‘Nothing fit me’: nationwide consultations with young women with breast cancer

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Accepted for publication
12 December 2005

Keywords: breast cancer, Canada, focus groups, qualitative inquiry, young women

Abstract

Objective There exists little research about the experience of breast cancer for young women in Canada. To address this gap, the Canadian Breast Cancer Network (CBCN) and the Ontario Breast Cancer Community Research Initiative undertook a research project to explore the information and support experiences, needs and recommendations of geographically diverse Canadian young women with breast cancer.

Setting and participants We consulted with 65 young women in 10 focus groups held across Canada. All women had been diagnosed with breast cancer at, or before, 45 years of age. During the consultations the women were asked to discuss their information and support experiences and needs, as well as resource recommendations related to their diagnosis, treatment and survivorship.

Main results The overarching theme, ‘Nothing Fit Me’, revealed that accessed information, support and programmes/services did not ‘fit’ or match the women’s age or life stage. When we asked for their recommendations the young women suggested that information and support match their age and life stage and that health-care providers create and implement several topical workshops concerning, for example, sexuality, lymphedema and reconstruction.

Conclusion The findings will be used by the CBCN as a general platform from which to conduct further research and/or action strategies. The CBCN will also implement the recommendations from this groundbreaking work as this network formulates a national strategy for young women with breast cancer.

Introduction

In 2004, over 21 000 Canadian women were diagnosed with breast cancer.[1] Though breast cancer is primarily a disease that affects older women, 22% of all women with breast cancer are below the age of 50 years,[2] and more women below the age of 40 die of breast cancer than of any other type of cancer.[3] Additionally, the disease in young women is more likely to be more aggressive.[4,5]

While the facts about the incidence of breast cancer abound, less is known about how women experience a diagnosis, ensuing treatment and aftercare. Some researchers have examined the breast cancer experience from the perspective(s) of older women,[6,7] but fewer have focused specifically on younger women.[8,9]

Researchers who have examined breast cancer from the perspective(s) 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;[10–12] the importance of understanding financial barriers;[13,14] the unclear potential consequences of early menopause or impaired sexuality during and following treatment;[15,16] how the strain of the diagnosis can contribute to poorer adaptation to diagnosis;[12,17,18] how the diagnosis affects their partners/spouses/family members;[11,12,19] and how women with children cope with parenting.[19–21]

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.[22] 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.[11,14,22–25] 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.[10,11]

The information gathered from the aforementioned research provides a starting place for planners to create relevant programmes/services, information and support for young women. However, more study is warranted and until now, none of the above research includes the perspectives and experience of geographically diverse Canadian young women.

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 the information and support experiences of young women who live with breast cancer, hence our research question: What do young women with breast cancer perceive are their information and support experiences, needs and recommendations related to their breast cancer diagnosis, treatment and survivorship?

For the purposes of the current investigation young is defined as those women diagnosed with breast cancer at or 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.

Methods

Participants/consultation process

Qualitative methods are particularly suited for understanding the lived experiences of individuals about whom there is paucity of research.[8,26] A qualitative research methodology enabled the research team to inquire into participants' subjective experiences of breast cancer. As a result, 10 focus group consultations were held nationally with 65 young women. We chose the method of focus groups for data collection because the Community Capacity Building arm of the Canadian Breast Cancer Initiative of Health Canada funded this project to specifically inquire into the lived experience of geographically diverse young women with breast cancer, and we were able to reach more women from across Canada using this method. Moreover, efforts to build community capacity require assembling a group(s) of appropriate stakeholders. Additionally, because young women are in the minority of women diagnosed with breast cancer, CBCN and the research team wanted to offer an opportunity for young women to meet other young women with the same disease. The women who participated in the consultations were diagnosed with breast cancer at or before the age of 45 years and were between 1 and 5 years post-diagnosis.

