively or in addition, they may use the spaces under each aspect of life on their own Issues sheets for this session.

7. Could we have a quick round of **one** thing you **celebrated** or **one** thing you **learned** through these stages?

CBCN Consultation Facilitator's Copy

Focus Group III – Post-treatment and Supportive Care Stages

Some of the following questions and probes may not need to be posed because the participants may get to the issues on their own as the discussion proceeds. However, these questions capture the essential points we wish the group to address.

All day you've been reliving your journey through diagnosis and treatment of breast cancer. You survived your treatments and our probing of your thoughts, feelings and wishes about them—you really are “Survivors” with a capital “S”! Thank you!

We're on the home stretch now. We hope it will be a little easier for you to think back over your lives since you completed your treatments. That's what we'd like you to do for this last Focus Group. Then we'll do a quick review of our accomplishments today.

1. What was it like to be finished with treatments?

Probes:

- How did you feel, physically?
- How did you feel about yourself?
- What was your greatest relief or joy?
- How did your life change?
- How did it affect your family life?
- How did it affect your work and other activities?

2. For those of you who have had a recurrence of cancer, what kinds of thoughts did you have regarding how aggressively you might pursue further treatments?

Probes:

- What influenced your decisions most?
- What has been different about this experience?

3. What kinds of services and support did you have once your treatments were finished?

Probes:

- Have you been involved in a support group? If so, what sort(s)?
- How did you find out about that?
- Was it helpful to you? How?
- If you did not join a support group, why not?
- What services were available to you?
- How did you find out about them?
- Did you use them? If so, how were they helpful to you?
- If you did not use them, why not?

4. Have you been involved in giving support or taking part in advocacy activities? If so, what have you done?

Probes:

- Why have you involved yourself in this way?
- How has it helped you?
- Are there other ways you would like to be involved in support and/or advocacy activities?

5. **Recommendations:**

Using the aspects of life listed on the left side of your answer sheet, please write your recommendations for changes in services and support during the **post-treatment** and **supportive care** stages of breast cancer?

If time and space permit, invite participants to rotate to the various flipcharts for each aspect of life and record their recommendations. Alternatively or in addition, they may use the spaces under each aspect of life on their own Issues sheets for this session.

6. Let's hear another round of **one** thing you **celebrated** or **one** thing you **learned** through these stages!

Appendix B

Focus Group ~Participant Evaluation Form

Do you feel the facilitator provided sufficient direction for participants?

YES NO DON'T KNOW

Did you feel the facilitator created an atmosphere in which you felt safe to share your personal experience? If not, why not?

B – Meeting Organization

Were you satisfied with the organization of the consultation:

i) Meeting Room

ii) Meal selection

iii) Accommodation (if applicable)

Did you feel that the number of participants invited was:

APPROPRIATE NOT ENOUGH TOO MANY

Do you have any comments regarding the agenda or the structure of the day (too many or not enough items to cover, enough time, etc)

Additional comments and/or suggestions for improvement?

Thank you for completing this evaluation!

APPENDIX C

Focus Group Demographics and Statistics

DEMOGRAPHICS CBCN ~RURAL WOMEN

CURRENT AGE RANGE

AGE RANGE	NUMBER of RESPONSES	PERCENTAGE
30 – 39 years of age	7	4 %
40-49	37	24 %
50-59	73	46 %
60-69	33	21 %
70-79	4	3 %
80-89	1	
BLANK	2	
TOTAL	N= 157	

AGE AT DIAGNOSIS

AGE RANGE	NUMBER of RESPONSES	PERCENTAGE
20-29 years of age	3	2 %
30 – 39	21	13 %
40-49	65	41 %
50-59	45	29 %
60-69	15	10 %
70-79	0	
80-89	0	
BLANK	8	5 %
TOTAL	N=157	

AGE AT 2ND DIAGNOSIS

AGE RANGE	NUMBER of RESPONSES	PERCENTAGE
20-29 years of age	0	
30 – 39	2	
40-49	4	3 %
50-59	9	6 %
60-69	2	
70-79	1	
80-89		
BLANK/OR NOT APPLICABLE	130	83 %
RECURRENCE NOTED, BUT UNKNOWN AGE	9	6 %
TOTAL	N= 157	

MARITAL STATUS

STATUS	NUMBER of RESPONSES	PERCENTAGE
Single	8	5 %
Married	106	67 %
Common-law	9	6 %
Separated	0	
Divorced	10	6 %
Widowed	19	12 %
Blank	3	2 %
Combination –given change in status across treatment	2	
TOTAL	N= 157	

CHILDREN

NUMBER OF CHILDREN	NUMBER of RESPONSES	PERCENTAGE
0	14	9 %
1	21	13 %
2	61	39 %
3	24	15 %
4	18	11 %
5	9	6 %
6	4	3 %
7	1	
8	1	
Blank	4	3 %
Total	N= 157	

ABORIGINAL GROUP/ETHNIC ORIGIN

	NUMBER of RESPONSES	PERCENTAGE
English/Caucasian/ Canadian	54	34 %
European descent	30	19 %
South African	1	
Asian	1	
~Aboriginal ~ 13		8 %
North American Indian	3	
Metis	6	
MicMac	2	
LIA	1	
Status Treaty	1	
Blank	59	38 %
Total	N= 157	

RESIDENCE

TYPE OF RESIDENCE	NUMBER of RESPONSES	PERCENTAGE
1- Village	42	27 %
2- Town	59	38 %
3- City	40	25 %
4- Farm /Rural/ Country	14	9 %
BLANK	2	
TOTAL	N= 157	

POPULATION

POPULATION RANGE	NUMBER of RESPONSES	PERCENTAGE
1- 0-5,000	92	59 %
2- 5,000- 10,000	24	15 %
3- 10,000 – 15,000	9	6 %
4 – 15,000 – 20,000	10	6 %
5 – 25,000 +	20	13 %
BLANK	2	
TOTAL	N= 157	

DISTANCE FROM SURGICAL SERVICES

Given that many individuals are travelling on local roads, mileage counts have been calculated assuming that individuals are able to drive 60 km/hr. While this may not reflect travel times for individuals closer to major cities, the majority of respondents are living in remote areas, where highway access is not applicable.

