

rethink
breast cancer

BREAST CANCER

in YOUNG WOMEN IN CANADA

A NEEDS ASSESSMENT

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A NOTE FROM RETHINK ● ● ●

For over ten years, Rethink Breast Cancer has been working directly with young women with breast cancer, offering support for the issues unique to their age and stage of life. Diagnosis during pregnancy, effects of chemotherapy on fertility, risk of menopausal symptoms or osteoporosis, feelings of isolation, questions about sexuality, childcare, relationships, dating, employment and money are some of the challenges for women diagnosed in their 20s, 30s and early 40s. While Rethink has heard about these concerns first-hand from the young women we support, very little empirical research has been done to fully understand the distinct challenges young women with breast cancer face. Few studies exist to help us understand the notable gaps in the support and care of this patient population. This is why we commissioned a full-scale National Needs Assessment for Young Women with Breast Cancer, which we present to you in the following report.

Rethink Breast Cancer was founded in 2001 with the mission to help young women concerned about and affected by breast cancer. At a time when breast cancer was almost exclusively viewed and treated as an older woman's disease, we recognized that there was a significant number of women being diagnosed with breast cancer in their 20s, 30s and early 40s, and that their experience was very different from those being diagnosed later in life. We saw a major gap in breast cancer awareness and support, and we sought – as we continue to do today – to fill it with innovative programming aimed entirely at young people.

Breast cancer is the leading cause of cancer death in women aged 20-49.

In 2002, the Canadian Breast Cancer Network and the Ontario Breast Cancer Community Research Initiative released a qualitative report on young women with breast

cancer entitled, *Nothing Fits Me*. It was one of the first breast cancer reports to focus solely on young women, zeroing in on their information and support experience through consultations with 65 women in 10 focus groups. It became a tool for breast cancer organizations to help inform their education and support programming. One of the big findings from the report was that young women need information and support that match their age and life-stage. Ten years later, this need still holds true, despite the many changes in how and where this information and support are being delivered.

Over 4,400 women under the age of 50 were diagnosed with breast cancer in 2011.

Rethink's needs assessment is an extensive effort to understand the whole experience for young Canadian women with breast cancer – from diagnosis through treatment and post-treatment. We felt that a study of this kind was long overdue – that Canada's cancer-care community needs to start operating from a more fact-based understanding of the challenges and gaps in the education, support and treatment of young women with breast cancer. A large-scale quantitative study such as this one provides the breadth and scope necessary to move beyond anecdotal evidence and affect much-needed change.

To truly serve all Canadian women diagnosed with breast cancer, it is imperative that we understand the specific issues that young women face across the provinces.

The aim of our needs assessment report is to provide an essential and timely benchmark for all healthcare workers, government and community activists – a comprehensive tool to inform and measure the impact of their initiatives, as well as our own.

A NOTE FROM RETHINK

The study has found that younger women, across all the provinces, have a more difficult experience with breast cancer and are more dissatisfied with the healthcare provided to them, than their older counterparts. Many young women are unsure how to navigate the healthcare system and have a particularly difficult time transitioning from active treatment into their “post-cancer” lives. These challenges, along with the difficulty of finding age-specific information and support can lead to a resounding sense of isolation and greater compromise to their mental and physical health.

We know there are many factors that will affect a woman’s experience with breast cancer: socio-economic status, educational history, geography and cultural background to name a few. Our needs assessment set out to understand, in a broad way, what factor age plays in the breast cancer experience. To truly meet the needs of all breast cancer patients in Canada, it is imperative

that more studies are done which examine all the factors that create unmet needs.

Our needs assessment shows that age does have an impact on the breast cancer experience and creates challenges that are not being met by our current systems. More work needs to be done to meet the needs of young women with breast cancer today and our hope is that with this new and decisive evidence, advances in their support and care will be made.



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ACKNOWLEDGMENTS ● ● ●

RETHINK BREAST CANCER IS GRATEFUL TO ALL THOSE WHO TOOK THE TIME TO COMPLETE THE SURVEY AND SHARE THEIR EXPERIENCES OF BREAST CANCER. THEIR CONTRIBUTIONS WILL HELP TO ENSURE THAT THE UNIQUE NEEDS OF YOUNGER WOMEN WITH BREAST CANCER ARE BEING MET.

Thank you to everyone who helped to publicize the survey and who helped encourage people to participate.

We would also like to thank the many national and local breast cancer organizations and community workers who participated in the National Needs Assessment Meeting in June 2012 for their valuable feedback.

The report was written by Janet Dunbrack, MJ Decoteau and Alison Gordon. Thanks to Allen Braude and Samantha Yaffe for their assistance in editing the report, and Rosemary Collucci and Ashley MacIssac Butler for additional report development.

The report was designed by Paulina Perzynska.

Rethink Breast Cancer acknowledges with gratitude the generous support of the project provided by Roche Canada, Amgen Canada and the Canadian Breast Cancer Foundation - Ontario Region, and the assistance of Summit Strategy Group who conducted the research for the project.

Many thanks to the Rethink Breast Cancer staff who assisted in the development and execution of the research for this report.

