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Canadian Breast Cancer Network
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'NOTHING FIT ME':

The Information and Support Needs of Canadian Young Women with Breast Cancer

FINAL REPORT

Canadian Breast Cancer Network in partnership with the Ontario Breast Cancer Community Research Initiative

National Consultation with Young Women with Breast Cancer, 2002

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'NOTHING FIT ME': THE INFORMATION AND SUPPORT NEEDS OF CANADIAN YOUNG WOMEN WITH BREAST CANCER

> "*I think it's time that more of us women had a voice for young women out there that yes, breast cancer, damn it, happens to young women and something's got to be done for the women forty-five and younger*." (Winnipeg)

INTRODUCTION

In the fall of 2001 the Canadian Breast Cancer Network (CBCN) and the Ontario Breast Cancer Community Research Initiative (OBC CRI) met to formulate a research plan to investigate experiences of young women who live with breast cancer - a topic that to date has received little attention in Canada. The CBCN had received funding from the Community Capacity Building arm of the Canadian Breast Cancer Initiative of Health Canada to specifically inquire into the lived experience of young women. The results of this inquiry will be utilized to create a National Strategy to meet the information and support needs of young women with breast cancer.

Young has been defined in several ways. We define young as those women diagnosed with breast cancer before the age of 45. We chose this age-range of women because they are more likely to be pre-menopausal, have young children, and are more likely to be in the paid work force.

Background

In 2002, 20,700 women will be diagnosed with breast cancer (Canadian Cancer Society, 2002). Breast cancer is primarily a disease that affects older women. Still, 23% of all women with breast cancer are below the age of 50 years (Canadian Cancer Society, 2001). Although the incidence of breast cancer for this age group has remained the same for 10 years, more women below the age of 40 die of breast cancer than of any other type of cancer (Canadian Cancer Society, 2002). Additionally, the disease in young women can be more aggressive (Swanson & Lin, 1994; Xiong et al., 2001). Primary health care physicians can increase the gravity of the situation for young women by doubting the seriousness of breast lumps and delaying diagnosis and treatment (Menon et al., 1992).

While the facts about the incidence of breast cancer abound, less is known about how women experience having breast cancer. Some researchers have examined the breast cancer experience from the perspective(s) of older women (Gray et al., 2000; Pistrang & Barker, 1995) but far fewer have focused specifically on younger women.

Researchers who have examined breast cancer from the perspective of young women have begun to unravel the impact of age and life-stage on this experience. They have identified several issues salient to young women, including how women cope with the 'untimeliness' of the diagnosis and the intrusiveness of the illness (Bloom et al., 1998; Siegal et al., 1999; Dunn & Steginga, 2000); the importance of understanding financial barriers (Alferi et al., 2001; Schnoll et al., 2002); the unclear potential consequences of early menopause or impaired sexuality during and following treatment (Knobf, 2001; Schrover, 1994); how the strain of the diagnosis can contribute to poorer adaptation to diagnosis and treatment (Siegal et al., 1999; Lewis et al., 2001); how the diagnosis affects their partners/spouses/family members (Siegal et al., 1999; Northouse, 1994; Dunn & Steginga, 2000); and, how women with children cope with parenting (Dow, 1994; Lewis et al., 1993; Northouse, 1994).

Experiencing a cancer diagnosis and treatment as a young parent is especially challenging. For example, parents have reported not knowing how much information about the cancer and the side effects of treatment to communicate to their children (Elmberger et al., 2000). The difficulty of parenting is compounded for single mothers and mothers of pre-school children - two groups of women with breast cancer requiring much more understanding (Elmberger et al., 2000; Rayson, 2001; Dunn & Steginga, 2000; Schnoll et al., 2002; Shands et al., 2000; Lewis et al., 1996). Researchers have noted that young women with children require additional support, including instrumental support, such as help with child-care, meal-preparation, and house-cleaning (Bloom et al., 1998; Dunn & Steginga, 2000).

The information gathered from the aforementioned research can guide planners to create relevant programs/services, information and support for young women. However, none of the above research explores the experience of Canadian women. The aim of this research report is to fill this gap.

METHODS

Participants

Ten consultations were held nationally with 65 young women. In addition, we conducted three teleconferences with five young women from rural Canada (TOTAL=70). The women who participated in the consultations and/or teleconferences were diagnosed with breast cancer before the age of 45 years and were between one to five years post-diagnosis.

Two day-long consultations were held over five consecutive weekends in the winter of 2002 in each of the following five cities: Vancouver, Winnipeg, Toronto, Montreal, and Halifax. The women were recruited through newspaper ads (Vancouver, Halifax and Montreal), CBCN's Outreach Bulletin, breast cancer support groups, community cancer organizations, cancer treatment centres and clinics with the aid of health care providers and associates/board members of CBCN.

By in large, the consultations were organized according to the following categories: single moms, child-free women, moms with children 0-8 years, and moms with children 9-16 years. Due to difficulties in recruiting single moms in Vancouver we held one consultation day for a group of partnered and single moms with children of all ages. Similarly, we organized two consultations with young mothers with children of all ages in Montreal (versus children of specific age groupings) to accommodate women from Anglophone and Francophone communities (see Table 1).

Teleconference participants were located in northern Manitoba, Newfoundland, New Brunswick, and the Yukon. These teleconferences were not organized according to category membership though the facilitator noted whether or not the woman had children and the ages of the children (see Table 2 for numbers of women in each category).

A staff person from the OBC CRI facilitated all consultations and teleconferences with the exception of the Francophone consultation, which was conducted by a Francophone facilitator. Staff from the CBCN recruited participants, organized, recorded, and documented the proceedings at all consultations.

Table 1 – Composition of Groups x Location

Location	Composition of Group Consultation Day I	Composition of Group Consultation Day II
Vancouver	Single and Partnered Moms with children age 0-16	Child-free women
Winnipeg	Moms with children 0-8 years	Moms with children 9-16 years
Toronto	Single moms 0-16 years	Child-free women
Montreal	Anglophone Moms with children 0-16 years	Francophone Moms with children 0-16 years
Halifax	Moms with children 0-8 years	Moms with children 9-16 years

Table 2 – Number of Participants x Category

Group Type	# of Participants
Single Moms	14
Child-free Women	21
Partnered Moms: children 0-8 years	16
Partnered Moms: children 9-16 years	11
Partnered Moms: children 0-16 years	8
	N=70

Note: young, rural participants are included within these categories

Each consultation occurred over one full day and the teleconferences were between one to two hours in length. All consultations were audiotaped and the facilitator and/or CBCN staff person recorded field notes. During the consultations the women discussed their information and support needs, current resources, and recommendations related to their diagnosis, treatment and survivorship (see Appendix A for interview guide). At the conclusion of the consultation the women completed a demographic form (including current age, age at diagnosis, birthplace, diagnosis and treatment information, household income, and number of dependents) (see Appendix B) and an evaluation form (see Appendix C).

Once the analyses were completed all participants were mailed a copy of the draft report and a feedback survey. Participants were encouraged to provide feedback about the relevance of the findings to their life experience and to what they heard expressed during the consultation. The participant's responses to the draft report will be illustrated and discussed in the Participant's Validation of the Findings section following the Recommendations.

Analysis

The consultation participants provided a wealth of information concerning their breast cancer diagnosis, treatment and survivorship. The staff at the OBC CRI analyzed the data from the consultation transcripts, field notes, demographic forms, and evaluation forms that were collected at each consultation day or teleconference session.

The primary investigator and the research assistant conducted a content analysis by reading the transcripts, field notes, and evaluation forms and then met to formulate the coding framework (Patton, 1990). The codes developed initially were used to do a more detailed coding of the focus group transcripts using the NVivo qualitative software package. Once the detailed coding was completed, the research team categorized and documented meaningful patterns found in the data.

During the consultations and teleconferences (herein referred to only as 'consultations'), the women described their experiences related to their cancer diagnosis, treatment, and aftercare. Some of the stories we heard are common to all women facing a breast cancer diagnosis, but a substantial portion of their discussion was focused on the particularities associated with being young and having breast cancer. A fuller rendering of the common information/support issues faced by women with breast cancer, regardless of age, are documented elsewhere (Mills et al. 1999; Bilodeau & Degner, 1996; Northouse, 1989). As such, most of this report will focus on the unique information and support needs and recommendations for young women.

DEMOGRAPHICS

Selected demographic characteristics

All seventy participants (100%) completed the demographic form (see Appendix D for the breakdown of the participant's demographics). The ages of the women ranged from 29 to 51 years at the time of the consultation. The average age of the participants was 41 years. At diagnosis, the women’s ages ranged from 26 years to 46 years. The average age at diagnosis was 37 years. The first language for most (89%) participants was English, followed by French (9%). Of those who completed the question concerning ethnocultural origin (n=55) most (71%) identified themselves as Caucasian.

Sixty-seven per cent of the young women were married or living with their partner. Most of the young women had children below the age of 16 years (70%). A substantial minority of the women was child-free (30%). Of the young women with children (n=49), about a third (29%) had one or more children under the age of 9 years, nearly half (41%) had one or more children over the age of 10 years, and a quarter of the women (24%) had children both under the age of 9 years and older than 10 years. The ages of four children were unidentified. Two women also cared for the elderly.

Eleven (16%) of the 70 women had had a recurrence at the time of the consultation. Many (66%) of the women reported currently working either full- or part-time. A minority of women (14%) was unable to return to work or was unemployed due to cancer or sick/disability. Forty-eight per cent of the respondents who completed the question about income (n=59) reported an annual household income of less than $60,000. Most women (76%) had insurance coverage beyond provincial health insurance but a quarter of the women (24%) did not.