	NUMBER of RESPONSES	PERCENTAGE
1 – less than 15 kms/15 minutes	39	25 %
2- 16 km-30 km /15-30 minutes	21	13 %
3- 31 km-60 km/30-60 minutes	14	9 %
4- 61-90 km/ 1 – 1 ½ hours	19	12 %
5- 91-180 km/1 ½ hours-3 hours	18	11 %
6-181-360 km/ 3 – 6 hours	19	12 %
7- 361-600 km/ 6-10 hours	5	3 %
8- 600 – 1,000 km / 10-15 hours	8	5 %
9- 1,000 – 2,000 km	2	
9+ - 2,000 – 3,500 km	5	3 %
Respondent noted two different distances, depending on type of surgery/treatment	2	
Respondent did not answer or marked not applicable	5	3 %
TOTAL	N=157	

DISTANCE FROM CHEMOTHERAPY

Given that many individuals are travelling on local roads, mileage counts have been calculated assuming that individuals are able to drive 60 km/hr.

	NUMBER of RESPONSES		PERCENTAGE	
	N-157	N-129	N-157	N-129
1 – less than 15 kms/15 minutes	43/157	43/129	27 %	33%
2- 16 km-30 km /15-30 minutes	14/157	14/129	9 %	11 %
3- 31 km-60 km/30-60 minutes	9/157	9/129	6 %	7 %
4- 61-90 km/ 1 – 1 ½ hours	12/157	12/129	8 %	9 %
5- 91-180 km/1 ½ hours-3 hours	16/157	16/129	10 %	12 %
6-181-360 km/ 3 – 6 hours	13/157	13/129	8 %	10 %
7- 361-600 km/ 6-10 hours	4/157	4/129	3 %	3 %
8- 600 – 1,000 km / 10-15 hours	4/157	4/129	3 %	3 %
9- 1,000 – 2,000 km	2/157	2/129	1 %	2 %
9+ - 2,000 – 3,500 km	4/157	4/129	3 %	3 %
Respondent noted two different distances, depending on cycle in treatment	8		5 %	
Respondent did not answer or marked not applicable	28		18 %	
TOTAL	N=157	N=129 *		

*Variations in sample size are due to women's differing treatment regimes

DISTANCE FROM RADIATION

Given that many individuals are travelling on local roads, mileage counts have been calculated assuming that individuals are able to drive 60 km/hr.

	NUMBER of RESPONSES		PERCENTAGE	
	N-157	N-126	N-157	N-126
1 – less than 15 kms/15 minutes	3	3/126	2 %	2 %
2- 16 km-30 km /15-30 minutes	5	5/126	3 %	4 %
3- 31 km-60 km/30-60 minutes	9	9/126	6 %	7 %
4- 61-90 km/ 1 – 1 ½ hours	4	4/126	3 %	4 %
5- 91-180 km/1 ½ hours-3 hours	23	23/126	15 %	18 %
6-181-360 km/ 3 – 6 hours	29	29/126	18 %	23 %
7- 361-600 km/ 6-10 hours	11	11/126	7 %	9 %
8- 600 – 1,000 km / 10-15 hours	12	12/126	8 %	10 %
9- 1,000 – 2,000 km	4	4/126	3 %	3 %
9+ - 2,000 – 3,500 km	21	21/126	13 %	16 %
Respondent noted two different distances, depending on type of surgery/treatment	5		3 %	
Respondent left blank	24		15 %	
Respondent did not answer or marked not applicable	7		4 %	
TOTAL	N=157	N=126 *		

*Variations in sample size are due to women's differing treatment regimes

ACCESS TO TRANSPORTATION FOR TREATMENT

	NUMBER of RESPONSES	PERCENTAGE
1 – Own Car	76	48 %
2 – Friend, Relative to drive	20	13 %
3- Other – Plane, Bus, Train	19	12 %
1,2 combined	9	6 %
1,3 combined	15	10 %
1,2,3 combined	7	4 %
2,3 combined	3	
Respondent left blank	8	5 %
Total	N= 157	

YEARS SINCE DIAGNOSIS

AGE RANGE	NUMBER of RESPONSES	PERCENTAGE
1- less than 1 year	24	15 %
2- 1 – 2 years	20	13 %
3- 2-3 years	24	15 %
4- 3-6 years	41	26 %
5- 6-10 years	20	13 %
6- 10-15 years	10	6 %
7- 15 – 20 years	7	4 %
8 – 20 +	7	4 %
Respondent left blank	4	3 %
Total	N= 157	

STAGE

	NUMBER of RESPONSES	PERCENTAGE
1- Stage I	41	26 %
2- Stage II	44	28 %
3- Stage III a	21	13 %
4- Stage III b	4	
5- Palliative	2	
6 – Stage 2 - 3	5	3 %
7 – Stage 3-4	1	
Respondent left blank	32	20 %
Respondent noted unknown	6	4 %
Total	N= 157	

SURGERY

	NUMBER of RESPONSES	PERCENTAGE
Lumpectomy only	48	31 %
Mastectomy only	72	46 %
Both- Lumpectomy and Mastectomy	25	16 %
Not applicable or Blank	12	8 %
Total	N= 157	

TREATMENT

	NUMBER of RESPONSES	PERCENTAGE
1- Chemotherapy	26	17 %
2- Radiation	13	8 %
3- Tamoxifen	18	11 %
4- Other- alternative treatments	2	
5- All – Chemo, Radiation, Tamoxifen	34	22 %
6- Chemo and Tamoxifen	12	8 %
7- Chemo and Radiation	26	17 %
8- Radiation and Tamoxifen	12	8 %
Respondent left blank	7	4 %
Respondent noted not applicable	7	4 %
Total	N= 157	

OF YEARS SINCE COMPLETION OF TREATMENTS

	NUMBER of RESPONSES	PERCENTAGE
1- less than 1 year	30	19 %
2- 1 – 2 years	19	12 %
3- 2-3 years	19	12 %
4- 3-6 years	31	20 %
5- 6-10 years	12	8 %
6- 10-15 years	5	3 %
7- 15 – 20 years	4	3 %
8 – 20 +	3	
Respondent left blank	18	11 %
Current	8	5 %
Respondent noted not applicable	8	5 %
Total	N= 157	