EXECUTIVE SUMMARY ● ● ●

This report presents highlights of a national needs assessment survey, commissioned by Rethink Breast Cancer, on the current experience of young women with breast cancer in Canada. In its comprehensive approach, the survey analyzes the entire breast cancer experience of young women, from diagnosis, through treatment and survivorship. The learnings from the survey will serve as a tool for stakeholders to improve patient education, advocacy and support programs for young women and provide valuable insights for the many stakeholders in the breast cancer field.

Young has been defined in several ways in the breast cancer community. For our survey, we define young as those women diagnosed with breast cancer under the age of 45.

A total of 574 women who had been diagnosed with breast cancer during the previous six years responded to the bilingual online survey. 65% of survey participants were ages 20 – 45. 35% were ages 46 – 69.

All regions of Canada were represented except the northern territories. Two-thirds of women responded in English and one-third in French. The urban-rural split was 86% to 14%. Unless otherwise indicated, the information below refers to women age 45 and younger.

Our survey found that the age at which a woman is diagnosed with breast cancer impacts her experience with breast cancer; from diagnosis through treatment and survivorship. In most areas, younger women had a more difficult time with the physical and emotional challenges of a breast cancer diagnosis and treatment.

Most of the young women surveyed (64%) found their lump or other sign of breast cancer themselves. However, after they found a lump, only two-thirds sought immediate medical attention, while one-third waited to see if it went away, or they initially ignored it.

A woman's age also impacts how a doctor responds to her concern about a change in the breast. 1 in 5 young women surveyed felt her concerns were not taken seriously, and the youngest age group surveyed, ages 20-29, were the least likely to feel their doctor took them seriously.

Younger women with a breast cancer diagnosis tend

to be proactive in conducting their own research about treatments, as well as in discussing their research and treatment options with their doctors. Many women surveyed relied on web-based research and advice from other women who had undergone treatment.

Young women surveyed tended to have chemotherapy recommended more often than older women (82% vs. 65%) and this treatment course can make for greater difficulty financially, emotionally and physically.

Finances were a major concern for the younger women surveyed and many of the respondents were shocked to learn that not all costs of treatment are covered by public health services. Women ages 20-29 were least likely to have private insurance to cover additional costs, such as drugs to treat the side effects of treatment.

Young women had a hard time figuring out the health care system throughout their breast cancer experience. Almost half of the women ages 20-29 surveyed said they had difficulty navigating the health care system. During treatment, those women treated in hospitals with nurse patient navigators had an easier time dealing with the complexities of the healthcare system.

Younger women expressed a higher level of overall stress. They indicated a stronger fear of the cancer spreading or recurring, and of dying. They also had a higher level of concern about the effect of their cancer on loved ones. Women in their 20s were highly stressed about the effect of their breast cancer on their parents, while women in their 30s and early 40s were more worried about the impact on their children and spouse/partner.

Reflecting a feeling of isolation in their experience with breast cancer, almost all the young women surveyed expressed the desire to connect with a woman their own age who had been through a similar experience. Young women who were able to make that connection identified it as one of the most helpful forms of support. However, many young women were unable to find another woman their own age who had also been diagnosed with breast cancer.

Physical changes were identified as a major challenge for young women going through breast cancer. The impact of treatment on the bodies of this age group can

EXECUTIVE SUMMARY

be particularly difficult with early menopause and loss of fertility being some of the unique side effects of treatment for younger women. Over 65% of the young women surveyed also identified the loss of libido as a major side effect of treatment.

The impact of breast cancer does not end when treatment is over. Many women identified this period as extremely turbulent. Once they were no longer distracted with managing treatment, they were forced to deal with a flurry of emotions. Many women who wanted support during this transition phase found it hard to access. With the end of regular medical monitoring, many women felt abandoned by their medical care team and left to deal with their fears on their own, in particular the fear of the cancer recurring. 59% of young women identified a difficulty in transitioning from regular to occasional medical monitoring. New and continuing concerns about family members needing support coupled with many of the long-term side effects from treatment (e.g. lymphedema) were identified as ongoing challenges faced by the young breast cancer survivor.

Many of the young women looked forward to transitioning out of active treatment into work, life and everyday activities, but were surprised by how difficult they found this phase both physically and emotionally. The expectation by others that because they are young they will easily bounce back is another major source of stress. Returning to a career, especially a developing one, which is more common for younger women, can be particularly daunting. Long absences from work due to treatment means several lost career opportunities and a life-long impact on earnings. While support does exist for this stage in the breast cancer journey, many of the young women surveyed were not aware of it or could not find support geared to their age and life-stage.

Although the survey found some areas in which young women are getting the treatment and support needed, it identified many areas that call for significant improvement. To have an acceptable standard of breast cancer care for all women in Canada, the resounding needs of younger women – from diagnosis through post-treatment – must also be addressed and met.