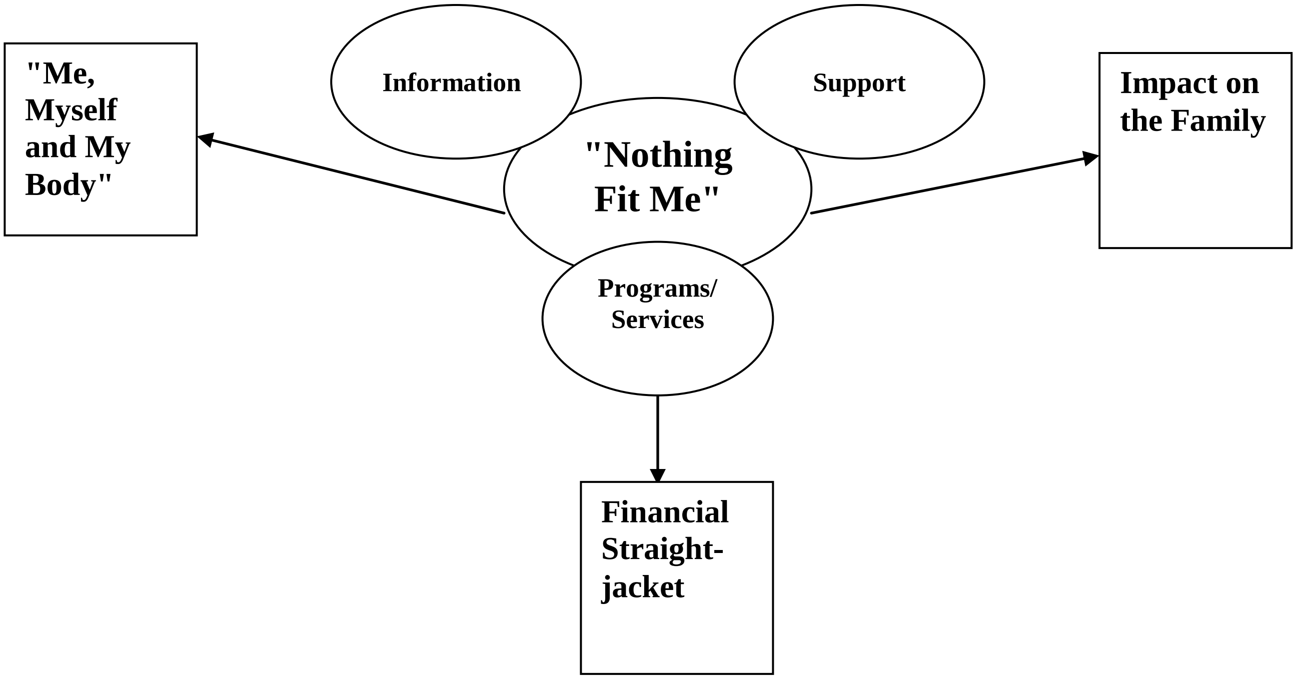
Other notable responses include that a large minority (20%) of all of the young women with whom we met had reconstructive surgery and/or had utilized complementary/alternative medicine/treatments (19%).

QUALITATIVE FINDINGS

The women with whom we spoke had very similar issues to other breast cancer survivors, however they also noted the ways in which being ‘young’ seemed to present several barriers to effective diagnosis, treatment and after-care. The overall theme that captures the way that these women feel about information, support and programs/services offered once diagnosed and treated with breast cancer is “Nothing Fit Me”. Other themes include: 1) Me, Myself and My Body 2) Impact on the

Family, and 3) Financial Straightjacket (see Figure 1). Each of these themes is explored next. Please note that unique information offered by the categories of women (single moms, child-free women, moms with children 0-8 years, moms with children 9-16 years) has been highlighted and is peppered throughout the findings section. Information gathered about the young and rural women will be presented immediately following the "Other themes" section.

Figure 1 - Thematic representation of information/support needs of young women



Nothing Fit Me

> "*I was bombarded with pamphlets and booklets and I read everything possible I could get my hands on, but I found that none of it really suited me or my specific situation…I found that* nothing fit me.*"* (Winnipeg)

Women told the research team that dealing with a breast cancer diagnosis encroaches on their already extremely busy lives. Young women are managing the diagnosis of cancer, treatment, and after-care in the context of jobs (paid and/or unpaid), and for many, child-rearing. Trying to plot a pathway through the breast cancer experience for themselves, and often for their families', presents a formidable challenge.

> "One thing that occurs to me that I think is (a) significant difference between an older person getting cancer and a younger person is…when you're young and you get a cancer diagnosis I believe it changes the entire trajectory of your life…I don't think it happens

> as much with an older person because they’ve had more of the foundations of their life." (Vancouver)

To help them through this diagnosis they require information and support from the cancer care system and from community-based cancer organizations. Generally, breast cancer survivors want more, and improved access to, information to aid them to cope with breast cancer. The young women participants felt that often the information about, and support for, young women simply didn't exist and where the information and support existed it didn't 'fit' their needs. These issues are outlined next.

Information

During the consultations, women spoke repeatedly about the lack of information about breast cancer in young women as well as the lack of information for their families and friends.

> *"…why we’re here (at the consultation) is because the information for young women with breast cancer just isn’t there."* (Vancouver)

> *"I mean the bottom line it is that all the information that we have is geared to women over 50."* (Vancouver)

> *"I had done some research and read the books and read stuff and so I was prepared for some questions, but it was just like 'no, no, no, that (information) is not for you, you’re too young.'"* (Vancouver)

The consultation participants told the research team they could not find answers to their questions about, for example, the effects of adjuvant therapies on fertility, the signs and side effects of early menopause, how to talk about their cancer in new relationships, how to relate to themselves sexually following treatment, how to contemplate dating, the risks of reconstruction for women with or without aggressive tumors, and information about complementary/alternative medicines/treatments.

> *"You have all this information, a ton of it but what (about) young women who haven’t had children yet perhaps would like to have information on fertility in case they get into induced menopause and I was so amazed that for such a huge issue there was no information on that."* (Vancouver)

When generic information was available the women felt it was inappropriate for their age group or that health providers didn’t know enough about young women to provide accurate information. For instance, information about the effects of Tamoxifen exists but there are few studies about the effects on women under 50 years. In another example, young women were told to have yearly mammograms for a few decades yet little knowledge exists of the cumulative effects of mammography.

> *"I’m about to have them (mammograms) for the next 40 years of my life and that’s too long…it’s just the accumulation and they don’t have the studies to tell us…"* (Toronto)

Some information about young women with breast cancer was not difficult to access. The women explained that information about survival rates and/or about the sometimes-aggressive nature of the disease in young women was readily available but was also quite distressing to read.

> *"Sometimes websites can be a field of terror."* (Montreal)

The young women often spoke about the lack of information for their children and spouses. Although they found a few resources concerning how to communicate about cancer to children, the women found that these tools did not apply to very young children or to adolescents.

> *"I had to handle crying episodes every evening such as 'I don't want you to die'. At that time, I had to ask the hospital if they didn't have something written up for children, to try and explain…because I didn't know how to reassure them. You can't swear to children that you won't die. It isn't true! You can't swear that you won't be sick anymore. You can't do that! At one point, the hospital lent me a book…but too demanding for a four-year-old. He doesn't understand. For them, it's much too abstract…It's excellent for a child of eight or nine, but four?"* (Montreal)

> *"I guess it's a different sort of circumstances when your children are younger because they don't really understand but when they're teenagers they probably know a lot more than you do and you kind of tend to think of them as still a child. There was nothing to give them to read."* (Halifax)

The women felt that information for their spouse was also in short supply and/or was not conveniently packaged to be palatable to their partners.

> *"I want information where I could say to him, I'm dealing with this, go watch the video, just on any topic surrounding breast cancer."* (Winnipeg)

> *"…it's taking something in where they can be macho and I'm just doing what (they) always do, just watch the set."* (Halifax)

Several young women also discussed the importance of, and lack of information communicated to, much younger women about the risk factors and incidence of breast cancer.

> *"…you've got people who (have breast cancer and are) younger than 30. Where do you get to these women to reach them about risk factors and let them know and I think it's reaching kids in the high schools."* (Vancouver)

Support

Because the young women confront cancer in the midst of their lives, and at a life-stage when young people are not typically facing life-threatening illnesses, they remarked on the difficulty of accessing support from their spouses, friends, and other breast cancer survivors.

> *"I have a mother-in-law dying of cancer, I have my son, I have work, I said I'm not just trying to be a cancer patient, I'm trying to be a human being…I am my own support system because I've got all these other things to do."* (Vancouver)

> *"As for the social aspect, the social support, outside of medicine, I found that lacking."* (Montreal)

> *"People in our age group, just don't know about this. I found it hard that friends didn't acknowledge it and didn't know what to say."* (Young, rural woman)

'Nothing fit me' also related to the lack of support for caregivers. The young women were concerned that their caregiver friends would not know where to turn for support.

> *"I'd like to know if there's any support for people who support you."* (Vancouver)

> *"There really is a lack of support for people that are supporting you and giving them direction, especially for younger people cause I think…that's expected with older people…but with younger people, it's just people don't even know where to start."* (Toronto)

When young women did find support from breast cancer support groups, one-to-one peer counselors or dragon-boat teams, they frequently felt that they didn’t 'fit in' with the other group members because of age or life-stage.

> *"I wanted to find someone who was just like me."* (Halifax)

> *"…ladies over fifty, they’re in a different wave of thinking cause they’re more going into retirement. Like we’re still, like we don’t fit in really with them because they’re not looking at it in the same way."* (Vancouver)

> *"There was a support group here locally. It was run by a woman who was 38 at the time…Most of the ladies though are quite a bit older and most did not have treatment after their mastectomy. It seemed very different than what I had gone through."* (Young, rural woman)

> *"There was one kind of support group here, I didn’t really like it. I was the youngest person there…I didn’t feel like I got the kind of support I needed. I felt isolated and alone there because it seemed they were all older women and their kids all grown up and they had their spouse…also I’m native and there was not one other native person there so that was another thing that made me feel isolated."* (Young, rural woman)

Several women at each consultation commented upon how they were very supported and better able to go through the breast cancer experience when they found a ‘fit’ with similar others. The women stressed the importance of peer support with other women of a similar age with similar life situations (either having or not having children; having, or not having a spouse). In order to find this fit, some young women started their own support groups.