OF YEARS SINCE COMPLETION OF 2ND DIAGNOSIS TREATMENTS

	NUMBER of RESPONSES	PERCENTAGE
1- less than 1 year	6	4 %
2- 1 – 2 years	2	
3- 2-3 years	0	
4- 3-6 years	1	
5- 6-10 years	1	
6- 10-15 years		
7- 15 – 20 years		
8 – 20 +		
Current	6	4 %
Current-alternative	1	
Respondent left blank	3	
Respondent noted not applicable	133	85 %
Respondent noted recurrent and treatment, but did not give dates	4	
Total	N= 157	

OF YEARS SINCE COMPLETION OF TAMOXIFEN TREATMENTS

	NUMBER of RESPONSES	PERCENTAGE
1- less than 1 year	12	8 %
2- 1 – 2 years	7	4 %
3- 2-3 years	4	
4- 3-6 years	9	6 %
5- 6-10 years	2	
6- 10-15 years	1	
7- 15 – 20 years	0	
8 – 20 +	0	
Current	22	14 %
Respondent left blank	6	4 %
Respondent noted not applicable	87	55 %
Respondent noted tamoxifen treatment, but did not give dates	7	4 %
Total	N= 157	

RECURRENCE

	NUMBER of RESPONSES	PERCENTAGE
1- Yes	24	15 %
2- No	107	68 %
Unsure-currently waiting for results-suspected recurrence	4	3 %
Blank-unknown	2	
Blank-assume no recurrence given other information provided	2	
Assume no recurrence, but questions not asked (Quebec groups)	18	11 %
Total	N= 157	

APPENDIX D
Recommendations

RECOMMENDATIONS

LEGEND

ΨΨΨ- noted in most if not all focus groups

ΨΨ - noted in at least half of the focus groups

Ψ - noted in at least 2 focus groups

A) SUPPORT

Provision of Supportive Services

Support should be offered automatically ΨΨΨ

Support should be considered part of treatment ΨΨΨ

Programs and information needs to be brought to rural women, who do not drive into the city

Support and Information needs to be made available with the understanding that cancer affects the whole family

Access to counselling immediately after diagnosis ΨΨΨ

Survivors should visit in the hospital ΨΨΨ

Have member of support group in the waiting rooms at clinics to allay apprehension/fear Ψ

Overall Support, for managing system

Need for expanded coordination among home care, other social services, community medical services, family physicians, and treatment centres outside rural areas, etc. ΨΨΨ

That a specific person be appointed to act as a resource to give information to women and families upon recent diagnosis

Regional nurse as coordinator of oncology treatment and follow-up care

Need a patient navigator in rural areas ΨΨΨ

Need a patient advocate, a contact person for the social/financial support, to remove the fears for themselves and their families ΨΨΨ

Need patient navigators who are people living/working in the local communities, who are linked to various resources and natural networks of support/information within the rural area ΨΨΨ

Need to have a visitor with experience with the same procedure, to talk to the patient ΨΨΨ

Training of Persons to provide Support

Need trained support group leaders to deal with grief and loss ΨΨ

Trained people to offer relaxation and other programs that benefit cancer patients Loan out tapes through health centres or doctor's offices

Volunteers should be better equipped to be even more useful and efficient ΨΨ

Train women who have gone through diagnosis/treatments to help others ΨΨ

Types of Support Needed

Someone to talk with, about sexuality ΨΨ

Family psychosocial support should be provided ΨΨ

Access to medical support – prosthetics/lymphedema ΨΨΨ

Telecommunications through telephone/e-mail/chat rooms/websites to connect breast cancer patients with peers, to greatly expand woman's ability to get the kind of empathic support they want and need ΨΨ

Better home care services are needed
Have professionals acknowledge spiritual needs and effects on emotional/spiritual life after diagnosis
Have a social worker immediately available at cancer centres to provide support
Better post-treatment follow-up is extremely important, but currently neglected ΨΨ
Make resources as available after treatment, as they are, during treatments
More individual/group support for patients undertaking chemotherapy

Support Groups

Survivors should be given access to support groups, immediately ΨΨΨ
New strategies need to be developed to get new members to attend. i.e. business cards, breast cancer consultant Ψ
Talk to people, to start up support groups in all communities ΨΨ
Have services like driving, childcare for support group meetings ΨΨ
Support groups for spouses ΨΨΨ
Support groups for children ΨΨΨ
Support groups for family members, friends and others concerned ΨΨ

Agencies

CCS should be promoted as a support for rural women Ψ
Practical support initiatives to see if needs of rural breast cancer patients needs are being met
Ψ

B) MEDICAL SYSTEM

Overall Coordination

More coordination between medical system and support community ΨΨΨ
Better coordination of services/supports ΨΨΨ
Cohesive system in place for follow-up for chronic diseases
Improved coordination of services ΨΨΨ
New equipment
Less lapsed time in between each of the steps in dealing with cancer (no extended waiting)
ΨΨΨ
More efficient route from discovery of lump to final diagnosis ΨΨΨ
Members of the health team treating you should confer together. Perhaps a team manager would help with this ΨΨ
Organize mammogram buses for women ΨΨ
Recommend that the breast screening truck be available to women in the north at least one a year (now it is every three years) and to those women over 30 years of age, who have a family history ΨΨ
Better admissions procedures into hospitals (some place to lie down when waiting for lumpectomy) ΨΨ
Prepare appropriate settings for chemotherapy treatments ΨΨ
Should implement special long-term stay protocols for women coming in from out of town Ψ
Interdisciplinary team approach with expertise in cancer skills, psychological supports, broad representation of health care fields, and continuity of care ΨΨ

Organization with mandates to coordinate dissemination of information should be encouraged to do so in rural areas Ψ