Two, daylong consultations were held over five consecutive weekends in each of the following five cities: Vancouver, Winnipeg,

Table 1 Composition of groups × location

	Composition of group	
Location	Consultation day I	Consultation day II
Vancouver	Single and partnered mothers with children age 0–16	Childfree women
Winnipeg	Partnered mothers with children 0–8 years	Mothers with children 9–16 years
Toronto	Single mothers 0–16 years	Childfree women
Montreal	Anglophone mothers with children 0–16 years	Francophone mothers with children 0–16 years
Halifax	Mothers with children 0–8 years	Mothers with children 9–16 years

Toronto, Montreal and Halifax. The women were recruited through newspaper ads (Vancouver, Halifax and Montreal), CBCN's newsletter, 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. The research team was interested in the perspectives of this self-selected sample of women as a means to initially explore their subjective concerns. We decided not to select participants randomly as we were not attempting to generalize the experience of breast cancer for all young women. Rather for expediency and to organize consultations nationally, we utilized: (i) systematic, non-probabilistic sampling through CBCN's existing network of members and breast cancer support group connections;[27] and (ii) secondary selection through advertising in local newspapers.[28] Non-probabilistic sampling is best for accessing both a wide range of informants and specific key informants.[27] The limitations of this decision are discussed in the Conclusion.

Our analysis of the existing literature led us to wonder about patterns of experience clustered around having breast cancer and raising children. As a result, the current consultations were organized according to the following categories: single mothers, childfree women, mothers with children 0–8 years and mothers with children 9–16 years. Due to difficulties in recruiting single mothers in Vancouver one consultation day was held for a group of partnered and single mothers with children of all ages. Similarly, two consultations with young mothers with children of all ages were organized in Montreal (vs. children of specific age groupings) to accommodate women from Anglophone and Francophone communities (see Tables 1 and 2).

Co-author PG, from the OBC CRI, facilitated all consultations 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.

On the day of the consultation, the facilitator provided an icebreaking activity and then offered women the opportunity to recount their story related to their breast cancer diagnosis and treatment. In our research experience, we have realized that women must have the possibility to speak about their breast cancer diagnosis early in any research engagement. The participants utilized the remaining hours in the day to address the following three domains of material: (i) significant strengths and gaps in information for young women at pre-diagnosis, diagnosis, treatment, post-treatment; (ii) significant strengths and gaps in support for young women at pre-diagnosis, diagnosis, treatment, post-treatment; and (iii) suggestions about how to assist young women living with breast cancer to access the information, support and services across the cancer trajectory. We formulated

Table 2 Number of participants × category

Group type	No. of participants ($n = 65$)
Single mothers	13
Childfree women	19
Partnered mothers	33

questions pertaining to these domains and utilized supporting probes such as, 'what were the most important support needs that were or were not met?' Facilitators utilized a flip chart to categorize participants' responses over the course of the ensuing conversation. All individual preferences expressed during the consultation were documented on the flipcharts, audiotapes and in field notes recorded by the facilitator and/or CBCN staff person. 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) and an evaluation form.

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 in relationship to what they heard expressed during the consultation.

Analysis

The consultation participants provided a wealth of information concerning their breast cancer diagnosis, treatment and survivorship. Regarding the interpretation of qualitative research, the research team took the relativist stance that the participants were experts of their own experience; that is, those involved in co-constructing knowledge were considered to be competent to do so in a group.[29]

The staff at the OBC CRI analysed the data from the consultation transcripts, field notes, demographic forms and evaluation forms that were collected at each consultation day. Women's individually expressed responses were then thematically grouped using the process of content analysis. When analyzing the data, researchers attended to aspects of the text such as: frequency, specificity, extensiveness and intensity of comments.[30]

The research team conducted a content analysis by reading the transcripts, field notes and evaluation forms, and then met to formulate the coding framework.[31] Initial or *a priori* codes anticipated from existing research, such as 'Information', 'Support', and 'Programmes/services' were used to facilitate a more detailed coding of the focus group transcripts using the NVivo 2 qualitative software package (QSR International Pty Ltd, Victoria, Australia) which revealed themes such as 'Lack of information for families', 'Lack of emotional support for young women. Once the detailed coding was completed, the research team categorized and documented meaningful patterns found in the data.

During the 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.[19,32,33] As such, most of this report will focus on the unique information and support needs or gaps and recommendations for young women.

Selected demographic characteristics

All 65 consultation participants completed the demographic form (100%) (see Table 3). 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 to 45 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 (72%) identified themselves as Caucasian.

Sixty-six percentage of the young women were married or living with their partner. Most of the young women had children below the age of 16 years (71%). A substantial minority of the women was childfree (29%).