> *"When I went into the city for treatment there were 32 women sitting around a table all who had breast cancer. When I came back home there was nothing. There was a group about an hour away and we came back and decided to start our own group."* (Young, rural woman)

> *"The best thing that ever happened was someone invited me to a support group and I didn’t want to go. I went and I really enjoyed it, and that night there were 2 women who were in their 40’s and I thought well they are in the same age group as I am."* (Young, rural woman)

> *"I asked for somebody who had been my age and was a few years down the road and so then they started getting this one lady who called me and was just lovely. She was a fifteen year survivor…she had been 40 and so she could really relate and that was wonderful because that was the pot of gold at the end of the rainbow because she survived, she lived and she learned how to be an advocate throughout the whole process."* (Toronto)

The participants also expected, but didn't always find, support from health professionals. At every consultation, the young participants complained that health professionals did not provide them with timely assistance to deal with their emotional and mental health concerns.

> *"…at the (breast) centre was a social worker who could assist with emotional and family issues. I wish I had been advised to follow this path initially rather than make a (surgery) decision based on expedience while still in a state of shock."* (Young, rural woman)

> *"…it must have taken I'd say five months before my doctor strongly recommended that I go for therapy, to go see a psychologist….This is nonsense. Within two years I had experienced a divorce and this relationship that had also floundered. The cancer and the move came in succession and, basically, why didn't someone talk to me earlier? Why wasn't I steered toward that? So yes, I was totally isolated at that level.* (Montreal)

The young women participants also relayed their concern about the lack of emotional support for their children and spouses.

> *"…there's nobody there to help the kids through it"* (Halifax)

> *"Once I was at a hospital, I was looking for support groups for kids but I couldn't find any…the support groups for me were in English as well. I would (have) liked my kids to have had (French language) support."* (Montreal)

> *"I found my husband wished he had a group to go to, to talk about issues."* (Halifax)

> *"I know from my husband when I sort of picked up myself and I was doing fine, which was a year probably this fall, he crashed…It was like he finally had permission to crash and he had no supports and really, there needs to be supports out there for men. And he's young and none of his friends, you know, they talk about what, hockey or whatever, they don't talk about that kind of stuff …"* (Halifax)

In terms of instrumental support, the young women who had children reported how the cancer-care system lacked child-care facilities and lacked the awareness that women needed to make child-care arrangements to accommodate their medical appointments.

> *"I told them (cancer clinic staff) that they should have childcare facilities. You know you take your kids to IKEA and they have childcare…the hospitals and clinics should have childcare too!"* (Montreal)

> *"…it would be nice to have a daycare."* (Halifax)

If the women were required to stay in the hospital/cancer clinic following surgery or to undergo treatment, hospital staff typically did not inquire into the women's needs relative to their children. For some women, time spent away from their children was part of a successful recovery. For others, time with their children was necessary.

> *"…because my kids are young, my doctor said I could stay 2 nights after my mastectomy. After 1 night there was a lot of pressure from the nurses for me to go…that I had been in the hospital long enough."* (Young, rural woman)

> *"cause you want to get your kids through this too and you can't not see an eighteen month old for three weeks. That's cruel."* (Halifax)

Finally, women spoke about wanting instrumental assistance from services and programs outside the cancer system to help with making meals, cleaning the home, child-care and medical care.

> *"I couldn't cook anything and you know my husband had a job and my kids were a bit too young to be making their own meals and stuff but there's nowhere in the community…we haven't lived that long in the community…some strangers were kind enough to bring food to our house but…I'm thinking VON but there like nobody comes to make sure you're doing okay."* (Halifax)

Programs/Services

Even within the cancer care system the women spoke about 'not fitting' into the profile of a typical breast cancer patient. 'Ill-fitting' experiences were reported at diagnosis, throughout treatment, and at follow-up.

Several women relayed that when they came to their physicians because of concern about a lump or pain in their breast, they were met with disbelief. Though the women realize that as a group they are less likely than older women to have breast cancer, they wanted their physician to take their concerns seriously, immediately.

> *"I was angry…when I first went to my doctor and I told him about the lump and he said it was nothing, yeah, that and I kept on asking for a mammogram and he kept putting it off."* (Winnipeg)

> *"And even the person who did my biopsy said about a hundred times 'oh you're too young, I'm sure this will be nothing.'"* (Toronto)

> *"Dismissing frightened women can be a death sentence - my cancer was deemed aggressive and might have spread much further had I waited a few more months since no real concern was expressed by my physicians."* (Young, rural woman)

> *"Waiting with this is likely death."* (Toronto)

> *"When my doctor finally referred me to a surgeon and I called, most of them said, 'well it will take two months or three months' and I said, 'no, no, no, no, I am young, I have breast cancer in my family and I need this lump on my arm removed now!'"* (Montreal)

Faced with having to go for a mammogram, they were concerned that this imaging tool was not precise enough to detect a tumor through dense breast tissue. The women were frustrated that a new method to detect tumors had not yet been utilized.

> *"…when you're younger mammograms aren't picking it up in the first place. Then why are we going each year through that being exposed to that and maybe there's a better way for young people."* (Toronto)

> *"…the mammograms don't work with young women. Find something that does."* (Winnipeg)

The distress about the delay in diagnosis was compounded by the women's concern that their oncologists' were making treatment decisions without substantial research by which to measure the impact of these treatments on pre-menopausal women. The consultation participants argued the need for young women to aggressively pursue novel or definitive diagnostic testing and to advocate that treatment research be done specifically with pre-menopausal women.

> *"Because I was young…as we are, they didn't know what to do with me."* (Vancouver)

> *"…they say Tamoxifen's different for pre- and post-menopausal women and again they don't tell you the difference."* (Toronto)

> *"My oncologist, basically having to go against his own will to have to do something…but there was no research, nobody could provide any evidence to anything for a woman who was 28."* (Vancouver)

> *"...the treatments (are) dedicated to people that are older where twenty to thirty years is going to be probably maximum life for them where when you're younger twenty*

> *or thirty years ..the chemo, the radiation, what's it going to do to us?"* (Toronto)

> *"I think we not only have to be proactive with our breast health but our treatments and everything throughout the whole process."* (Winnipeg)

The last issue related to the lack of fit of programs/services for young women within the cancer system concerns follow-up. Relative to older women, living several more decades cancer-free is the main goal for young women. Though women of all ages are seriously concerned about follow-up once they have completed treatment, young women are especially adamant.

> *"I would have liked to have somebody that was in the know giving you the pros and cons of all the different options and because you're younger, you've still got half your life left, so what can you do so that you're not going to get it (breast cancer) twenty years down the road."* (Vancouver)

> *"I feel they should have a whole physical…an MRI or something of that nature, at least once every two years…you know when you're first diagnosed and you go through the bone scan, liver scan, the ones for the lungs, you should have that at least once every two years…it would probably save a couple lives."* (Toronto)

> *"(I have) excellent follow-up, no gaps in follow-up in Cape Breton. Follow-up every 3 months for 1 year and then every 6 months for the following year. End up seeing my oncologist or surgeon every 6 months."* (Young, rural woman)

Other themes

Me, Myself and My Body

> *"That was the hardest thing for me when I was diagnosed with breast cancer was to hear I was going to go into menopause…That bothered me more than anything cause my mother was still going through menopause and I was like what do you mean it's going to be permanent? Like I found that really difficult, that was probably the biggest challenge for me, just for me, myself and my body."* (Halifax)

A breast cancer diagnosis and treatment taxes women's bodies physically, mentally, spiritually, and sexually. Many women who've had a breast cancer diagnosis struggle with recovering in all of these domains but younger, pre-menopausal women need to consider issues such as, fertility, early menopause, and some of the effects of Tamoxifen on their bodies. The theme "Me, Myself and My Body" delves into these aforementioned concerns expressed by the consultation participants as well as others such as, body image, reconstruction, sexuality, dating, and mental and spiritual health.

Almost all of the young women, especially the child-free women, were greatly concerned about the lack of, or mis-information provided by their physician, oncologist, or radiologist about early menopause and possible infertility.

> *"…they don't say this (treatment) might take you into early menopause."* (Toronto)

> *"I've had the attitude in the health sector 'yeah, you might go into menopause', you know? Like it's not really a big deal."* (Vancouver)

> *"The one thing I would say about chemically induced menopause is that there isn't a whole lot of information out there and even when you ask they just kind of throw their arms up in the air."* (Winnipeg)

> *"…young women who haven't had children yet perhaps would like to have information on fertility in case they get*

> *into induced menopause and I was so amazed that for such a huge issue there was no information on that."* (Vancouver)

The young women also relayed their confusion and turmoil about using Tamoxifen. They were concerned about the association of this adjuvant therapy with infertility and early menopause. The women lamented the lack of information or guidance from health professionals.

> *"I was looking for people who were dealing with the pregnancy issue…who were questioning whether or not to take Tamoxifen and everybody that I knew was taking Tamoxifen or deciding if they were going to take Tamoxifen but they weren't dealing with pregnancy…needing to have the right information in order to make that very difficult decision in whether to take hormone therapy or not…so it felt like life or death…"* (Toronto)

> *"And she (nurse) said if you stop having your period for a year on the Tamoxifen then you can consider yourself menopausal and you're at an age where, I'm going on 36 in April, where it could push you into (menopause) having had chemo and my doctor told me nothing about this…there was no information that this was even a possibility."* (Toronto)

After wading through treatment considerations, women described the difficulties associated with relating to their bodies pre- and post-surgery and post-adjuvant treatment.