Access ~ To testing/treatment

Every woman who asks for a mammogram gets one ΨΨΨ
Access to breast screening programs for survivors ΨΨΨ
Do not deny a woman testing/screening. ΨΨΨ
One should not have to fight to be allowed to take such a test ΨΨΨ
Mobile breast screening programs for everyone ΨΨΨ
Breast screening available at age 40 (mammograms/ultrasounds)ΨΨΨ
Lower age to 40-49 for breast cancer detection programs. ΨΨΨ
More lymphedema centres opened ΨΨΨ
Access to one or two (lymphedema) sleeves at any one time Ψ
Lympho-press provided for as long as required Ψ
Be able to have radiation in hometown ΨΨΨ
Enable pathological analyses in rural areas, to avoid delays Ψ
Access to all support programs ΨΨΨ
All hospitals should provide the sentinel-node biopsy as a surgical procedure ΨΨΨ
More efficient biopsy results ΨΨ
Provide ongoing follow-up in relation to treatment and extent of need
Availability and accessibility of clinical trial drugs for women with a recurrence
More complementary therapies available Ψ

Access ~ Equality of services

Same level of services available in major centres should also be available in rural areas ΨΨΨ
Good networking, information gathering and increased accessibility will make a difference ΨΨΨ
Have a primary nurse as they have in some cities ΨΨ
Improved circulation of mobile screening units to smaller communities ΨΨ
Equal access to information, support and services ΨΨΨ
Equitable access to all services, oncologists, radiation, new drugs, clinical trials ΨΨΨ
Availability of all services to all breast cancer patients ΨΨΨ
Breast Cancer Surgery should be considered essential
All hospitals should provide the same level of services (I had great surgical services, however not all hospitals do)
It would be nice to have a trained nurse/doctor that was in my own city. (I am again losing my MD and really don't like the idea of seeing someone different each time I need an appointment)

Access ~Rural sensitivity

Timelines of appointments and sensitivity to rural women's situations would reduce anxiety, fatigue, and family hardships, as well as financial burdens ΨΨΨ
Consideration for rural women and travel time when booking appointments ΨΨΨ
Acknowledgement of travel, appointments upon arrival, no early morning appointments ΨΨΨ

One-stop shopping, breast screening, biopsy, post-op care all in one place ΨΨ
Have workshops or education accessible via conference calls, to give rural women opportunity to seek professional opinions ΨΨ
When someone comes in for treatment from the rural areas, arrangements ought to be made to meet and guide them through the day ΨΨ
Radiation treatment available in all rural areas ΨΨ
Fax results to GP rather than requiring rural women to drive to centre, just to pick up results
Support/relaxation programs for all available in rural community ΨΨ
Find ways to provide peer support to women in isolated areas Ψ
(teleconference/internet/phone/yearly meetings)

Access ~Other

Biopsies to be done under general anaesthetic ΨΨ
Have a women's wellness clinic for investigation of suspicious findings ΨΨ
Pre-chemo blood work, should be done at local hospital, rather than in the city, given the blood work necessary the day before treatment Ψ
Legalization of marijuana as a treatment regime Ψ
Volunteers ΨΨΨ
Lymphedema centres need to be set-up so that women may receive preventative treatment and instruction ΨΨ
Shelters (housing resources) should be open seven days a week
Follow-up post-op physiotherapy prior to discharge from hospital
Have a cancer clinic or special nurse where survivors could go to have breasts checked over, or if questions come up ΨΨ

Physicians

Need to ask patients if they need more information ΨΨ
Should inform women of all options ΨΨΨ
Need to provide more information on site ΨΨΨ
Consistent follow-up
Consistency in Physicians ΨΨΨ
More doctors (especially in rural areas) ΨΨΨ
Need to have a local specialist that women can see, because a lot of the doctors in rural areas, don't know about breast cancer Ψ
Doctors need to be more diligent and thorough in the breast exams that they do

Education for physicians / health care providers

System Issues

Important for rural physicians and health care providers to be informed about why the system works the way it does ΨΨΨ
Change doctors/nurses attention ~ let them know what support groups can do ΨΨ
Doctors need to promote volunteers, so that volunteers can offer their experience
Doctors should be aware of new surgical procedures and where they are being performed ΨΨΨ
Should be more discussions on treatment with several days in lectures, to let the patient have time to think

More support from G.P during cancer diagnosis/surgery/treatment
Continuity of seeing the same oncologist with each visit Ψ

Genetic Risk

Educate physicians that breast cancer can be transmitted through paternal lines

Doctor/Patient Communication

Educate physicians not to give breast cancer diagnosis over the phone, especially when women live alone ΨΨΨ

Physician communication skills training ΨΨ

Each person should be given options for their own treatment, rather than being told what to do.

“Please take time to really listen to the patient” ΨΨΨ

Doctors concern about not scaring patients is ridiculous ΨΨ

Treat the whole person and not just the cancer ΨΨΨ

C) INFORMATION

“We need information that is clear, simple, plain, complete and reassuring”

“Important for rural women and providers to be informed about reasons why system functions the way it does {guidelines}”

Resources locally

There is a need for more resource materials in local libraries ΨΨ

Provide books/resources to survivors through a book mobile once a month

Put resources in women’s centres in rural areas ΨΨ

Host community education sessions about breast cancer. Teach BSE Ψ

Have an assigned oncology nurse or contact to assist with accessing information on coordination of services in the region (rural area) Ψ

Create videos for those living outside of urban cities, that women can rent from their local libraries

If any suspicion of a breast lump, give women a number they can call to access a health care professional

More information about what is available to help financially (Trillium, where to stay in cities for treatment, driving programs etc) ΨΨΨ

More information about the resources available, ‘after-treatment’ ΨΨ

Education Programs/Information campaigns

Need for more education/awareness programs (Pink poster campaign) ΨΨ

Send out message about mammograms, so that women are not terrified about having mammograms

Reach to recovery advertisements and promotions should show younger women, possibly with children, or child bearing age, that encourages younger women to ask for help

Promote and encourage BSE ΨΨ

Increase information available for women who have completed their treatment

Simulation programs with artificial breasts with lumps in Health Centres and doctors offices, for women to learn what lumps feel like while doing BSE.