KEY FINDINGS

- Younger women are more likely to **delay seeking medical attention** when finding a change to their breast (such as finding a lump)
- Younger women are more likely to feel their **concerns are not taken seriously by health care providers**
- Younger women are **less likely to be satisfied with the diagnostic process**
- Younger women have **more difficulty navigating the healthcare system**
- Younger women have more **difficulty finding women their own age to connect with** (this was articulated as very important to the majority of the young women surveyed)
- Younger women are **concerned about fertility but many are not getting proper attention for it** (more than 50% of the young women surveyed who were concerned about fertility were not sent to a specialist)
- Younger women **need support for their parents** and young **children**, as well as for their **spouses/partners**, which can be hard to find and adds additional stress
- Younger women (under 30) are **less likely to have private insurance**, which can offset the costs of treatments that are not publicly covered
- Younger women have **more difficulty transitioning out of active treatment** and experience increased worry around long-term treatment effects and cancer recurrence

The survey was designed to provide an overview of the experience of Canadian young women with breast cancer. Some topics, such as economic impact of breast cancer, living with metastatic breast cancer and the effect of breast cancer on relationships were not part of the scope of the survey as they have been covered in other recent Canadian studies. Rethink Breast Cancer is grateful to all the women who took part and shared their experiences in the needs assessment survey. The insights and data gathered by the survey will be used to determine how we can develop initiatives and work with partners to improve the cancer journey for young women across Canada.

METHODOLOGY AND PROFILE OF SURVEY RESPONDENTS ● ● ●

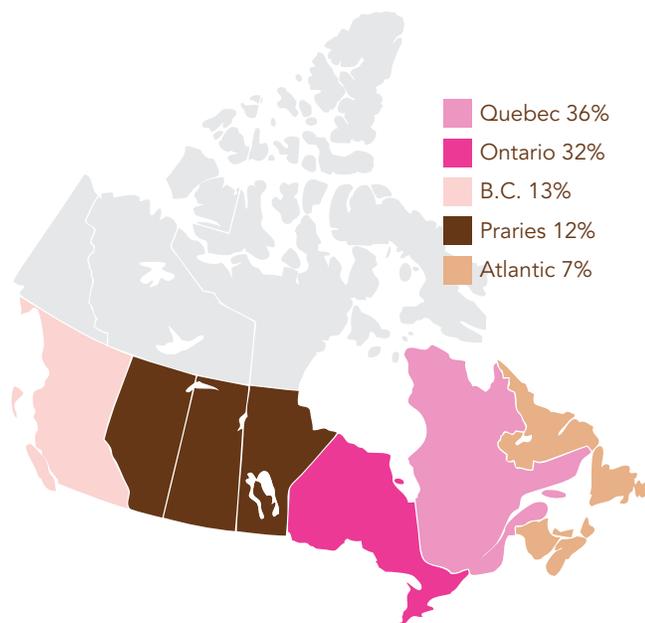


Fig. 1. Survey respondents by region

IN HONOUR OF its 10th anniversary, Rethink Breast Cancer commissioned a National Needs Assessment for Young Women with Breast Cancer. The bilingual online survey was open to women in Canada who had a diagnosis or recurrence of breast cancer during the previous six years. The goal of the survey was to identify the needs of women age 45 and under, by learning more about their breast cancer journey, including how their experiences compare and contrast to those of older women.

The online survey was conducted from June 2011 through October 2011 by Summit Strategy Group. The survey consisted of multiple choice questions and sections where women could add their own comments.

Of the 574 women who responded to the survey, 372 (65%) were ages 20 – 45, the rest were ages 46-69 (Fig. 2). Women responded from all regions of Canada except the three northern territories. The percentage of respondents from each region was: Quebec (36% of respondents), Ontario (32%), the Prairies (12%), British Columbia (13%) and the Atlantic Provinces (7%) (Fig. 1). Two-thirds of women responded to the survey in English and one-third in French. The urban to rural distribution was 86% to 14% (Fig. 3).

Women involved with Rethink Breast Cancer programs constituted 20% of the respondents (28% of women age 45 and under).

This report presents highlights of this Needs Assessment, focusing on all phases of the breast cancer journey of young women – from diagnosis, through treatment and return to life after treatment. Quotations throughout the report are from the comments made by survey respondents 20 - 45 years old.

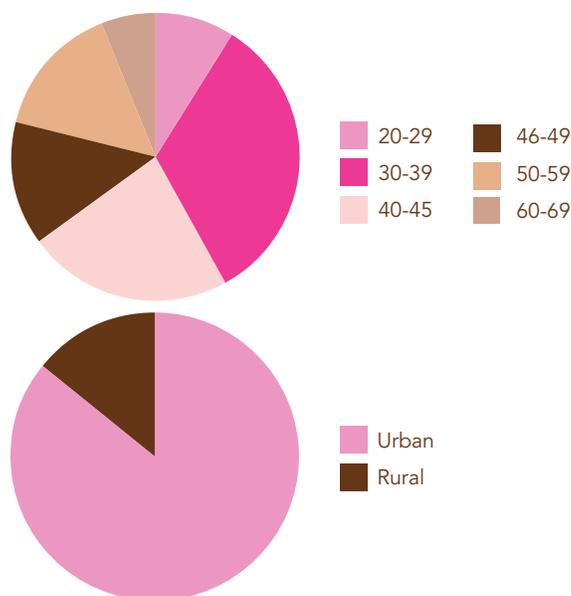


Fig. 2 & 3 Survey respondents by age & Urban or Rural

I get a little frustrated with the mainstream image of a breast cancer patient as an elderly woman. I feel that young women have **DRASTICALLY** different issues to deal with – from fertility to their own mortality. While I don't mean to minimize what a 65 year old, retired grandmother with a Stage 1 cancer goes through, I do believe that a 35 year old, single woman with a Stage 3 diagnosis faces a very different set of circumstances.