> *"It would have been nice to just have something that felt like it was a thirty year old body and this is what they look like afterwards cause it was very horrible …spend the weekend and tell me on Monday which you prefer, a lumpectomy or mastectomy…so just literature that's really for us with pictures of us."* (Toronto)

> *"I'm 30 I want a bra that's sexy…I still want to feel like a woman. I don't want to look like a grandmother, I want to look like a woman my age, even if I've had a mastectomy. So I found that…really frustrating."* (Montreal)

> *"I've gained 25 pounds on chemotherapy…it does happen to a lot of women…(the physician) said that can take up to a year after treatment to lose. Great, It's been two years and I still haven't lost it, so yeah, I think that's an issue because again it's body image."* (Vancouver)

> *"…when you first get diagnosed, all you say is, take the breast off, do whatever you have to do, I want to live. And for me it took some assimilation, it took some time. I had to grieve for that breast. You have an altered body image. You are not the same person physically as well as emotionally."* (Winnipeg)

One way in which women described coping with a wounded body image was to have reconstructive breast surgery, although it was not a remedy for everyone. Women talked both about the benefits and costs of reconstructive surgery as well as about the lack of information about this surgery.

> *"if you're ever looking to do reconstruction it's (the scar is) never totally gone, cause I have scarring and you still see scars, but boy you still feel so much, my body image and my self image went back up after I had my reconstruction, they really did cause I felt I'd come a little bit full circle."* (Winnipeg)

> *"Or how you have it with reconstruction, like one of my big things was sensation. I*

> *don't have the sensation, I don't have sexual stimulation on that side, so when they put the nipple on and they took it from this nipple because I breast fed my kids, and they put it there and I was concerned I would lose sensitivity there, and to this day I don't like my husband touching (my breast)…It's a loss, it changes your sexuality. It changed mine…"* (Winnipeg)

> *"…there's no information out there about reconstructive surgery"* (Halifax)

In a related matter, young women, especially single moms and child-free women, described the utter silence surrounding sexual dysfunction, how to understand the sexual changes to their bodies, and how to feel sexual again with others.

> *"(health providers) ignored my questions about sexuality and having children. They kept saying we will talk about that later on. Then menopause started and again I was left on my own to learn about what was going on."* (Young, rural woman)

> *"One thing that's not discussed is being single...there should be more education on how to get past that, to get your self-esteem because to be honest, it's not easy being single, especially if you've had a mastectomy, when you don't feel whole, and that's a big issue to be able to go on in life and feel that you can be with a partner and feel sexy and desirable."* (Toronto)

> *"…we have to be more informed on sexuality because you can get a lot of problems that people don't know about and not just with the breast but with the treatments that affect a lot of other things…It's like an accelerated change of menopause, so you can be 40, 45, but you actually have the body of one of 65 and 70…"* (Toronto)

> *"What makes us women without breasts?…The information needs to be there…"* (Toronto)

The issue of new relationships was especially topical for the single-moms and single, child-free women.

> *"But a single parent getting back into dating is hard enough but getting back into dating …and the breast cancer thing particularly…"* (Toronto)

> *"…when meeting someone I think, I can't have kids so say you meet someone who wants kids? Well that takes out that whole group of people who want to have children and when do you tell them you know, 'hi, nice to meet you, I have breast cancer', you know?"* (Vancouver)

> *"I hope that one day I'll meet the man of my dreams but since my diagnosis I've gone out on 2 dates. Both guys knew…that I'm a breast cancer survivor and I know that both of them got scared away after having the first date because it is such a part of my life."* (Vancouver)

As we mentioned earlier in the report, the participants were discouraged at the lack of psychological help/guidance from health care professionals. Faced with several competing demands as young women and often as young mothers, they felt emotionally ill-prepared to face breast cancer diagnosis and treatment.

> *"…you read all that stuff and it talks about hair loss, it talks about getting wigs and it talks about all that stuff but it doesn't tell you that emotionally it's going to destroy you."* (Vancouver)

> *"The panic attacks just took me totally by surprise."* (Toronto)

> *"…the chemotherapy put me into depression."* (Winnipeg)

Finally, the young women also spoke about the importance of focusing on their spiritual health.

> *"that's the one part of your life that you're really mad at."* (Halifax)

The fact that only a minority of women (19%) reported using complementary/ alternative medicines on the demographic form belies the degree to which women discussed using such treatments during the consultations. In all but one consultation, women described using several complementary/alternative pathways to healing including lymphatic drain, meditation, visualization, imagery, therapeutic touch, reiki, massage, homeopathy, and Chinese medicines. The women would have preferred that health professionals be more open to discussing spirituality and treatments to complement the traditional care they were receiving.

> *"…I would have liked to be told about, when I was diagnosed…meditation, visualization. I never practiced it but I know it brings you tremendous inner peace and I would have liked to be steered to that approach in order to help me unwind, to remove that little distress I was feeling inside, all the fear I had, you know, really, to learn to relax…"* (Montreal)

> *"like spirituality, the holistic approach to medicine, there is something to be said…to people getting better"* (Winnipeg)

> *"…doctors should be more open-minded towards alternative therapies."* (Toronto)

Impact on the Family

> *"That was my obsession in the first few weeks…how was I going to get through this and get my family through it?"* (Halifax)

While most women with breast cancer are concerned about how their diagnosis affects others in their families, younger women are more likely to be living with children or adolescents, living in new marriages and/or caring for aging parents. These relationships pose unique challenges for young women with breast cancer. The women spoke at great length, in particular, about their children and their spouses.

As we mentioned earlier in this report, the participants felt strongly that there was little information or support to help them help their children 'get through' their breast cancer diagnosis.

> *"you worry about everything when it comes to your children, you just want them to do well, it's such a huge issue. It's as big an issue as the cancer."* (Halifax)

They remarked that there was little suitable material for children below the age of seven and for adolescents. Interestingly, mothers of children 0-8 years and mothers of children 9-16 years suggested different ways in which their children lacked information and support. Mothers of children 0-8 years suggested that they wanted to manage information about their cancer to their children. Mothers of older children thought that it was more appropriate to have an 'expert', such as a teacher, guidance counselor, or mental health professional, to manage that information.

> *"There should be more information on children and how to support them or communication with them in regards breast cancer. There should be more resources, and oncologists to deal with them."* (Montreal)

> *"I think the most important thing is to first, have access to a child psychologist…I didn't know how to answer them (questions). Another thing is that it would*

> *be a good idea to send information to the education system, because the kids have reactions in school and the teachers aren't too clear on how to manage that. Another solution would be to actually go in schools… explain it."* (Montreal)

The partnered women found that having a breast cancer diagnosis put a strain on their relationships. The young women spoke about the ways in which they lost touch with their spouses while managing their diagnosis, treatment, and life after treatment. They would like a way to deal with this strain.

> *"I think it's really, it's really hard on the males because…I didn't know it was nine hour surgery, I was so out of it the first week…and he had to see all that, I missed it, and I think it's really hard on them and it's hard for you to focus on them…but I was really focused, on him too but on my children really."* (Halifax)

> *"I think that this thing has been really hard on him and I think he has run away from it because he has accepted a position (in another city) so he's commuting and not home every weekend. So I'm on my own with three kids and I'm handling it fine, but I didn't think I'd be able to…you know, he has run away in a way, and I'm angry with him for that."* (Halifax)

> *"I wish I had better tools to deal with my partner."* (Toronto)

Financial Straightjacket

The latitude for coping financially with a breast cancer diagnosis at an earlier age is much more narrow, especially if women work part-time and don't have benefits. The situation is even more grave if women don't have more than the basic provincial insurance coverage, as was the situation for nearly a quarter of the consultation participants. They must deal with a reduced income for the duration of treatment and sometimes beyond, must deplete savings, and/or remortgage their home. According to pilot data from Ontario, expenses related to treatment are approximately $650/month for breast cancer patients (Longo, 2002). When cancer patients are covered by private insurance, out-of-pocket expenses cost an average of $425/month. When expenses aren't covered by private insurance, that figure can increase to an average of $780/month (Longo, 2002).

The women in these consultations spoke often of the financial toll of a cancer diagnosis. Single moms, child-free women and young, rural women suffered financially even more so. The participants described having to make very difficult choices between, for example, working during their treatments versus taking time off work; feeding themselves versus feeding their children; and depleting life savings versus having no money to afford treatment expenses.

> *"…sometimes with young people who get sick I mean we don't have anything…so the financial stress is…there's not a house to mortgage, there's not a husband who can make some extra money, there's nothing."* (Vancouver)

> *"I had to go back to work. I just had to financially. And I go to work even though it's an effort. I come home from work and I'm exhausted. Some people just don't get it, why I have to work, and how hard it is for me to go to work – I feel like an outsider."* (Young, rural woman)

> *"…you're trying to deal with your disease, you're trying to think positive and you're trying to reduce your stress and what am I going to feed my kids like I have 30 days to feed them and I have enough money for 10, so there's going to be 20 days when I'm not going to eat myself cause I want my kids to eat."* (Winnipeg)

> *"I didn't qualify for unemployment or any kind of benefits and because of the type of work I'm in, in acting, I'm self employed…we had to take our…RRSP's out to be able to afford for me to take the time off because my husband was adamant…that if I didn't want to go to work that I not have to, but you know now we're in a position where we don't have you know a savings that I mean at least we had that…but I'm left with the guilt feeling that now I've spent his retiring savings money and what if I'm not around to help him build that back up."* (Toronto)

Unanticipated treatment related expenses included some medications, bandages, transportation fees, cost of lodging if receiving treatment (especially radiation) away from home – none of which is paid for by universal health care system in Canada.

> *"I didn't know I had to pay for my chemo drugs."* (Halifax)

> *"…I had no pharmacare, so at twenty dollars a pill I'd be sitting there looking at this and my husband is going, 'honey, take a pill', 'honey it's twenty dollars', 'take the pill', and it's awful, they don't cover it, and that's my biggest peeve."* (Winnipeg)

> *"In terms of the stuff that is not covered, I personally had a problem in that the breast remained open during six months. This means that during six months, there had to be packing put in it and all that…I can tell you it cost me approximately $800 in bandages and that's not reimbursed because it's off-the-shelf."* (Montreal)

> *"It all adds up, parking every day while you're going for radiation."* (Winnipeg)

> *"I make very little money so I rely on the transit and I was so humiliated that I was you know a cancer patient and I still had to …ride the bus."* (Vancouver)

> *"I didn't know about CCS or anything or that they have assistance for people who can't afford prosthesis. I was walking around for a year lopsided after my mastectomy because I didn't have the money…for a cheap one is around $500."* (Young, rural woman)

> *"At the bare, bare minimum you shouldn't have to worry about anything to do with your healing and your cancer treatment…you shouldn't have to pay for any of those drugs."* (Winnipeg)

Once treatment was finished the women were not ready to return immediately to work. Yet they were not granted the latitude to fully recover.