Signs and symptom cards or pamphlets for BSE or early detection like those that are available for heart and stroke

More education and information on exercise and lymphedema for long term care and maintenance ΨΨ

Education/Prevention for Younger People

Improved education for women, especially young women ΨΨΨ

Standardize breast health education with younger women and men in high school curricula Ψ

Information needs to be provided on the impact of fatigue/post-treatment side effects for children/young adults to understand

Visits to high school girls once a year as part of the curriculum

Education/Information for families

Create information videos to show and prepare children/family about what's ahead in terms of treatment/surgery

Books/videos to tell children about cancer Ψ

Information for spouses to read Ψ

Teach about the need for Insurance (Medical/Life), which should be acquired at a young age

Information about risk factors/healthy lifestyles and challenging misinformation about these

Better information about risk factors

There needs to be better information available for families of women with cancer. ΨΨΨ

Information packages

There should be a standardized package given to all women (including resources, supports, support group contacts, survivor names, choices in treatment, transportation possibilities, accomodation avenues etc. upon diagnosis ΨΨΨ

Provide newly diagnosed women with resources, before surgery

Recommend to Canadian Medical Association that doctors should provide a kit of resource information upon diagnosis, which should include information about reconstruction ΨΨΨ

Standardize the information that women get upon mammogram and diagnosis, so that no one slips through the cracks.

Provide step by step information about all tests/procedures/side effects ΨΨΨ

Consistent information of process and treatment effects ΨΨ

Information about upcoming and new treatments

Provide an intelligent breast cancer guide ΨΨΨ

D) FINANCES

Information regarding reimbursements

Criteria be revised for remote location category for support ΨΨ

Make sure financial obligations are explained to patient ΨΨ

Create a clear document that explains which drugs are covered, and whyΨΨ

Provide financial counsellors upon diagnosis to discuss financial needs and financial aideΨΨ

Information about travel grants needs to be made available ΨΨ

Promote availability of travel subsidies and income tax refunds for rural/northern women ΨΨ

Most women don't even know that you can claim mileage on your income tax Ψ

Information upfront about financial resources and family support available ΨΨΨ

Funding access

Up front coverage of medical costs required for control of side effects ΨΨΨ
Coverage for 2 bra's and 1 or 2 prosthesis every 4 years for women under 65 years of age, with no extended health coverage ΨΨ
Pay expenses-reimbursements up-front, and pay for family member to travel with patient ΨΨΨ
Lump sum provided up-front to cover medical expenses. There should be NO need to go to USA for treatment. ΨΨ

Funding for:

Childcare/travel ΨΨΨ
Regardless to distance, treatment needs to be covered, and organizations should be available that can help with this.
Childcare should be covered during surgery and treatment ΨΨΨ
Homecare if you have children
Transportation for radiation
Lodging/travel/food/childcare ΨΨΨ
Accommodation, if cancer clinic is over 4 hours away from patients home
Living (lodging) expenses should be covered as a result of living in a rural area ΨΨ
Medication/prosthetics/travel ΨΨΨ
All medication should be covered ΨΨΨ
Provide financial support, due to loss of wages Ψ
Support groups ΨΨ
Transportation and provincial travel reimbursements ΨΨΨ

Equality of funding

Northern grants to be the same for North as they are for the South ΨΨΨ
Coordination of funding, with no provincial cancer control and funding and services, it is all controlled by each region, which makes it very uneven Ψ

Legislative Change regarding financial assistance

Legislation to ensure job security through all phases of treatment (like maternity leave) ΨΨΨ
Get extended sick-leave benefits, similar to maternity leave, so there is a job to go back to ΨΨΨ
Job security during treatment and recovery should be assured through legislation
We have understanding employers, but no commonality of wage replacement plans for both short term and long term ΨΨ
Provincial welfare needs to consider the needs of cancer patients, especially rural cancer patients undergoing treatment Ψ

Work

Flexible work hours post-treatment ΨΨ
Education at the work place, about recovery time post breast cancer treatment
Rural workplace, need to change attitudes as often work is not 40 hours, full time, with benefits ΨΨΨ
Alternate job opportunities if person is unable to perform regular duties

E) FAMILY/SOCIAL CONCERNS & ISOLATION

I was worried about spending the money on medication, when I have 4 kids to care for Ψ
Some women can't leave their families. Not enough money to look after kids (and receive treatment). No support system to drive them to treatments ΨΨ
Some women are very marginalized Ψ

F) ISSUES WITHIN CITY/LOCATION OF TREATMENT

Accommodation

Need to have guaranteed lodging at time of scheduled treatments ΨΨ
Accommodation should be provided the night before treatment, and the night after appointments ΨΨ
Good to have the lodge at \$35/per day for the lodge, important to continue Ψ
Expand facilities for lodging and meals to accommodate all who are travelling for treatment ΨΨ
Overnight stay and meals, especially in the winter ΨΨ

Services

Treatment hospitals should really help rural women who are away from home ΨΨ
To have someone to talk to go out and have a coffee with, when you are out of town for treatment. I felt very alone.

G) TRAVEL

Information about travel grants, needs to be made available ΨΨΨ
Travel escort should be provided to help patient with travel arrangements, baggage and emotional support Ψ
Patient should be allowed to make choice of how to travel due to their condition Ψ
Travel grants need to be equalized north/south Ontario ΨΨΨ

H) OTHER

Most important

Find a cure for breast cancer!

Overall

More working together of holistic/natural and western scientific knowledge ΨΨ
Give community health nurses the recognition they deserve for being an integral part of the process
More privacy in the medical system during tests/appointments
Not have so many societies with cancer in their 'name'
Create awareness-Take Action!

Self-Advocacy

Individuals need to learn/be taught to advocate for themselves ΨΨΨ
Empower women to make a more informed choice about treatment, support and services needed. ΨΨ
Be open and honest about your breast cancer with your children and husband ΨΨ
Be honest with yourself about how you feel and what you should do for yourself

Government Support

Need for more money to hire staff to build networks Ψ

Use government strategies to recruit doctors to rural areas, and have them stay for a certain amount of time ΨΨ

Incentives to doctors to stay in rural/northern areas ΨΨ

Recruitment and retention of quality health care professionals in this province ΨΨ

A good substantive budget for Canadian cancer centres so that they can serve 'all' cancer patients

Money for rural support groups ΨΨ

More funding for breast cancer treatments, research etc ΨΨ

Research

Issues needing further investigation include gaining a better understanding about rural cancer rates and what exactly rural people want and need to learn more about, with regard to cancer prevention and treatment Ψ

Questionnaire should be developed for women at the time of diagnosis to see what they have in common (risk factors) Ψ

See if there is a link between breast cancer and multiple sclerosis (M.S.), due to a number of women being diagnosed with both Ψ

Questions such as risk factors for all diagnosed to complete, and then sent to a central office to compile results. Make these results available, to all women.