30-39, BC, Urban

**BREAST CANCER
IN YOUNG WOMEN
IN CANADA**



BREAST CANCER IN YOUNG WOMEN IN CANADA

A WOMAN DIAGNOSED with breast cancer in her 20s, 30s and early 40s faces physical, emotional and circumstantial challenges unique to her age and stage in life. These challenges – and the stresses they breed – are compounded by the medical community’s understanding and response to the particular needs and concerns of young women, which are often vastly different from those of older women.

When young women get breast cancer, it often spreads more aggressively, leading to tougher treatments and lower survival rates¹. Age-specific issues young women face around sexuality, fertility, diagnosis during pregnancy, childcare and financial security pose distinct healthcare and support challenges.

In a world where breast cancer is still predominantly understood, communicated and treated as an older women’s disease, the needs of young women with breast cancer are too often missed and unmet, leading to undue suffering throughout an already extremely difficult journey.

DIAGNOSIS

A BREAST CANCER diagnosis for a young woman usually begins with her reporting a change in one of her breasts to her doctor. Of the young women surveyed, 64% found their own lump, 13% of young women reported that their doctor found a lump and 8% said it was detected through a screening (e.g. a mammogram). In addition to finding a lump, the next most common symptom reported was pain or discomfort in one or both breasts, which helped lead women to seek medical attention.

Although most young women found a lump themselves, 42% reported that they rarely or never checked their breasts. Relationship status impacted how frequently women checked their breasts. Women who were single, separated or divorced were less likely to check their breasts regularly than women who were partnered or married.

Once they had found a lump, one-third of the young women surveyed either waited to see if it went away or worsened, or ignored it. The main reasons for not seeking immediate medical attention were: waiting to see if it would go away (46%); not being concerned about it (23%); and fear (15%). The youngest women surveyed, ages 20-29, were most likely to wait, search for information on the internet or ignore the lump.

When a woman seeks medical attention for a problem with her breasts, age should not be a factor in the diagnosis of breast cancer. However, the younger a woman was, the less seriously she felt her concerns were taken by her doctor.

“You are only 31 years old. It’s probably not cancer” and dismissed me. I wrote him a letter telling him not to be so dismissive of young women when they present themselves with similar abnormalities in the future. 30-39, British Columbia, Urban

I wish my doctor actually took me seriously during the first visit, not months later. 20-29, Prairies, Urban

17% of young women felt that their concerns about changes to their breasts were not taken seriously by their doctor. Of those who found a lump or other symptoms themselves, 18% felt they were not taken seriously by their doctor. In contrast, only 5% of those whose symptom was detected by a doctor or through screening felt their doctor did not take them seriously.

My GP thought it was nothing to worry about, my radiologist said she was 99% sure it was

¹ Partridge, A.H. et al., “Breast Cancer in Younger Women”, in J. Harris (Ed.), Diseases of the Breast, Philadelphia, PA: Lippincott Williams & Wilkins, 2009, pp. 1073-1083 and Susman, Ed Breast Cancer ‘Different’ in Younger Women <http://www.medpagetoday.com/MeetingCoverage/SABCS/36324>

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nothing and my surgeon said, “Don’t worry, you don’t have cancer” prior to my diagnosis. The medical profession needs to be aware that breast cancer can happen in your 20s. 20-29, Ontario, Urban

After a breast exam, the next steps in the diagnostic process can include a diagnostic mammography, ultrasound, MRI and biopsy. Because younger women have denser breast tissue, mammography is not as effective as ultrasound in detecting breast cancer². Women under 40 were the most likely to receive an ultrasound instead of, or in addition to, a mammogram. Women 20-29 were the most likely to also receive an MRI and least likely to receive a mammogram. 71% of the young women were satisfied with the diagnostic process, with close to 60% receiving a diagnosis within one month.

I think my doctor and I worked well together to get a proper diagnosis. She knew I was a very healthy woman, and I knew my body well - well enough to know that something was not right. My doctor promised not to stop with tests until we found out what was happening. 30-39, Prairies, Rural

Unfortunately, 1 in 5 young women indicated that they were somewhat or very dissatisfied with the diagnostic process, a gap that needs to be closed.

They kept telling me it was an infection. Several ultrasounds and a biopsy later the cancer had doubled in size. I’m angry they

didn’t order a biopsy right away when the tumour was only 3cm. Instead it was 6cm by the time they realized I had cancer. 20-29, Prairies, Urban

I was told multiple times by multiple health professionals that I was “too young”. I started to believe it even though I knew something was wrong. The radiologist who did the ultrasounds did not specialize in breast ultrasound and was quite dismissive that I was even going for these appointments. She missed the changes and increase in size because of her attitudes and beliefs. 20-29, Prairies, Urban

TREATMENT

Treatment for breast cancer can involve surgery, radiation and/or chemotherapy. The treatment phase can be brief, if only surgery is required, or can last for several months. During this time, young women are confronted with the need to choose among treatment options, deal with treatment side effects, navigate the healthcare system and find support. At the same time, they experience heavy emotional stress, health and body issues, as well as the impact of their breast cancer on family and friends.