> *"You need more than sixteen weeks sick leave when you are going through chemotherapy…I took sixteen weeks off to take my last batch of chemotherapy and that took me where I had to be back to work the week after my treatment…I filled out…Canada Disability, and I got a form back to them saying that my cancer wasn't serious or long term. (Another participant) In other words, you weren't* dying from it, so you didn't qualify." (Winnipeg)

> *"It's interesting, with my old GP…that was one of the things that got me really upset was he said, 'well you've been off for so long, you should be ready to go back to work.' He has no concept of the mental stress and anxiety that a person goes through."* (Winnipeg)

Young/Rural Women

The CBCN and OBC CRI staff hosted three teleconferences with five young and rural women. Because of the difficulty recruiting these women this sample of women is small. Please refer to the CBCN/OBC CRI report entitled "Perspectives of Rural Women with Breast Cancer" (2001) for a full description of the information and support needs and recommendations of Canadian rural women - a majority (60%) of whom were below 50 years of age when they were diagnosed. The information collected from the women in the teleconferences is highlighted below. Because the information from the women in the teleconferences is similar to the information presented in the "Perspectives of Rural Women with Breast Cancer" (2001) rural report, we have grouped their contributions into two of the rural report themes: 'Dealing with Isolation' and 'Having to Travel'.

Dealing with isolation: A few of the young, rural women spoke about feeling isolated and alienated from their home communities when they needed to stay in other communities to receive treatment; from other young breast cancer survivors; and, from members of their own communities.

> *"(I) stayed in a rooming house that felt like a jail. I was totally isolated from everybody else. I stayed in my room the whole time. All week I looked forward to going home on Friday. It effected me mentally, leaving my kids, I would want to prepare everything for the kids. So when I left Sunday everything would be taken care of…I felt really disconnected as I just waited for Friday so I could go home."*
>
> *"I went to a support group in town, it was for all cancers…there were women with breast cancer but like I say they were all talking about their grandchildren…"*
>
> *"Being from a small town I got incredible support. Sometimes though that's hard. One day I got 17 phone calls as the news spread. The support was wonderful but at times it would have been wonderful to be somewhere anonymous where you weren't 'that woman with breast cancer.'"*

Having to Travel: The young women explained that they traveled between 60-120 kilometres for surgical services, 6-75 kilometres for chemotherapy and 60-300 kilometres for radiation. The women reported often needing to leave their communities for support, information and treatment - not an option for some women. Sometimes the decision not to leave was made because of the fact the women had children.

> *"It's not an option for me to travel to St. John for a support group, even if it is a young women support group."*
>
> *"…there was no information in our town. I had to go into the city to find any books on breast cancer."*
>
> *"I thought speed was the factor, I had to make a decision about whether to go away or have surgery locally. Since I had kids, they were 6 and 11 at the time, and I didn't want to be away from them, I chose to have my surgery locally. Now I don't think that was the right decision as I did end up having to go to the city for a mastectomy."*
>
> *"…it was 8 hours to radiation. Because I was rural and I had to go into the city, I had to stay in the city Monday to Friday... It was though incredibly time-consuming…and the costs, economics were considerable. It means women leaving their families. So many women don't go for treatment because of finances, because they can't leave their kids."*

RECOMMENDATIONS

At the conclusion of the consultations, each woman had the opportunity to recommend their top three suggestions to improve the breast cancer experience for young women. These recommendations are listed below under the headings: Information, Support, and Programs/Services. All recommendations provided by the women are recorded by consultation site in Appendix E. A synopsis of the recommendations can be found in Appendix F.

Information

The young women noted that they want information geared to their age group and life-stage. They want information specific to the needs of young women along with generic information, such as prevalence rates, effects of treatment, and community and hospital support services for themselves and their families, provided to them at diagnosis as part of a standardized kit.

The information they would specifically like included in the kit for young women includes:

- Fertility
- Body image
- Early menopause
- How to talk to children
- Post-treatment support resources
- Treatment side effects
- Financial guidance

The consultation participants suggested that information not pertinent at diagnosis be provided to them in a staggered way over the course of treatment and following treatment. To impart staggered and up-to-date information the women proposed that the information be offered on CD Roms, video, the internet, and specific and relevant web-sites.

> *"…in the territories, they have started doing videos as far as information is concerned because people have to leave their homes and go for treatments and surgery…they're making informational videos about this is the hospital, this is where you go, this is the pre-op procedures…which is helpful as you were talking about the unknown, fear of the unknown. At least if you know a little bit about what you're in for, it removes some of that fear."* (Winnipeg)

The women also recommended that children, spouses, and friends receive information about breast cancer on two occasions: at diagnosis and at treatment completion. At diagnosis women wanted age-appropriate information about how to communicate with their children about cancer. For the parents of pre-school aged children, the women recommended that information/books be available. For the school-aged children and adolescents, the young women suggested that a professional such as a guidance counsellor, teacher, mental health specialist or doctor convey the information. At the conclusion of treatment, the women proposed that their husbands/partners receive information about support groups for spouses along with information about what the women are experiencing.

> *"…definitely written, after it's all done, something for your family to understand what you're going through and the mental stress, so that your husband will understand that you have your worries about death."* (Winnipeg)

Finally the women recommended that information about breast cancer be provided both to girls/young women in high schools and to the wider public. They suggested that a survivor deliver information about breast cancer and breast self-examination to high school students and that documentaries, posters, and commercials about a diverse group of young women with breast cancer be created and distributed to the public.

Support

The women were adamant that efforts continue to be made to connect young women with breast cancer either through community- or hospital-based support groups, or one-to-one peer counseling either face-to-face or by telephone. They expressed great enthusiasm for the creation of a young women's telephone hotline.

In order to attend community-based support groups the women suggested the provision of child-care services. One woman offered the idea of approaching the local high school to ask students to mind the children as part of their community service requirement.

The women also recommended that they support themselves and each other through advocacy work. They were encouraged by the efforts of the Young Survival Coalition (YSC) in the United States whose main goal is to,

> *"change the face of breast cancer by: advocating to increase the number of studies about young women and breast cancer; educating young women about the importance of breast self-examination and early detection; and being a point of contact for other young women with breast cancer."* (YSC, 2001, Young Women United Against Breast Cancer sheet, p.1)

The YSC is interested in building a database of information about young women so that research about, for example, the specific effects of treatment on pre-menopausal women or improved ways to detect tumors, can go forward. The consultation participants also wanted changes to the age-orientation of breast research in Canada:

> *"have a database of information…and how can we add more into that to cover issues for young women."* (Vancouver)

> *"…research doesn't seem to be coordinated…it's all sorts of pockets of research…there needs to be a national strategy put together for research…you know they say for pregnancy that they just can't find enough young women that are having children that have breast cancer…."* (Toronto)

> *"…(we need) to have a Young Survival Coalition like they (the Americans) do…to have that organization like that here. … And having conferences here in Canada I mean the fact that we have to go down to Philadelphia to go to a conference on young women is…I mean it's dedicated that we went but it means there's a need."* (Toronto)

Programs/Services

The women proposed several ideas for the ways in which the programs and services offered currently in the cancer care system could be modified to meet their, and their families needs. They also suggested the creation of new programs and services.

First and foremost the women spoke about the need for 'navigators' to assist them through the cancer care system. Most felt the 'navigator' should be a breast cancer survivor very familiar with cancer care programs and services both within the institution as well as in the community.

> *"I needed a general contractor to look after my health"* (Winnipeg)

The women noted that the 'navigator' would be especially helpful if the cancer care system was organized as a 'one-stop-shopping' clinic. Both consultation groups in Montreal described such an institution:

> *"The clinic has all the services available in their facility. The ultrasound and the mammography. (In) a three-hour period you get everything done and you find your*

> *results fast…not like the hospitals where you have your mammogram one day and then two months later they schedule you for an ultrasound…in (the) clinic all specialized doctors are in the same building and when you have been diagnosed in these specialized clinics they have a team of doctors from all disciplines that answer your questions and brainstorm the best treatment option for you on the spot."* (Montreal)

Second, in order to address the lack of information available for young women, they suggested that health care providers within the cancer clinics or community-based cancer service providers create and implement several topical workshops. Examples of the workshops the young women would attend include:

- dating
- sexuality
- lymphadema
- reconstruction
- recurrence
- financial help
- nutrition & exercise

Third, as we mentioned earlier in this report, the women emphasized that on-going follow-up to treatment was imperative. They suggested meeting with a breast cancer nurse or a clinical-breast-examination-trained physician once every six months.

Financial assistance was another much-sought-after recommendation. The women want subsidized medications, treatment-related travel, and treatment-related child-care. They would also like guidance concerning medical tax-exemptions and on how to lengthen the time spent away from paid-work in order to facilitate their recovery. The young women from Winnipeg and Montreal relayed their experience with two very helpful services:

> *"And with the financial stuff…I was noticing that Hope (Breast Cancer Information and Resource Centre) does have funding available for people…bursaries and such… so that people like us that don't have the money can still get the care."* (Winnipeg)

> *"Me, I was lucky, do you know what the pharmacist did? He advanced credit to me. Every time I went to get $1,600 worth of injections, he would advance credit to me for three weeks, waiting for my insurance cheque to come in."* (Montreal)

Finally, the women recommended the provision of instrumental and emotional support from the cancer care system. The consultation participants requested assistance with meal-making, child-care, and house-cleaning in their homes; child-care facilities at the treatment centres; and, the provision of professional emotional and/or spiritual support for them and their families.