APPENDIX E

Responses to Stakeholder Feedback Form

- 1) Rural women with breast cancer have difficulties accessing high quality information in a timely manner.
N= 66
9 Disagree
8 Uncertain/Neutral
49 Agree
- 2) Rural women with breast cancer have difficulties accessing peer and professional support in a timely manner
N= 67
7 Disagree
4 Uncertain/Neutral
56 Agree
- 3) Rural women with breast cancer have difficulties accessing appropriate medical and nursing services
N= 66
11 Disagree
10 Uncertain/Neutral
45 Agree
- 4) Rural women with breast cancer have more difficulties than do urban women accessing high quality information, peer and professional support, and medical and nursing services.
N= 67
9 Disagree
2 Uncertain/Neutral
57 Agree
- 5.) Dealing with social isolation is a major problem for rural women with breast cancer
N= 67
6 Disagree
7 Uncertain/Neutral
54 Agree
- 6.) Having to travel for treatment is a major problem for rural women with breast cancer
N= 61
0 Disagree
2 Uncertain/Neutral
59 Agree
- 6.) Inadequate financial programs create a major burden for rural women with breast cancer
N= 62
0 Disagree
7 Uncertain/Neutral
55 Agree

8.) Coping with a changed work life if a major problem for rural women with breast cancer

N= 60
2 Disagree
8 Uncertain/Neutral
50 Agree

9.) Standardized, and locally sensitive, information packages should be made consistently available to women with breast cancer in all regions of Canada

N= 61
0 Disagree
1 Uncertain/Neutral
60 Agree

10.) Systems need to be developed to better help newly diagnosed breast cancer patients living in rural areas navigate the health care system

N= 62
0 Disagree
1 Uncertain/Neutral
61 Agree

11.) Systems need to be put into place to ease the financial burden for rural women with breast cancer

N= 62
0 Disagree
4 Uncertain/Neutral
58 Agree

APPENDIX F
Feedback About the Report

- I believe that financial help for women living with breast cancer are extremely important, i.e. some have no benefits at work, leaving them impoverished during treatments. Health care for middle/lower income families is VERY IMPORTANT. Also, I believe a woman diagnosed with breast cancer has to be put on an automatic recall for a yearly mammogram, otherwise, she may fall through the cracks.
- Many of the services needed to help women cope with breast cancer diagnosis treatment, follow up, and ongoing support are available, but the word doesn't get out. A patient navigator could, probably, fill this gap.
- In recent times, there seems to be a trend of trivializing the disease. Really, it's like having an attack of appendicitis; I was told by one recently diagnosed patient (she is stage 3)! The term care is thrown around and everything is so much better now. In fact, treatment hasn't really changed at all.
- I never felt that I did not receive all treatment available. My concern is that doctors spend more time listening!
- This is in the report, but I cannot stress enough the need to have immediate financial help available to the patient. Work stops immediately, but the bills do not!
- Support for the family. Counsel for all ages of children, spouses and their families. Teachers should be given a workshop on dealing with students who mothers are facing treatment and explain the side effects to chemo, and how to deal with the students when they notice that their behaviour has changed. It would also be helpful to give a workshop on how to identify personal changes and not to assume that they are going through a phase or behaviour has changed for another reason. My son could not deal with my being sick and is showed in his schoolwork, but the teachers didn't pick up why his behaviour had changed until it was too late. To this day he cannot go into the high school.
- I think the report covered most concerns facing rural. I personally feel content with a trusted person is important (availability by phone, or in person is comforting. Usually a person who has had breast cancer is living a positive lifestyle now).
- Examples of programs, which already exist: i.e. Cancermount, Reach for Recovery, Living with Cancer Support Groups, Cancer Connections, Chemo Outreach Centres.
- Seems pretty thorough!
- Women with carynoed cancer and all other cancers besides breast cancer - "ALL CANCERS." Women who have cancer and there name is not passed on, someone certified be able to assist them.
- This may be the appropriate place to comment, but I am not sure we really got to the "core" of the "rural women." I am sure that many women are facing a grimmer plight than what was obviously present at the conference. I expect the concerns are basically the same as those expressed, but the day-to-day grind that mom and the other family members, spouses, etc., NEED help too. I feel is/was NOT ADDRESSED right at the heart of the matter. How do we really reach, or should I say "reach IN" and let these people women, men, families know WE CARE.
- (Not just rural woman) consideration of other pre-existing diseases (e.g. R.A.) when patient going through the system. Taking patient off hormones without a replacing drug can cause problems later. Suggestions: involve medical expertise of pre-existing disease at every stage of decision making in cancer treatments.
- We feel that all the important issues facing Rural Women were covered in the report, but every rural area is different. In our area, we are most fortunate to have excellent doctors and nurses who give loving care and attention. Perhaps more so than in a big city environments.
- The report is comprehensive and the financial aspects are paramount. Long-distance phone calls connections with other women in another community add up. Getting women comfortable calling

others and a good listing of who will entertain calls out to women when they are diagnosed. Often the day or time of diagnosis is when women are overwhelmed and may need to speak with someone experiencing or has experienced such news.