Table 3 Selected demographics

Demographic category	Percentage
Current age ($n = 65$)	
26–30 years	5
31–35 years	9
36–40 years	29
41–45 years	31
46 and up	26
Age range at diagnosis ($n = 65$)	
26–30 years	11
31–35 years	17
36–40 years	34
41–45 years	38
First language ($n = 65$)	
English	89
French	9
Other	2
Ethnocultural group ($n = 54$)	
Caucasian	72
Canadian	7
Jewish	5
First Nations	2
French Canadian	4
Other	10
Relational status ($n = 65$)	
Single	17
Married/living with intimate partner	66
Separated/divorced	16
Widowed	1
Dependents ($n = 65$)	
Children	71
No children	29
Age breakdown of dependents ($n = 46$)	
One or more children <9 years	30
One or more children 9–16 years	41
Children both < and >9 years	22
Age of children unknown	7
Selected treatments ($n = 65$)	
Reconstruction	
No	78
Yes	22
Complementary/alternative treatments	
No	80
Yes	20
Recurrence ($n = 65$)	
No	85
Yes	15
Education ($n = 65$)	
Primary School	2
Secondary School	12
Post-Secondary School	78
Graduate School	8
Main work activity ($n = 65$)	
Unemployed due to cancer	8
Unemployed for other reasons	0
Working full-time	46
Working part-time	19
Sick leave or disability	8
Retired	0
Homemaker	15
Student	4
Household income range ($n = 59$)	
Less than $20 000 CDN	12
$20 000–39 999	17
$40 000–59 999	19
$60 000–79 999	19
$80 000–99 999	10
Over$100 000	23
Health insurance beyond provincial coverage ($n = 65$)	
No	23
Yes	77
If yes ($n = 50$):	
Available through own work	56
Purchased outside of work	4
Available through partner's work	40

A minority (22%) of all the young women with whom we met had reconstructive surgery. A similar percentage (20%) of women reported using complementary/alternative medicines/treatment. Ten (15%) of the 65 women had had a recurrence at the time of the consultation. A large majority (86%) of women had post-secondary education. Many (65%) of the women reported currently working either full- or part-time. A minority of women (16%) indicated that they were unable to return to work because of their cancer or because they were 'sick or disabled'. Forty-seven percentage of the respondents who completed the question concerning income ($n = 59$) reported an annual household income of less than $60 000CDN. Most women (77%) had insurance coverage beyond provincial health insurance but almost a quarter of the women (23%) did not.

Qualitative findings

The women with whom we spoke had very similar issues when compared with other breast cancer survivors, however, they also noted the ways in which being 'young' seemed to present several barriers to effective diagnosis, treatment and aftercare. The overarching theme that captures the way that these women feel about information, support and programmes/services offered once diagnosed and treated with breast cancer is 'Nothing Fit Me'. The participants also offered recommendations to mitigate their experienced difficulties. These recommendations were grouped into three themes: 'Information', 'Support', and 'Programmes/services' and are provided at the conclusion of the findings section. Each theme is explored next.

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*. (Partnered woman with children 0–8 years, 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 aftercare in the context of jobs (paid and/or unpaid), and for many, childrearing. 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…(Childfree woman, 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 perceived that often the information about, and support for, young women did not exist and where the information and support existed it did not 'fit' their needs. Their 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.

Lack of information for young women

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

When generic information was available the women felt it was inappropriate for their age group or that health providers did not 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 and how hormone therapy might interfere with fertility.

> 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…(I) need(ed) 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… (Childfree woman, Toronto)

Many women relayed that they were not informed about the associations of adjuvant therapy or endocrine therapy and menopause.

> 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 (health professionals) just kind of throw their arms up in the air. (Partnered woman with children 9–16 years, Winnipeg)

> 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. (Childfree woman, Vancouver)

Young women, especially single mothers and childfree 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.

The issue of new relationships was especially topical for the single mothers and single, childfree women.

> …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? (Single or partnered mother, children 0–16 years, Vancouver)

Women also described the difficulties associated with relating to their bodies pre- and post-surgery and post-adjuvant treatment.

> …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. (Partnered woman with children 0–8 years, 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 about the lack of information about reconstruction and about both the benefits and costs of reconstructive surgery.

Finally, the young women also spoke about the importance of focusing on their spiritual health. The fact that only a minority of women (20%) reported using complementary/alternative medicines on the demographic form does not reflect the great degree to which women discussed using such treatments during the consultations. In all but one consultation session, 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 providing information about spirituality and treatments to complement the traditional care they were receiving.

Lack of information for families

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? (Francophone mother, children 0–16 years, Montreal)

Interestingly, mothers of children 0–8 years and mothers of children 9–16 years suggested different ways in which their children lacked information. 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 counsellor or mental health professional, manage that information.