> *"…maybe there's a way that they could have like a counselor or somebody that can kind of to understand that we are we are going to lose a piece of ourselves."* (Winnipeg)

> *"…maybe this leads to a recommendation – that is, when a woman is first diagnosed, that she be linked to a psychologist…as soon as she is diagnosed… Immediately. Not for her to go home but to go to the psychologist's office and have a good cry…"* (Montreal)

PARTICIPANT'S VALIDATION OF FINDINGS

Once the analyses were completed the 70 participants were mailed a copy of the draft report of the findings from the young women consultations and a feedback survey (see

Appendix G). Thirty-one per cent of the consultation participants returned the feedback forms (n=22). The young women were asked to read the draft report and then to indicate their level of agreement with fourteen statements related to the findings. The fourteen statements were scaled and participants had an opportunity to respond in the following ways: ‘strongly agree’, ‘agree’, ‘neutral’, ‘disagree’, ‘strongly disagree’. For purposes of analysis participant’s responses were categorized into ‘agree’, ‘neutral’ and ‘disagree’. The degree to which participant's agreed with the statements are illustrated below in Table 3.

Over 80% of the respondents agreed with 13 of the 14 summary statements. The respondents did not support the statement indicating that young women felt that the lack of regular follow-up was a major concern (only 55% agreed) however, 96% of young women agreed that systems must be put in place to ensure long-term follow-up of young women. Perhaps the participants who responded were not personally concerned with follow-up but felt that long-term follow-up services should be made available should they or others require it.

Item #15 on the survey provided respondents the opportunity to comment on concerns not mentioned in the report. Five of the twenty-two respondents chose to complete this item. Three of them echoed that the report covered all concerns expressed during the consultations, one respondent added that transportation to and from cancer treatment was a concern, and one woman underscored the necessity of providing the same resources for rural and urban breast cancer survivors.

Overall, the feedback received from the respondents strongly validates the findings derived from the consultations held across Canada with young women.

Table 3 – Feedback from Participants

Statement on Feedback Form	**% of Participants who ‘Agreed’**
Young women with breast cancer have more difficulties than do older women accessing information relevant to their age and life-stage.	96 %
Young women have difficulties finding age-appropriate information concerning how to talk about cancer to their children.	86 %
Young women with breast cancer have difficulties accessing peer and professional support.	86 %
Young women find it difficult to access age-appropriate emotional support for their children.	82 %
The lack of help with child-care is a major problem for young mothers with breast cancer.	86 %
The cancer care system does not sufficiently attend to the specific needs of pre-menopausal women in relation to diagnostic procedures, clinical trials, and available treatments.	86 %
The lack of regular follow-up to young women with breast cancer is a major concern.	55 %
Young women struggle with issues related to their body image (e.g., physical appearance, sexuality) following surgery and/or treatment.	96 %

Inadequate financial programs create a major burden for young women with breast cancer.	96 %
The cancer care system should provide two types of information to young women with breast cancer: 1) information about the specific issues faced by young women, and 2) standardized generic information about issues faced by any woman with breast cancer.	100 %
Systems need to be developed to better help newly diagnosed young women with breast cancer to navigate the health care system.	91 %
The cancer care systems needs to develop better diagnostic techniques and to more fully understand the effects of adjuvant therapy on young women with breast cancer.	100 %
Systems need to be put in place to ensure long-term follow-up of young women with breast cancer.	96 %
Systems need to be put in place to ease the financial burden for young women with breast cancer.	100 %

FINAL COMMENTS

During these consultations the young women didn’t talk about difficulties accessing already existing information, they stressed that *information about them must exist* and that already existing generic information must be *relevant to their life situations*. They highlighted the need for support, both emotional as well as practical/instrumental such as, childcare, help cleaning the home and preparing meals, and financial assistance. Young women also recommended that health providers attend to their unique age- and life-stage-related needs with relevant and timely programs and services. Finally, women spoke about the struggles they had with the changes to their bodies, the impact of their diagnosis on their families, and the major financial burdens.

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The CBCN and the OBC CRI hope that what we've learned from these consultations with 70 young women from across Canada will provide the impetus to mobilize the cancer care system to provide relevant information, support, and services to all young women with breast cancer.

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APPENDIX A – INTERVIEW GUIDE

YOUNG WOMEN STUDY - INTERVIEW GUIDE

INFORMATION

1. What are the significant gaps in information for young women What do you think are the most important information needs?
- At pre-diagnosis, diagnosis/treatment, after treatment
- How would have receiving this information effected you if you have had it?
- Would it have made you feel differently?
- What kinds of different decisions might you have made? (What are women really looking for)

SUPPORT

2. What are the significant gaps in support for young women? What do you think are the most important support needs?
- At pre-diagnosis, diagnosis/treatment, after treatment
- How would have receiving this information effected you if you have had it?
- Would it have made you feel differently?
- What kinds of different decisions might you have made? (What are women really looking for)

SUGGESTIONS

3. Do you have any suggestions/recommendations about how to help young women living with breast cancer get access to the services they need?

- What would have helped with some of the difficulties you've encountered through your journey?

BREAK

4. Other thoughts on personal experiences, experiences with supportive services etc.
5. How did it feel to be with us today ~ EVALUATION

Closing ~ Thank-you very much for coming to our focus group. Your thoughts, issues and insights are incredibly important, and we appreciate you taking time out of your lives, to share your experiences with us.

APPENDIX B - DEMOGRAPHIC INFORMATION FORM

YOUNG WOMEN AND BREAST CANCER STUDY
DEMOGRAPHIC INFORMATION FORM

In this part of the interview, we want to ask you some questions about yourself and your background. Please answer or check off the box concerning those questions you wish to complete. Thank you.

1. In what year were you born?

.__________________

2. In what country were you born?

.__________________

If other than Canada, what year did you immigrate?

.__________________

3. What is your first language?
θ English
θ French
θ Other? .__________________

4. To what ethno-cultural group do you belong? (e.g., African-Canadian, First Nations, Caucasian, Jewish, etc.)

.__________________

5. Are you?
θ Single
θ Married/living with intimate partner
θ Separated/divorced
θ Widowed

6. What is the highest level of education you had the opportunity to complete?
θ No formal schooling
θ Primary school
θ Secondary school
θ Post secondary school
θ Other? .__________________

7. What city/town do you live in?

.__________________

8. When were you first diagnosed with cancer? (month and year)

   .__________________

9. Which of the following treatments/surgeries did you receive for your breast cancer diagnosis? (check all that apply):
   - θ surgery
     - θ lumpectomy
     - θ mastectomy
     - θ prophylactic mastectomy
     - θ Other .__________________
   - θ radiation therapy
   - θ chemotherapy
   - θ hormone therapy (e.g., Tamoxifen)
   - θ stem cell or bone marrow transplant
   - θ reconstruction
   - θ complementary/alternative therapies (please describe) .__________________
   - θ none of the above

10. Has your breast cancer ever come back (have you had a recurrence)?
    - θ No
    - θ Yes

      If yes, which of the following treatments/surgeries did you receive for your breast cancer diagnosis? (check all that apply):
      - θ surgery
        - θ lumpectomy
        - θ mastectomy
        - θ prophylactic mastectomy
        - θ Other .__________________
      - θ radiation therapy
      - θ chemotherapy
      - θ hormone therapy (e.g., Tamoxifen)
      - θ stem cell or bone marrow transplant
      - θ reconstruction
      - θ complementary/alternative therapies (please describe)._______________
      - θ none of the above

11. Have you been diagnosed with another type of cancer?
    - θ No
    - θ Yes

      If yes, which type?

      .__________________

12. What is your main work activity (please check one)?
    θ Unemployed due to cancer
    θ Unemployed for other reasons
    θ Working full-time
    θ Working part-time
    θ Sick leave or disability
    θ Retired
    θ Homemaker
    θ Student

13. What is/was your occupation?
    .__________________

14. In which of the following ranges does your total household income lie?
    θ Less than $20,000
    θ $20,000-39,999
    θ $40,000-59,999
    θ $60,000-79,999
    θ $80,000-99,999
    θ over $100,000

14. Do you have a health insurance plan in addition to your provincial health insurance (e.g., Blue Cross; Manulife)?
    θ No
    θ Yes
        If yes, is this additional health insurance
        θ Available through your work
        θ Purchased by you
        θ Available through your husband's/partner's plan

15. How many, and how old, are the children or elderly persons that you have primary responsible for (i.e., financial responsibility, caregiving responsibility)?
    # of children: ._____ Ages of children: ._________________________
    # of elderly: ._____

16. Do you have any other comments/questions concerning the information on this form?

____
____
____
____
____
____

Thank you for completing this form

APPENDIX C – FOCUS GROUP EVALUATION FORM

YOUNG WOMEN AND BREAST CANCER
FOCUS GROUP EVALUATION FORM

1. Impressions

a) What did you like most about the focus group?

i) ____

ii)____

b) What did you like least about the focus group?

i) ____

ii)____

c) To what extent were the experiences shared by other women today similar to your own?

1 2 3 4 5

not at all similar very similar

Please explain any similarities and/or differences:

____

____

____

d) What do you feel are the most important issues facing young women with breast cancer?

____

____

____

2. Content

a) Within the focus group, three themes 1) Everything Depends on Now, 2) Out of Sync, and 3) Cancer is Invading my Whole Life were presented, reflecting younger women's experience with breast cancer. How well do you feel these themes represent your experience?

1 2 3 4 5

not at all similar very similar

Please explain any similarities and/or differences:

____

____

b) What are the top three ways that you would meet the information and/or support needs of young women living with breast cancer? (Your recommendations/suggestions)

i) ____

ii)____

iii)____

Note: gray shaded area above not applicable to this report

3. Focus Group Structure

a) Did the facilitator ask relevant questions about the issues faced by young women?