NAVIGATING TREATMENT

RESEARCH³ HAS SHOWN the importance of being a self-advocate in your healthcare and 79% of young women reported that they were proactive in their own research about treatments and discussed this research with their doctors. 72% of young women sought advice from other

² Yankaskas BC; Haneuse S, Kapp J, Kerlikowske K, Geller B, Buist DSM; for the Breast Cancer Surveillance Consortium. Performance of first mammography examination in women younger than 40 years. J Natl Cancer Inst 2010;102:1-10.

³ Barbara Hoffman and Ellen Stovall, Survivorship Perspectives and Advocacy, Journal of Clinical Oncology November 10, 2006 vol. 24 no. 32 5154-5159

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women who had received treatment for breast cancer. Overall, most young women felt that they were active partners in decision making about their treatment.

I feel that doing a lot of research and picking my own medical team based on my research really helped me through this journey. I am proud of myself for voicing my needs and concerns and making my own decisions. 30-39, Ontario, Urban

Most women chose the therapies that were recommended by their healthcare providers. And for most of them, some type of surgery was recommended (e.g. mastectomy, node dissection, breast reconstruction, bilateral mastectomy and oophorectomy⁴). Younger women were more likely than older women to have chemotherapy recommended with 82% receiving this recommendation (vs 65% of older women). They were twice as likely to be recommended targeted therapy such as Herceptin, Tykerb, or Avastin. This difference may be due to the tendency of breast cancer to be more aggressive in younger women.

Managing the side effects of treatment (e.g. nausea, loss of hair, fatigue) and accessing medication and treatments to deal with side effects were identified as an important concern for young women during treatment. Another concern was the long-term effects of treatments; loss of a breast, lymphedema⁵ and the long-term effects of chemotherapy that can persist for several years in some cases.

I think much more research needs to be done concerning YOUNG women (under 30) and

breast cancer. I don't believe we should be treated the same as women in their 50s. I think treatments should be more tailored to the individual as well, not just following the general protocol. I feel very strongly that we are over-medicated and I fear there will be grave consequences later. 20-29, Ontario, Urban

Many young women, especially those living in provinces without cancer-patient navigators⁶, had difficulty finding their way through the healthcare system. 36% of young women found it difficult to navigate the healthcare system, with women living in Ontario and Quebec the most likely to find it difficult. The problem was more acute for women ages 20-29, of whom 42% had difficulty.

While I was capable of managing my treatments, I certainly had to be on the ball. Had I not been proactive on several occasions, I would have been "forgotten" - for example, getting set up for radiation was almost forgotten, until I asked about it. I fear many people fall through the cracks if they are not informed and don't take the lead in their healthcare. 40-45, Ontario, Urban

You have to be your own advocate or have someone advocating for you in the system. 30-39, Prairies, Rural

Others, especially those from Quebec and the Atlantic region, had better experiences. CancerCare Nova Scotia, for example, provides a nurse-patient navigator program.

⁴ Oophorectomy is surgical removal of the ovaries as a cancer prevention measure for women at high risk of breast and ovarian cancer. Removal of the ovaries reduces the amount of estrogen and progesterone in the body, which can halt or slow cancers that need these hormones to grow.

⁵ Lymphedema is swelling in the affected arm, hand or chest wall caused by a buildup of lymph fluid due to the removal of lymph nodes by surgery, or damage to lymph nodes by radiation therapy or the cancer itself. Lymphedema can happen soon after treatment, months or even years later. It can be a temporary or a long-term condition. It's easier to manage if cared for early

⁶ Newfoundland & Labrador, Nova Scotia and Quebec have province-wide nurse patient navigation. In our survey, women from Quebec and the Atlantic region were most likely to respond that it was somewhat or very easy to navigate the healthcare system

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We have an excellent Breast Health Program that takes you from diagnosis, treatment, surgery - you just need to show up! 30-39, Atlantic, Urban

EMOTIONAL IMPACT

YOUNG WOMEN MAY be especially vulnerable to the negative effects of a breast cancer diagnosis as the young women in the survey gave higher ratings to emotional stress than the older women. The emotional challenges that ranked highest for young women during their treatment were: stress related to the fear that the cancer might spread or recur; the fear of dying; and, the concern about the effect of their cancer on loved ones.

My baby was only 9 months old when I was diagnosed. From one day to the next I became a young mother who might die.... 30-39, Quebec, Rural

In order to deal with emotional stress, many young women turned to others for support, including friends, family and their spouse/partner. Additionally, women sought peer support from other women with breast cancer, as well as from professionals and/or support groups.

90% of young women preferred face-to-face conversations with another person. 72% wanted resource materials such as brochures, DVDs and guides. 66% wanted online support and half preferred phone support. Some found it hard to track down relevant sources of support and were not given information by their cancer care team.