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. (Partnered woman with children aged 0–8 years, Winnipeg)

Support

Lack of emotional support for young women

Because the young women confront cancer in the midst of tumultuous 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. (Single or partnered woman, children 0–16 years, Vancouver)

When young women did find support from breast cancer support groups, or one-to-one peer counsellors, they frequently felt that they did not 'fit in' with the other group members because of age or life stage.

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 (having or not having children; having or not having a spouse). In order to find this felt congruence, some young women started their own support groups. Others found a fit with women who had been diagnosed as young women but who were years beyond that diagnosis.

> I asked for (support from) 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. (Childfree woman, Toronto)

The participants also expected, but did not 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. 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. (Childfree woman, Vancouver)

Lack of emotional support for families

While most women with breast cancer are concerned about how their diagnosis affects other family members, 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 spouses.

The participants frequently voiced that there was little emotional support to help them help their children to '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. (Partnered mothers, children 0–8 years, Halifax)

The partnered women found that having a breast cancer diagnosis put a strain on their spousal 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.

> 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. (Partnered mother, children 0–8 years, Halifax)

Lack of instrumental support

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! (Anglophone mother, children 0–16 years, Montreal)

Many participants voiced their great concern for the lack of instrumental support around expenses related to their cancer treatment. The latitude for coping financially with a breast cancer diagnosis at an earlier age is much narrower, especially if women work part-time and do not have health benefits.* The situation is more critical if women do not have more than the basic provincial insurance coverage, as was the situation for nearly a quarter of the consultation participants.

The young women participants described having to make very difficult choices between, for example, working during their treatments vs. taking time off work; feeding themselves vs. feeding their children; and depleting life savings vs. 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. (Childfree woman, Vancouver)

> I didn't qualify for unemployment or any kind of benefits…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 savings…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? (Childfree woman, Toronto)

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

> …I had no Pharmacare, so at twenty dollars a pill I'd be sitting there looking at (the anti-nausea pill) 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. (Partnered woman with children 0–8 years, Winnipeg)

Programmes/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.

Faced with having to go for a mammogram, the women were concerned that this imaging tool lacked the precision needed to detect a tumour through dense breast tissue. The women were frustrated that a new method to detect tumours had not yet been utilized.

> …the mammograms don't work with young women. Find something that does. (Partnered woman with children 0–8 years, 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.

> …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? (Childfree woman, Toronto)

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*All Canadian citizens have universal health care although that basic coverage varies province by province.

The last issue related to the lack of fit of programmes/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.

Recommendations

At the conclusion of the consultations evaluation forms were distributed and each woman had the opportunity to recommend their top three suggestions to improve the breast cancer experience for young women. The most frequently reported recommendations are listed below under the headings: information, support, and programmes/services.

Information

The young women noted that they wanted information geared to their age group and life stage, such as information about fertility, early menopause, body image and how to talk to children about their cancer. They also want generic information, such as prevalence rates, effects of treatment, and community and hospital support services for themselves and their families.

The consultation participants suggested that information for themselves that was not pertinent at diagnosis be provided to them in a kit and in a staggered way over the course of treatment and following treatment. To impart staggered and up-to-date information the women proposed that this cache of information be offered on CD ROMs, video, the internet and specific and relevant websites.

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 relevant 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. (Previous research suggests that providing the space to host information-based meetings for a large group of men and featuring expert speakers is a more palatable way to support men.[34])

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 counselling either face-to-face or by telephone. They expressed great enthusiasm for the creation of a national telephone hotline for young women.

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.

Finally, the women also recommended that they support themselves and each other through advocacy work, specifically advocacy to generate breast cancer research focused on pre-menopausal/young women in Canada.

Programmes/services

The women proposed several ideas for the ways in which the programmes 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 programmes and services.

First and foremost the women spoke about the need for a 'navigator' to assist them through the cancer care system. Most felt the 'navigator' should be a breast cancer survivor very familiar with cancer care programmes and services both within the institution as well as in the community. The women noted that the 'navigator' would be especially helpful if the cancer system was organized as a 'one-stop-shopping' clinic wherein the diagnostic instruments and treatment facilities would be located in one setting.

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 concerning, for example, dating, sexuality, lymphedema, reconstruction, recurrence, financial help, and nutrition and 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 6 months.

Financial assistance was another much-sought-after recommendation. The women would like 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.