YES ☐ NO ☐ DON'T KNOW ☐

Comments: ____

____

____

b) Were there any issues/topics that you feel should have been asked or addressed in the focus group that were not?

YES ☐ NO ☐ DON'T KNOW ☐

If yes, which issues/topics?____

____

c) Did you feel that the time allotted for the focus group was appropriate:

YES ☐ NO ☐ DON'T KNOW ☐

Comments: ____

____

d) Did you feel that the number of participants invited was:

JUST RIGHT ☐ NOT ENOUGH ☐ TOO MANY ☐

4. Facilitator's Process

a) Did you feel the facilitator created an atmosphere in which you felt comfortable to share your personal experience?

YES ☐ NO ☐ DON'T KNOW ☐

If not, why?____

____

b) Was the facilitator skillful at keeping the discussion focused and on topic?

YES ☐ NO ☐ DON'T KNOW ☐

Additional comments and/or suggestions for improvement?

____

____

____

Thank you for completing this evaluation!

PLEASE COMPLETE AND HAND-IN SEPARATELY

FUTURE CONTACT

In some instances, after a focus group has taken place, researchers like the opportunity to re-contact participants in order to ask more questions about the focus group topic and to ask for clarification or for their reflections about the findings.

While future involvement is certainly not part of the agreement for participating in today's focus group, we would like to know whether you would feel comfortable participating in the ways mentioned above in the future.

Could someone from the research team follow-up with you after today's focus group?

YES ☐ Name ____
Contact Information (address, telephone, e-mail)
____
____
____

NO ☐

Also, are you interested in receiving a copy of the final report of this research?

YES ☐ Please contact me at same address as above

OR

YES ☐ Name ____
Contact Information (address, telephone, e-mail)
____
____
____

NO ☐

Are you interested in being on CBCN's mailing list?

YES ☐ Please contact me at same address as above

OR

YES ☐ Name ____
Contact Information (address, telephone, e-mail)
____
____
____

NO ☐

Many thanks,
CBCN and CBCF CRI staff

APPENDIX D- SELECTED PARTICIPANT DEMOGRAPHICS

YOUNG WOMEN AND BREAST CANCER STUDY
SELECTED PARTICIPANT DEMOGRAPHICS

CURRENT AGE

CURRENT AGE	# OF RESPONSES	PERCENTAGE
26-30	3	4%
31-35	7	10%
36-40	21	30%
41-45	22	31%
46 and up	17	24%*
	N=70	

*Please note that percentages in all tables have been rounded up to the nearest whole number and so percentage total might be slightly above or below 100%

AGE AT DIAGNOSIS

AGE RANGE	# OF RESPONSES	PERCENTAGE
26-30	8	11%
31-35	12	17%
36-40	24	34%
41-45	24	34%
46-50	2	3%
	N=70	

YEARS SINCE DIAGNOSIS

# OF YEARS SINCE DIAGNOSIS	# OF RESPONSES	PERCENTAGE
> 5 years	2	3%
5 years	9	13%
4 years	14	20%
3 years	18	26%
2 years	14	20%
1 year	13	19%
< 1 year	1	1%
	N=70	

COUNTRY OF BIRTH

COUNTRY	# OF RESPONSES
Canada	65
Australia England Guyana Ireland USA	1 1 1 1 1
	N=70

IF OTHER THAN CANADA, YEAR OF IMMIGRATION

YEAR OF IMMIGRATION	# OF RESPONSES
1950 – 1959	1
1960 – 1969	1
1970 – 1979	0
1980 – 1989	1
1990 – 1999	1
2000 – current	1
	n=5

FIRST LANGUAGE

FIRST LANGUAGE	# OF RESPONSES	PERCENTAGE
English	62	89 %
French	6	9 %
Hungarian German	1 1	1% 1 %
	N=70	

ETHNO-CULTURAL GROUP IDENTIFICATION

ETHNO-CULTURAL GROUP	# OF RESPONSES	PERCENTAGE
Caucasian	39	71%
Canadian	4	7%
French Canadian	2	4%
Jewish	3	5%
English/Catholic Guyanese German-Canadian Italian /Jewish Cree First Nations	1 1 1 1 1 2	2% 2% 2% 2% 2% 4%
	n=55	

RELATIONAL STATUS

RELATIONAL STATUS	# OF RESPONSES	PERCENTAGE
Single	12	17%
Married/living with intimate partner	47	67%
Separated/Divorced	11	16%
Widowed	1	1%
	N=70	

HIGHEST LEVEL OF EDUCATION COMPLETED

EDUCATION LEVEL	# OF RESPONSES	PERCENTAGE
Primary school	2	3%
Secondary school	10	14%
Post Secondary school	53	76%
Other – Masters/Med School	5	7%
	N=70	

SURGERIES RECEIVED FOR BREAST CANCER DIAGNOSIS

SURGERIES	# OF RESPONSES	PERCENTAGE
Lumpectomy	24	34%
Mastectomy	27	39%
Prophylactic Mastectomy	0	
Lumpectomy & Mastectomy	11 (2 partial mastectomies)	16%
Mastectomy & Prophylactic Mastectomy	2	3%
Prophylactic Mastectomy and Other	1	1%
Other (Recommended surgery but declined)	1	1%
Lumpectomy & Other 2 – lumpectomy/node dissection 2- unknown what other is	4	6%
	N=70	

TREATMENTS RECEIVED FOR BREAST CANCER DIAGNOSIS

TREATMENT(S)	# OF RESPONSES
Radiation alone	3
Radiation in combination with other tx	27
Chemotherapy alone	4
Chemotherapy in combination with other tx	32
Hormone therapy alone	3
Hormone therapy in combination with other tx	19
Stem cell alone	0
Stem cell in combination with other tx	1
Reconstruction alone	3
Reconstruction in combination with other tx	11
Complementary/alternative treatments in combination with other tx	13

BREAST CANCER RECURRENCE

RECURRENCE	# OF RESPONSES	PERCENTAGE
No	57	81%
Yes	7	10%
Other 2nd primary Metastatic upon diagnosis Contra-lateral Suspected recurrence	 2 2 (counted as recurrence) 1 (counted as recurrence) 1 (counted as recurrence)	 3% 3% 1% 1%
	N=70	

RECURRENCE – SURGERIES

SURGERIES	# OF RESPONSES	PERCENTAGE
Lumpectomy	1	9%
Mastectomy	5 * (one person noted surgery, but didn't note what type)	46%
No surgery	5	46%
	N=11	

RECURRENCE-TREATMENT

TREATMENTS	# OF RESPONSES
Radiation alone	0
Radiation in combination with other tx	6
Chemotherapy alone	1
Chemotherapy in combination with other tx	5
Hormone therapy alone	1
Hormone therapy in combination with other tx	6
Stem cell alone	0
Stem cell in combination with other tx	0
Reconstruction alone	0
Reconstruction in combination with other tx	0
Complementary/alternative treatments in combination with other tx	0

DIAGNOSED WITH ANOTHER TYPE OF CANCER

OTHER CANCER	# OF RESPONSES	PERCENTAGE
No	68	97%
Yes	0	
Other 2 – pre-cancerous cells found in cervix	2	3%
	N=70	

MAIN WORK ACTIVITY

WORK ACTIVITY	# OF RESPONSES	PERCENTAGE
Unemployed due to cancer	5	7%
Unemployed for other reasons	0	
Working full-time	32	46%
Working part-time	14	20%
Sick leave or disability	5	7%
Retired	0	
Homemaker	11	16%
Student	3	4%
	N=70	

HOUSEHOLD INCOME

INCOME RANGE	# OF RESPONSES	PERCENTAGE
Less than $20,000	7	12%
$20,000 - 39,999	10	17%
$40,000 – 59,999	11	19%
$60,000 – 79,999	11	19%
$80,000 – 99,999	6	10%
Over $100,000	14	24%
	n=59	

ADDITIONAL HEALTH INSURANCE PLAN

HEALTH INSURANCE PLAN ON TOP OF PROVINCIAL COVERAGE	# OF RESPONSES	PERCENTAGE
No	17	24%
Yes	53	76%
If Yes-Available Through Own Work	30	56%
Purchased by you	2	4%
Available through partner's plan	21	40%

DEPENDENTS

DEPENDENTS	# OF RESPONSES	PERCENTAGE
1 child (0-8 years)	6	9%
1 child (9-16 years)	5	7%
2 children (0-8 years)	4	6%
2 children (9-16 years)	13	19%
2 children (split between)*	6	9%
3 children (0-8 years)	4	6%
3 children (9-16 years)	2	3%
3 children (split between)	3	4%
4 children (split between)	2	3%
5 children (split between)	1	1%
Ages unknown 1 child –1 2 children - 1 3 children – 1	3	4%
No children	21	30%
Elderly dependents	2 (in addition to caring for one child or to being child-free i.e., this category has overlap with above categories)	
	N=70	

* Note: 'Split between' indicates the children's ages are split between age groups 0-8 years and 9-16 years

APPENDIX E – RECOMMENDATIONS x FOCUS GROUP SITE

VANCOUVER

Information	Support	Programs/ Services
Find a cure or at least a way to co-exist with the disease	Parents/Families/ Partners – support	Navigator-cancer support (5) or Community “Services Coordinator”
Create a video/CD which gets regularly updated-to provide a young woman’s overview and suggests pertinent resources and research/treatment (2)	Connecting women-one-on-one with similar cancers (3)	More workshops on special topics(i.e. lymphadema/ recurrence/reconstruction)(2)
Written literature on young women and breast cancer-stages provided at dx (5 women)	Young Women – support/groups (8/9)	Follow-up with breast health GP's or nurses who can examine you every 6 months for lumps-irregularities rather than relying on busy oncologists/surgeons
Post-Treatment resources-listing of doctors and breast health nurses	Set up a young women’s hotline	More doctors time and effort in meeting the needs of young women
Public awareness that breast cancer can affect young women		Alternative therapy to be more recognized and funded
Information for Parents/Families/Partners		Financial Advisors Therapists-Individual/Family
Sessions/info in high school re breast cancer and support services that are available (4)		Financial support/resources when needed (2)
Young Women pamphlet/web – young-women focused-(i.e., fertility) (5)		Specific training for sex-therapists re: young women with breast cancer
Web-site/interactive components/internet		
Make information more efficient, accessible and appropriate to level of patient needs/education		
Up-to-date information answering my questions (i.e. freezing my eggs, body image, etc.)		