I had to be proactive and FIND [support], especially from women my age/stage of life. Online was best for that. 30-39, Prairies, Rural

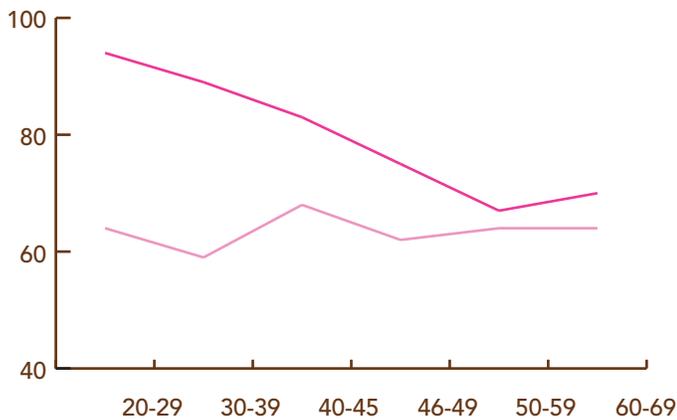
At diagnosis and during treatment, younger women were more likely than older women to utilize one-on-one professional support, one-on-one peer support from women who had breast cancer, online support and face-to-face group support. The type of support used varied across Canada. Women in Quebec were more likely to receive individual professional support than women in the rest of Canada, at diagnosis (47% vs. 28%) and during treatment (52% vs. 42%). During treatment, women in Ontario and the Prairie provinces were most likely to receive face-to-face group support (40% vs. 26% in the rest of Canada) and women in Ontario were most likely to access online support both at diagnosis (25% vs. 19% in the rest of Canada) and during treatment (31% vs. 24%). 88% of young women wanted to connect with women their own age, and 64% of this group were able to do so, usually through a support organization or an online resource. Over one-third of the young women who wanted to connect with another young woman were unable to do so (Fig. 4). Among young women who were unable to access support from a woman their age during diagnosis and treatment, the youngest women (age 20-29) were most likely to wish it had been available. Other than support from a spouse, family or friends, women 20-45 rated support from a woman their age who had breast cancer as the most useful support received, whereas women over 45 rated one-on-one professional support most useful.

Support from someone your age who has been through breast cancer is huge and it's great to be a part of that. 30-39, Prairies, Urban

I asked an organization to put me in touch with another young mother going through the same thing and this did me a lot of good to talk with her, and for her, too. 30-39, Quebec, Rural

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The groups in my area are mostly made up of older women. I'm on a Dragon Boat team and I am the youngest on the team. The ladies are wonderful but most are retired or nearing retiring and I'm dealing with a kindergartener. I feel as though I can't relate or truly express how I feel because I need to be respectful of their age. 30-39, Ontario, Urban



- Percentage of participants who thought that connecting with another woman their age was important
- Percentage of participants who actually connected with another woman their age

Fig. 4 Younger women who wanted to connect with another woman their own age with breast cancer had more difficulty finding this connection than older women.

FERTILITY

A BIG CONCERN of young women with breast cancer is the impact of treatments on fertility. With many treatments leading to suppression of ovarian function and/or early menopause, many young women worried

about how treatment might impact their future ability to become pregnant. While 84% of women ages 20-29 were concerned about fertility issues only 54% were referred to a fertility specialist. 47% of women ages 30-39 said they were concerned about fertility and only 20% of them were referred to a specialist (**Fig. 5**)

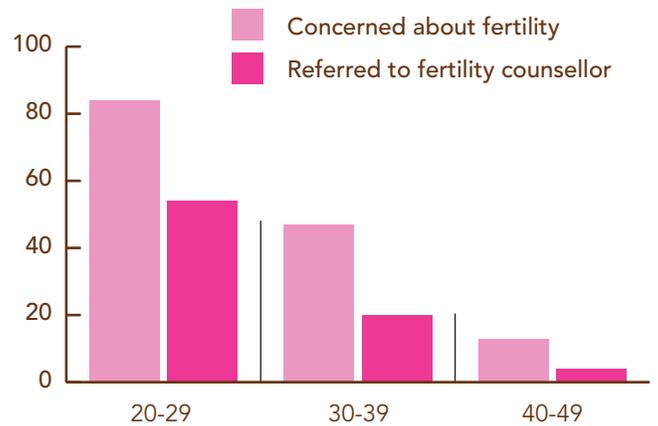


Fig. 5 While younger women were concerned about the impact of treatment on their fertility, many were never referred to a fertility counsellor.

I had to fight for a referral to preserve my fertility prior to treatment. 30-39, Ontario, Urban

The oncologist should have referred me the same day as my diagnosis to fertility counselling. It was actually done just two weeks before radiation and this limited my options in terms of fertility preservation. I'm very disappointed that options were taken away from me. 30-39, Quebec, Urban

Some women who were pregnant at diagnosis had devastating experiences.