Finally, the women recommended that the cancer system provide instrumental and emotional support such as 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 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… (Francophone mother, children 0–16 years, Montreal)

Participants respond to findings

Once the analyses were completed the 65 participants were mailed a copy of the draft report of the findings from the young women consultations and a feedback survey. Thirty-one percentage of the participants returned the feedback forms. The young women were asked to read the draft report and then to indicate their level of agreement with 14 statements related to the findings. The 14 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'.

Over 80% of the respondents agreed with 13 of the 14 statements that summarized the findings of the draft report (see Table 4). 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 one way to reconcile the differences between what was voiced about follow-up in the consultations and the level of agreement with that statement on the feedback survey is to suggest that feedback participants 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. Regardless, this difference in content provides more insight into existing data.[35] Overall, the feedback received from the respondents supports the findings derived from the consultations held across Canada with young women.

Conclusion

The purpose of this research was to explore, from the perspective of young women with breast cancer, what they perceive to be their information and support experiences, needs, and recommendations related to their breast cancer diagnosis, treatment and survivorship.

During these consultations the young women did not talk about difficulties accessing already existing information, they stressed that information about them must be developed and that already existing generic information must be made relevant to their life situations including issues associated with early menopause, sexual-

Table 4 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 programmes 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: (i) information about the specific issues faced by young women; and (ii) 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

ity, fertility and financial stress. 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 programmes and services.

The psychosocial issues identified by the consultation participants including early menopause and fertility, financial barriers, increased emotional distress, the effect of the diagnosis on children and partners, coping with parenting and the lack of instrumental support were also identified in the existing literature reported in the Introduction.

Issues revealed here and not found in existing literature include young women's vocalizations for the development of age/life stage appropriate information for themselves, suggestions concerning how to package information differently for children vs. teenagers, the need for young women only support groups, the need for better diagnostic equipment to provide earlier diagnosis and the assistance of a cancer system navigator.

Clinical implications

We know from existing literature that this age group of women with cancer is more distressed than the older traditional cohort of women with breast cancer.[12,17,18] The sources of this distress became clear to us during the consultations. The competing demands of concern for self, partner and family, the loss of sexuality and fertility, and the added stress of financial concerns were simply too much to cope with during an already intense life stage.[3] In order to at least address young women's concerns about the lack of information concerning early menopause, sexuality and fertility, we recommend that oncologists and oncology nurses inform women that if they undergo systemic therapy and/or endocrine therapy they will also likely experience early menopause.[36] We also strongly encourage oncology staff to inform women of their options regarding fertility prior to the possibility that they will lose the ability to conceive after receiving adjuvant chemotherapy and/or endocrine therapy.[36] Additionally, cancer centre professionals could provide young women with a referral to a gynaecologist. Making small changes to cancer centre protocols could deeply improve the quality of life of individual women and might satisfy the need for a 'navigator' – a short-term solution in a resource-strapped system.

Policy applications

Community capacity-building initiatives are required to realize more substantial changes such as, perhaps, reducing the financial burden for young women with breast cancer in Canada. The demographic information collected about these participants revealed that although they were a highly educated group, a quarter of women did not have more than basic health insurance, a third of the participant group was single and nearly a fifth of the sample could not return to work. Even though the average before-tax household income of $60 000CDN indicates that many young women lived in middle- to upper-middle income circumstances, the costs of cancer can be formidable, especially if that household income cannot be guaranteed due to the illness of the income earner. Two recently disseminated studies in Ontario, Canada revealed that the mean monthly out-of-pocket expenses for individuals with cancer (including those with breast cancer) were $213CDN excluding travel and $646 including travel costs.[37,38] The authors of these studies also relayed that factors associated with increased out-of-pocket expenses include: younger age, no private insurance coverage, longer distances to the clinic and more intense treatment – factors featured in the lives of many young women participants in this study. Only community-driven policy-directed activities can hope to mitigate the financial distress faced by many young women with breast cancer.

As was mentioned earlier, the Community Capacity Building arm of the Canadian Breast Cancer Initiative of Health Canada funded this project to specifically inquire into the lived experience of young women with breast cancer. The CBCN – the organization that received this funding and then partnered with the OBC CRI to implement the research – is poised to advocate nationally on behalf of young women with breast cancer.

For CBCN, the next stage includes utilizing the results of the research to create a national strategy and action plan to fill the gaps in information and support services for young women with breast cancer. CBCN intends to involve young women living with breast cancer to create and implement activities that would address and close some of these gaps. To this end, CBCN plans to host a national meeting of young women, charge them with developing activities and encourage them to join working groups to implement those activities.