- Access to treatment centres is long distances away, and travels cost and accommodations are expensive. Centre of most rural areas do not have support groups and some areas have long waiting lists for Mammograms.
- Very little, or almost no help for rural women in New Brunswick for Lymphedema. In my case, the only Physiotherapist trained in the therapeutic Boncloging and manual lymph drainage is located 250km away, and is the only so trained in the province.
- This is in the report, but I would like to emphasize that rural women (in my area-I have to pay anywhere between \$1,100 to \$1,400) to go to the capital city in my province to see a surgeon, or to go for treatments. Their fares should be paid or subsidized.
- Weather related problems to get to the hospital (snowstorms, whiteouts) that can be a major problem living in rural Canada at times.
- Options from a number of doctors as to her type of surgery. Sometimes she has her breast removed quickly in a small hospital without much time to access information.
- I would like to have a (1-800) number, that after being diagnosed with cancer, an oncologist would answer all medical concerns at any hour of day, or night for all Canadians.
- I would like to see the surgeons have a better knowledge of what the breast cancer patient should expect when she/he sees the oncologist.
- I can't think of anything. Most issues have been covered, or I've not encountered something different, or not mentioned. Good coverage of most everything.
- Report looks very good--thorough.
- In the Yukon, following cancer treatment, we have no contact wit the oncologists we saw in Vancouver. Oncologists fly to Whitehorse every few months, but not a breast cancer specialist. I'm wondering if urban breast cancer patient have more access to that after treatments are over.
- In Manitoba, rural women have difficulty accessing the resources that are available because the urban medical support does not refer to existing support groups; nor are they very aware of them.
- Offer psychological support to the family.
- The major obstacle is not being informed about the risk that all women face to be diagnosed with breast cancer. What is more problematic is that women don't even want to hear about it. The majority of groups work with women who are already diagnosed and already have breast cancer.
- The most important obstacle is the lack of positive support. When we watch television programs or conferences, for example Suzanne Lapointe's show, we hear about prevention, which is excellent, except that often women already have a breast cancer diagnosis and have to live with this. If what they see on the television are tears and panic attacks, there is nothing encouraging. It would be preferable that they have examples of strong women who know the enemy and can face it with determination. The big job is to surround oneself with resources that will help women to well prepare the husband, children to live through this difficult time calmly. We will find success and healing, in my opinion with a determined psychological attitude based on a likely possibility of cure and not on panic and fear. Developing a support program with people who have lived through cancer or recurrence would be ideal.
- Difficulty to find a family doctor. Allocate more money for research to be able to diagnose breast cancer with a blood test.

- Difficulties in reaching [contacting] doctors. Difficulties obtaining treatment in the rural area.
- Congratulations for the complex work that you are doing for women with breast cancer. You give a shape to the lives of people who are ill.
- A woman has breast cancer if we remove her breast completely, she won't need to go for radiotherapy and if she doesn't have any ganglions that are affected she won't have to have chemotherapy. You have in front of you a women in a state of shock who would surely choose to have her breast removed to avoid going through all the inconvenience of transportation, absenteeism and the costs to her family because we can't forget that doctors will suggest this to their clients. They proposed this to my mother under the pretext that it would be less complicated for her to have her breast removed than radiotherapy treatments. She refused. Even the oncologist asked her why she was so attached to keeping her breast, given her age of 77 years old (but a healthy 77 year old).

APPENDIX G

**Programs/Services for Rural Women that
Might be Models for Other Parts of Canada**

Model Program/Services

- **Newfoundland** - Dr. Jon Church Memorial University St. John's, NF: Newfoundland and Labrador Community Contact Program; Purple Lupin Kits.
- **Newfoundland** - Purple Lupin, Dr. Jon Church -Memorial University of NF and Lab.
- *(no province identified)* - There is a *Gabriel Krabb* (naturopath) from Pictour Co_ who has become very aware of knowledge and information about lymphedema. She is looking into setting up a program to educate volunteers to be resource people for women past mastectomy.
- **Nova Scotia** - Programs such as "The Pink Rose", are excellent in theory, but we can't seem to make it work as intended.
- **Prince Edward Island** - Cancer Support Group -
Prince County Hospital
Summerside, Prince Edward Island -Contact: Rev Charles Wagner
1-902-436-9131 ext.160.

Many members are Breast Cancer Survivors, but we have Hospice members, family members, and others who wish to attend. This blending of different people gives us a more appreciative feeling for each ___ other.

- **Prince Edward Island** - In PEI we have in place the Sunflower: Seeds of Knowledge Kit that is delivered at the time of the diagnosis. It travels to the surgeon or family doctor with the path report out of the hospital. It is filled with necessary information to make informed choices regarding surgery and treatment options, emotional support, where to get financial support and such, as well as the names of people that have experienced breast cancer that are available to talk to if needed. We are in the final stages of evaluating this project and will soon have more information on how well it is working.
- **New Brunswick** - After Breast Cancer diagnosis in the Saint John, NB area, ___ patients receive counseling at the Breast Cancer clinic, St. Joseph's Hospital. The very expert nurse there is Wendy Morris, who provides information kit. Our surgeons also, are expected to offer this kit (Purple Violet).
- *(no province identified)* - Our local support group has started a program that is a pattern of "Look Good, Feel Better" program. We have extended it to people of all ages and sex. This has given us an opportunity to set up times to share and to listen to their fears. We are still not reaching all.
- **New Brunswick** - In New Brunswick, Dr. Brian Sykes has set up a sensitive counseling service in a rural area. He partners a person with someone who actually had breast cancer at the same age as the newly diagnosed person. Dr. Sykes is a helping, kind person who has been respected in this community, and this process is very effective in this community.
- **New Brunswick** - We have a "Breast Friends" Support Group that meets once a month. Sometimes there are several shows up and some months no one comes, but our oncology nurse and another resource person is always there. Contact person is Kim Ross, oncology nurse at St. Stephen Charlotte County Hospital, 506-465-4733, or Theresa Comea contact for "Reach to Recovery", 506-466-5512.
- **Manitoba** - "Making Waves" - a program in Winnipeg at the M___ Hospital. Saw this on TV not sure of a contact person. It's ___ therapy for breast cancer survivors. It would be excellent to have the program in rural areas, as well as Winnipeg.
- **Manitoba** - In Neepawa, Manitoba we have a strong support group, as well as support from the two surgeons who do mastectomies. We also have a chemotherapy unit who is well informed. Having

radiation is still a big problem due to the fact -travel to Winnipeg is necessary. It causes a great financial burden. Out area is fortunate to have these services. Most of many are not so lucky.