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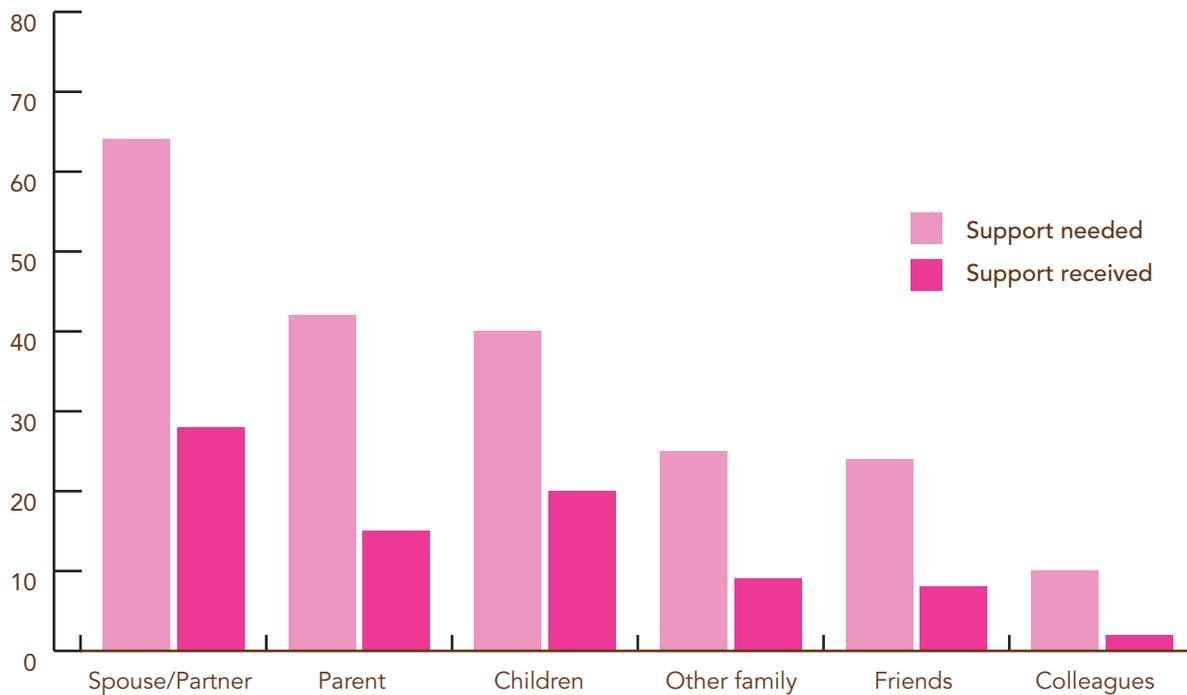


Fig. 6 While they were being treated for breast cancer, younger women felt their family members needed support but few family members received the support they needed.

I saw a specialist at the breast health centre who minimized the problem. He reassured me I could get pregnant with no worries – that the lump was benign – but he didn't order a biopsy. I got pregnant. I got my diagnosis when I was 13 weeks pregnant and the cancer was hormone-dependent...I had to get an abortion in order to undergo chemotherapy. 30-39, Quebec, Urban

PERSONAL & FAMILY ISSUES

THE PHYSICAL AND emotional challenges of breast cancer treatments can make coping with day-to-day life very difficult.

...Lack of energy. It's harder to get through

the day without feeling tired. It's hard to find clothes that fit and look good – not easy to be fashionable when you're 29 and missing a breast...It's hard to feel feminine with one less breast and no hair. I'm more emotionally fragile. 20-29, Quebec, Urban

I felt like I had to constantly put on a brave, positive and humorous approach to constantly reassure everyone around me that "I was fine" even when I wasn't. 30-39, Ontario, Urban

Additionally, concerns about personal relationships were top of mind for young women during their treatment, especially about how children, partners/spouses and parents were feeling and coping. Many young women felt their partners, children and parents could have benefitted

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from support. Among those who needed support, less than half of spouses and children and just over one-third of parents received support (Fig. 6). Reflecting their life stage, the youngest women, ages 20-29, tended to need support for their parents, whereas women ages 30-45 were more likely to need support for their partner/spouse and children. They also felt support was needed for other family members, friends and colleagues.

My mother needed support because she took it really hard. It took a long time for her to realize that things were going well and that I was at peace with what was happening. I tried to reassure her and succeeded a bit, but not enough. It's only now that she's starting to feel calmer. 30-39, Quebec, Urban

Many felt anxiety about the lack of support for their loved ones and about whether another family member might be diagnosed with cancer.

There was nothing out there to help my 5-year-old deal with her fear about my cancer. 30-39, British Columbia, Urban

There was no support for my spouse. He didn't know what to do when I wasn't coping very well. 40-45, Ontario, Urban

There isn't really a group for young husbands of women with cancer. 20-29, Prairies, Urban

My sister and I both had breast cancer at the same time. She has since passed away with

this terrible disease. I think education is the key to early detection. 30-39, Atlantic, Urban

Some young women received strong support from their spouse/partner.

My husband deserves a gold medal. He provided constant support and even thought I was beautiful during treatments, and just as beautiful with one less breast. Without him, I don't know how I could have gone through this difficult period as well as I did. 30-39, Quebec, Urban

Half of the young women surveyed had one or more children under the age of 12. Those mothers who were able to find parenting support articulated how important this resource was for their family.

My husband and daughter attended a support group in our area for families of loved ones who have cancer. They are still in touch with them today. It helped ease their fears and let them know what to expect. 20-29, Ontario, Urban

I went to see a counsellor and we talked about how to parent through the treatment, coping strategies, how to talk to the kids and that sort of thing. This really helped me, and my kids have been doing great. 40-45, British Columbia, Urban

There was a teacher at school who implemented a support system for our children

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should they need to talk to anyone. There should be more teachers like her. 40-45, Ontario, Urban

In addition to emotional support for their families, young women with children under 12 must also deal with the practical challenges of childcare during treatment.