Limitations of the study

The research question

The research team was responsible for collecting the information, support and service needs experiences from young women. Because we met with young women only the research team had no way of measuring for certain which experiences relayed to us by the participants were due to age alone or were features common to most women with breast cancer. However, because all participants were 45 years of age or less at the time of diagnosis, a criterion for participation, it is more likely that these women faced issues associated with early menopause and fertility while living life on their own or in young marriages with children living at home – concerns many older women with breast cancer do not also have to address. In addition, the research team relied on the existing literature to guide us to explore issues most likely to be shared by young women with breast cancer.[8]

The sample

The sample was largely self-selected. Though this research project did not intend to recruit a random sample of participants, we recognize that because the participants knew about the consultations through non-probabilistic and secondary selection sampling methods, they were also more likely to be affiliated with breast support groups or support activities (such as breast cancer survivor dragon boat teams). Following their diagnoses, many of these women sought out support groups perhaps because they did not find the support and/or information they were seeking from the cancer system. As a result participants' responses regarding gaps in the cancer system might be more intense than might be the support and information needs expressed by women who did not seek out additional support. Conversely, these self-selected participants might be more likely to self-advocate for missing resources, speak out about experienced short-falls in the cancer system and provide recommendations for needed change.

The method

We chose the focus group method as our data gathering technique because it was the most efficient method of gathering together geographically diverse Canadian women to share information and provide mutual support; would encourage others to interact and formulate theory generating ideas;[39] would aid participants to discuss taboo topics such as cancer; and, 'ensures that priority is given to the respondents' hierarchy of importance, their language and concepts, their frameworks for understanding the world' (p. 108).[39]

We were also cognizant that utilization of this technique might detract from eliciting diverse/unique viewpoints of participants or deeply understanding an issue or event. The use of this method might have also provided the environment to fuel anger responses, such as those expressed towards the medical community.[39] Given the opportunities and caveats that we faced using the focus group method we felt, on balance, that we more clearly understood what groups of young women with breast cancer had to say about their experiences and that these results could differ from findings gathered using an in-depth interviewing method.

Kitzinger recommends that researchers 'need to acknowledge the different types of discourses that may be expressed in the private and public arena or with peers versus with an interviewer' (p. 117).[39] We acknowledge that by using this technique, participants might have felt freer to address private concerns related to their cancer experience. We also noticed that participation in the groups stimulated anger responses towards the cancer system. However, we hope that the momentum generated by anger/other intense emotions could be assuaged by offering women an avenue for advocacy/policy change vis-a-vis the work available through the CBCN.

Future research

This qualitative study was both exploratory and descriptive. The groundbreaking findings generated from focus group generated data must be supplemented by in-depth interviews with young women with breast cancer in order to address the meaning of individual experiences.

To address the concern that breast cancer lesions in younger women are less likely to be detected,[40] future research for radiation oncologists might include the development and testing of diagnostic instruments other than mammography that have the ability to image tumours through dense breast tissue.

Although a national Canadian database about the identity and characteristics of young women with breast cancer does not to our knowledge exist, researchers might consider co-ordinating data available in provincial cancer registries in order to randomly sample young women with breast cancer, distribute an information/support needs assessment and encourage their participation.

Researchers undertaking future projects with this community of women in Canada, such as the development of specific clinical guidelines to address the gaps mentioned in this study, might consider employing a consensus development method, such as the nominal group technique – a useful method for retaining individual contributions.[41]

Finally, future research projects with this stakeholder group might also track the environmental impact of these initial research findings on programmes/services and policy change – sometimes a difficult but laudable goal of understanding the knowledge translation impact of social science research.

Acknowledgements

The Community Capacity Building arm of the Canadian Breast Cancer Initiative of Health Canada funded this project to specifically inquire into the lived experience of young women with breast cancer. The Ontario Breast Cancer Community Research Initiative and the Canadian Breast Cancer Network would like to thank the participation of the many young women across Canada who gave their time and experience to the quest to more fully understanding the information and support needs of young women with breast cancer. The Ontario Breast Cancer Community Research Initiative is a partnership of the Sunnybrook & Women's College Health Sciences Centre, the University of Toronto, the Centre for Research in Women's Health and funded by the Canadian Breast Cancer Foundation, Ontario Chapter.

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