- **Manitoba** - I know there are support groups in the rural areas, but I, for one, am having trouble getting my support group going. There are only one or two people that attend, and it's not enough to plan or do anything at the meetings. I am looking for a speaker to come out to speak at a meeting, but hope that there will be enough in attendance to make it worthwhile.
- **Saskatchewan** - Cancer Connections - CCS; Library of Resources at Public Library; Websites: Support Groups online, telephone support; Chemo Outreach Nurses.
- **British Columbia** - In BC the CBCF, the alliance for Breast Cancer information support sends all surgeon's in the province "Information Kits" which include the _____ to Gelman and _____ book. The "Intelligent Patient's Guide to Breast Cancer", 3rd edition as well as the new ____ practicing guidelines. However, there is low physician surgeon compliance, so this alliance who keeps accurate records of each surgeon's number of _____. We then did a pilot "poster" of "Did you get your ____? love."
- **British Columbia** - We have a program in place in our regional community hospital and clinic whereby the surgeons refer newly diagnosed women to a community contact who can access requested information, peer support, and pertinent resources. This referral is done when the pathology report is to be discussed from the woman's biopsy. A "business card" with the contacts name and telephone number is attached to the report by the surgeon's office staff person. The surgeon's refer prior to biopsy as well, if they feel the woman is in Dale Martin -community contact need of peer support, (204) 638-9144.
- *(no province identified)* - Support Groups; _____ driver program;
- **British Columbia** - I am only commenting on the first statement. I do not know of any such programs. But "Cancer Research", "Cure for Cancer", "Fight for a Cure. These are all externally directed slogans and suggests that I and others must direct our focus on FIGHTING this. These cells that are now a part of me/us. Could we somehow learn to love what is a part of me, even if it is cancer? Maybe we could "Love It to Death." What has it taught me? What is it teaching me? Where do I go from here? Where do we, a family, go from here? God is love and I am a part of God. How do I love all that is a part of me? Over Please.
- **Nova Scotia** - Dragon Boat teams keep survivors in touch; Joanne Cunmminger, Aberdeen Hospital, New _____, NS.
- *(no province identified)* - Emotional Support groups with layperson facilitators trained through the Canadian Cancer Society.
- **British Columbia** - We do find our Breast Cancer Support Group is full of knowledge. We always seem to learn something new at these meetings.
- **Yukon** - Karen is very experienced and can provide you with information and documentation of this particular project. Barb Adel was the Navigator prior to Karen and will also be a great resource. Yukon Breast Cancer Navigator Project, 103A-107 Main Street, Whitehorse, Yukon Y1A 2A7; Email: navigatoryt@hotmail.com; Phone: 668-4265 * 1-888-234-1865.
- *(no province identified)*- I really don't know of any programs available.
- **Newfoundland** - I don't know of any.
- **British Columbia** - Don't know.
- **(written in French -province not identified)* - For the last 14 years, the Afds association has worked to decrease the rate of death due to breast cancer in the Northern region of Quebec. We feel that the

only way to succeed is to offer young women the possibility to get to know their breasts early on and to learn about the normal changes that happen at different stages of life. It is also important that they know about all the possible abnormalities of the breast that could put them at risk so that they will not ignore them if one of these symptoms presents itself. Early detection of breast cancer and the confidence to overcome it are the keys to success. The methods that work are education, training, support and counseling.

- **(written in French -province not identified)* - An awareness program for doctors who don't realize the real importance to closely follow their patients after [breast] exams if there is any doubt. Prescribed [breast] exams need to happen quickly and the results should be available without delay. If there is a waiting period, there should be ongoing contact between the patient and the doctor. Cancer is a common enough disease and [detection] shouldn't be left to chance. The psychological state of the patient, I will repeat, is an important factor in healing.
- **(written in French -province not identified)* - We, the women at the association at "Fleur de sein" have developed a bank of knowledge that should be taken into consideration. The work has already been done, we don't need any further expensive studies, repeated travelling that leads to meetings where subjects discussed become old [repetitive] over time. It's here too, where there are expressions of emotions that I consider harmful. There is room for emotions, constructive criticism and recommendations in certain circumstances, but meetings within the [health/breast cancer] network or with others shouldn't be used to solve personal problems or to try to make doctors, hospitals or governments more accountable.
- **(written in French -province not identified)* - **Association a fleur de sein – Regine Imbealt (418) 748-6905**
- **(written in French -province not identified)* - **Suzanne Hamel (418) 748-7914**
- **(written in French -province not identified)* - We would like there to be nurses trained to do clinical exams as well as [to teach] breast self-examination.
- **(written in French -province not identified)* - Train nurses so that they can do clinical breast exams.
- **(written in French -province not identified)* - People in very distant geographical regions are compensated for their expenses relative to their illness but nothing is provided for people who live, for example, 100 kilometers from the hospital where they have to be treated.

The Canadian Breast Cancer Network

The Canadian Breast Cancer Network (CBCN) is a survivor-directed, national network of organizations and individuals. CBCN is a national link between all groups and individuals concerned about breast cancer, and represents the concerns of all Canadians affected by breast cancer and those at risk.

Membership

The CBCN has 74 partners and over 150 member groups, including breast cancer support groups and advocacy and affiliated groups across Canada, while over 500 individual members, advisors and supporters represent individuals, local support groups, the medical and research community, regional networks, and provincial and national organizations.

Membership is \$25/year (and can be waived on request). To join, simply call 1-800-685-8820 or email membership@cbcn.ca for more information, or visit the CBCN website at www.cbcn.ca.

CBCN documents

CBCN documents are available online or in print, in both English and French. Contact CBCN to request copies:

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Website: www.cbcn.ca

Available documents

- 'Nothing Fit Me' : The Information and Support Needs of Young Women with Breast Cancer, 2001
- Perspectives of Rural Women with Breast Cancer, 2001
- National Strategy and Action Plan: Young Women with Breast Cancer, April 2003
- National Strategy and Action Plan: Rural, Remote and Northern Women with Breast Cancer, April 2003
- Results of the National Survey on the Financial Cost of Having Breast Cancer, May 2004
- Political Parties Responses to the 2004 CBCN Survey on the Financial Cost of Having Breast Cancer, May 2004
- CBCN's Federal Election 2006 Campaign, Political Party Responses to CBCN's Five Questions, January 2006



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