WINNIPEG

Information	Support	Programs/ Services
More take home information from start to after care-to be provided by oncologist (5)	Offering balance in support groups through exercise such as yoga, music, meditation, thought provoking ‘reflections’otherwise depressing and sad	Government needs to become more aware of sick leave and disability for cancer patients-lobbying for more support-financial/educational (2)
Understanding ‘after-treatment’ effects/ information for others to understand after-effects (2)	More family support	Physicians to increase the time needed to recover from treatment and to support you with medical leave/absence
Better education in schools/breast self-exams (3)	Make sure all women are contacted after diagnosis-support	Provide better imaging procedures for young women
More specific and prevalent statistics on young women	Emotional support to women who request/need it	General Practitioners to be more knowledgeable on follow-up care and concerns
Provide more and improved information for survivors	Being proactive as survivors in getting information out to each other	Book extra time for appointments with health care providers (to ask questions)
Pamphlets and tapes	Have support groups with other young women	Continue to provide workshops(like today) where our voices can be heard
Information for family coping closer to diagnosis or at time		Programs educating others (including the medical profession) with regards to psychological aspects of B.C.
Provide information on body image/understand how difficult losing body parts are to us as women		Spirituality component/room available at oncology/medical centres
Incorporate cultural difference (i.e posters with people of colour)		Lower age of mandatory mammograms from 50 to 25 or 30.
		Have health navigator in all centres
		Ensure all women get drugs, services despite financial ability (2)

TORONTO

Information	Support	Programs/ Services
Help information on child care, paying bills etc	Consider a mentoring network (2)	Do more tests, to help you mentally keep going (no guarantees) but security of knowing you are being watched-helps mentally
Be given information on 'after surgery'	Support dealing with living-knowing you could die from this, or fear of recurrence, or dealing with loss in support groups	Workshops on sexuality and dating (4)
Communicate within the community of available services	Get young women together in group situations	Doctors need to listen more and believe us
More awareness, T.V., commercials, documentaries		Resources for children-Groups/therapy (2)
Supply list of support groups with diagnosing doctors		Resources for financial help
Have the same resources and information in all centres/areas		

MONTREAL

Information	Support	Programs/ Services
Information more accessible (3)	Buddy programs (a member who has been through it)	Doctors should be more informed about resources
Ways women can help themselves-nutrition, exercise etc.	Be part of panels for research and discussion	Doctors are overworked but someone should be there to answer all questions about medical treatment/side effects.
Standardized kits for information on subsidies	Support groups	Provide a psychologist/ support for children/spouse (2)
Internet	Support after treatment	Support at diagnosis-immediately provided with a resource person at our disposal
Information for friends and family for coping with cancer and the emotional complications (2)	Get involved in other groups (awareness programs, advocating in schools and other organizations)	Speed up procedures
Inform the general public about how they can help someone with a serious illness (i.e. home support etc)	Young Survival Coalition expansion to Canada	Available child care or subsidies/practical support at home (3)
	Educate women about rights	Centralizing information at one site- (i.e online information or telephone site) (2)
	Participate in groups such as this one	Better screening tools
	Environmental Groups and Breast Cancer groups partnering to help in developing a prevention strategy (2)	Open/create more multi-disciplinary clinics (2)
		Follow-up care and screening
		Alternative therapies-both for prevention and treatment
		Financial support-either through taxes or free services/medications
		Lengthen the leave of absence time from work after treatments) (2)

HALIFAX / NOVA SCOTIA

Information	**Support**	**Programs/ Services**
Staging of Information	Network of women survivors that could be contacted early in the diagnosis to answer questions	Navigator-A survivor in hospital to help people through the process (2)
Simple FAQ’s of step by step-to use as a reference	Networking with other young mothers (2)	One point of information for newly diagnosed women
Information booklets passed out at diagnosis	Young Women one-to-one peer support (5)	Recognition of child care issues by cancer centres
Informative and factual web-sites	Young Women- Support Groups (3)	One place where women can go for all their needs-testing, diagnosis, treatment advice, support and information
Better literature with positive messages up-front	Families-Support for spouse/children	
Information that is in a format that is digestible	Generic support groups	
Multi-media approach	Advice/Suggestions for other women- Become involved in your treatment from the get go	
Accessible information		
More information given at diagnosis (2)		
Information about diagnosis to children/how to talk to children		
Advertise (newspaper) that support is available from other women		

YOUNG/RURAL WOMEN - TELECONFERENCES

Information	Support	Programs/Services
Phone conferencing sessions	Every woman diagnosed to spend a day with a variety of people who could provide support and information in a non-threatening way (e.g. not test results, but a nutritionist, counselor, another survivor, learn relaxation strategies etc.)	Group sessions-locally and provincially on relevant topics
Provide Information on internet	Let women know they are not alone in the disease, that there is hope	Financial help with travelling costs
We need to know how else we can help ourselves besides receiving standard treatment (surgery/chemo/radiation)	More support groups for young women	Coordination of appointments in larger centers whenever possible
Information for family	Support for the family	Docs to have more information about resources - let docs know about these services
Rural physicians should provide links to supports and specialists at diagnosis		

APPENDIX F– RECOMMENDATIONS OVERALL

RECOMMENDATIONS ~ OVERALL

Information	Support	Programs/ Services
Information for families of women with breast cancer available at diagnosis (children, spouses, friends) ΨΨΨ	Networking with other young women and/or young mothers ΨΨΨΨ	Navigator program – Survivor or other resource person to aid women through process of diagnosis-after-treatment ΨΨΨ
Information/Media about breast cancer. Need to put a new 'face' on breast cancer, which incorporates cultural differences, and creates more general public awareness (inform public how to help someone who is ill) ΨΨΨ	Support for women living with breast cancer-including young women breast cancer support groups offered to all women (after-treatment, resources available, buddy programs-survivor contacts) ΨΨΨ	Young women focused workshops. Topics proposed-lymphoedema, recurrence, reconstruction, sexuality and dating, fertility, gender/body issues, nutrition, exercise. ΨΨΨ
Appropriate information should be made available at diagnosis and should be stage appropriate (FAQ's, diagnosis, treatment, after-tx). Info should be positive up-front, digestible, simple, accessible-take-home, and standardized ΨΨ	Support for families of women with breast cancer. Should be available at diagnosis (children, spouses, friends) (also in Programs/Services) ΨΨΨ	Better Screening/Follow-up care (imaging techniques-lower mandatory age- and after-treatment follow-up) ΨΨΨ
Information for younger women-adolescents in high schools about BSE and breast cancer ΨΨ	Young women's hotline for women to call for information/support- (Young survival coalition expansion to Canada) ΨΨ	One–Stop breast health care clinics with multidisciplinary teams (diagnosis/testing/support) ΨΨΨ
Young women focused information & research (statistics, prevalence, fertility, body issues, after-effects etc) Information should be written, on video or C.D., web-sites, interactive websites, should be updated regularly ΨΨ		Financial support either in the form of free services /medications, tax-free exemptions, longer disability/leave of absence ΨΨΨ
		Support offered to women for child care and meal-making, house-cleaningΨΨ
		Support/education offered to various health and other professionals (sex therapists, financial advisors, therapists) about psychosocial effects of breast cancer Ψ
		Spirituality component/room available at oncology/medical centres Ψ

ΨΨΨΨ noted in all 10 of the focus groups
ΨΨΨ noted in at least 6 of the focus groups
ΨΨ noted in at least 4 of the focus groups
Ψ noted in at least 2 focus groups

APPENDIX G - YOUNG WOMEN REPORT FEEDBACK FORM

Young Women Report Feedback Form

We need your feedback about the enclosed report, “'Nothing Fit Me': The Information and Support Needs of Young Women with Breast Cancer”. Please complete the questions below and mail or fax your response to the CBCN no later than November 15th, 2002.

1) Young women with breast cancer have more difficulties than do older women accessing information relevant to their age and life-stage.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

2) Young women have difficulties finding age-appropriate information concerning how to talk about cancer to their children.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

3) Young women with breast cancer have difficulties accessing peer and professional support.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

4) Young women find it difficult to access age-appropriate emotional support for their children.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

5) The lack of help with child-care is a major problem for young mothers with breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

6) The cancer care system does not sufficiently attend to the specific needs of pre-menopausal women in relation to diagnostic procedures, clinical trials, and available treatments

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

7) The lack of regular follow-up to young women with breast cancer is a major concern.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

8) Young women struggle with issues related to their body image (e.g., physical appearance, sexuality) following surgery and/or treatment.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

9) Inadequate financial programs create a major burden for young women with breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

10) The cancer care system should provide two types of information to young women with breast cancer: 1) information about the specific issues faced by young women, and 2) standardized generic information about issues faced by any women with breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

11) Systems need to be developed to better help newly diagnosed young women with breast cancer to navigate the health care system.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

12) The cancer care system needs to develop better diagnostic techniques and to more fully understand the effects of adjuvant therapy on young women with breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

13) Systems need to be put in place to ensure long-term follow-up of young women with breast cancer.

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

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

1	2	3	4	5
Strongly Disagree	Disagree	Uncertain/ Neutral	Agree	Strongly Agree

15) Please list any important issues facing young women that are not in the report and should be.

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The Canadian Breast Cancer Network

The Canadian Breast Cancer Netwok (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:

CBCN, 300-331 Cooper Street, Ottawa, Ontario, K2P 0G5
Telephone: 613-230-3044; Toll free: 1-800-685-8820
Email: cbcn@cbcn.ca
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

CBCN RCCS
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