I am very fatigued and must nap once a day. I am caring from my children at home, and have not found the energy to return to work. 30-39, British Columbia, Urban

It really isn't easy being young and the parent of young children and having to continue working full time 30-39, Quebec, Urban

I have tried to remain as positive as possible in my life – even before all this...right now it is the day to day recovery and taking care of my two minor children. 30-39 Prairies, Urban

For the young women surveyed, childcare was mostly provided by family members, a spouse/partner or a friend/neighbour. 21% relied on childcare outside the home, with women in British Columbia most likely to do so (39%) and those in the Prairies and Atlantic region least likely (13%).

FINANCIAL STRESS

THE FINANCIAL IMPACT of breast cancer can be enormous for women and their families. Costs that must be covered out of pocket during treatment add

up, especially for those without private insurance. Personal and family income may decline when time is needed to be taken off work. Return to work after treatment at the same earning level may also be a challenge. The impact is largest for women who undergo chemotherapy. With 82% of young women with breast cancer receiving chemotherapy – 17% more than older women – breast cancer has an especially strong financial impact for younger women. For a comprehensive overview of the economic impact of breast cancer and the challenges of labour force re-entry, we recommend reading a report published by the Canadian Breast Cancer Network⁷.

It comes as a surprise to many patients that public health coverage does not include all costs of treatment. Treatments offered outside the hospital, prescription medications and medical supplies, for example, may not be covered. Many women who participated in our survey experienced financial stress that influenced the treatments chosen and their effectiveness. Women without private insurance were less likely to be informed by their oncologist about preventative treatment options for infections or other complications, and were also less likely to participate in clinical trials.

When I developed more serious side effects from chemo (severe stomach pains) the “good” drugs (i.e. the ones that would work right away) were not covered by Fair PharmaCare⁸ unless prescribed AFTER I had tried two other prescriptions first. However, my medical oncologist knew from experience that the first two drugs would not address my symptoms and would allow the condition to worsen. He suggested I skip ahead to the more effective drug immediately, if I could afford to pay for it

⁷ Canadian Breast Cancer Network. Breast Cancer: Economic Impact and Labour Force Re-Entry. 2010. Available at www.cbcn.ca/index.php?pageaction=content.page&id=2912&lang=en

⁸ Fair PharmaCare is a program of BC PharmaCare which helps British Columbians with the cost of eligible prescription drugs and designated medical supplies. Fair PharmaCare coverage is income-based. Families with lower incomes receive more assistance than families with higher incomes.

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myself. I thought this was APPALLING. It means people without the funds to pay cash for this drug must suffer these unbearable symptoms. I didn't think that's how our medical system worked. 30-39, British Columbia, Urban

I do not have insurance and I needed medication to increase my blood counts to get chemotherapy but the government would not cover it. Currently I have to find some way to pay for the drugs I need. 20-29, Ontario, Urban

During the first breast cancer treatments I did not have extended health as I had recently lost my job, so none of the support drugs (antibiotics, anti-nausea, etc.) were covered by PharmaCare. As a result, I had to use up all my savings and also had to cash in my RRSPs (because I had RRSPs I also did not qualify for government assistance). 40-45, British Columbia, Urban

Young women in their 20s were less likely to have private insurance than women in their 30s and 40s, who may be more established in their careers and insured through benefit plans at work. Lack of private insurance can influence how quickly diagnosis is sought and the type of treatment chosen. The survey showed that those without private insurance were more likely to wait to seek diagnosis following the discovery of a lump, compared to those with private insurance (64% vs. 36%). Those with private insurance were more likely to be on long-term treatment than those without insurance (39% vs. 26%). The survey also showed that even those with private insurance were not always automatically covered.

First, the insurance company agreed to pay the cost, then they refused. They finally agreed to

pay after a lot of hassle. 40-45, Quebec, Urban

POST-TREATMENT

THE CHALLENGES A breast cancer patient faces does not end with the conclusion of treatment. In addition to dealing with emotional stress, young women continue to have concerns about family members and persisting health issues once active treatment is complete. Reintegrating and moving on with less access to your cancer team and little support is no easy feat. Resuming a career and jumping back into everyday life is a critical stage of the breast cancer journey that requires a lot more wherewithal and support than is often available or had been expected.

EMOTIONAL STRESS

After active breast cancer treatment, women may still experience physical pain, isolation, depression and anxiety. The predominant fear of young women after treatment was that the cancer may recur or spread. Fear of dying was still present, but was less predominant than during the treatment phase. Concerns about how partners/spouses and children are feeling and coping were still present, but rated as less stressful than during treatment. The concern with other family members being diagnosed persisted.

My husband is stressed out from the long round of diagnosis, tests and treatments. He didn't stop working, so I know he's exhausted. He doesn't exercise anymore and he's gained weight. ...I still can't take care of my 15 month old son for a full day yet, which I really miss. 20-29, Quebec, Urban

Part of the transition to normal life activities is sexual intimacy, the potential for which may have been affected by treatment. 67% of young women reported a reduced interest in sexual activity post-treatment, which caused emotional stress and strain on relationships

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I hate having a low sex drive. 30-39 British Columbia, Rural

My sex drive has completely diminished. It is not because of the physical look of my body; that does not bother me. My libido is extremely low which can be very, very difficult for my husband. 30-39, Prairies, Urban

Another cause of emotional stress for young women is the adjustment to not seeing their care team as regularly. 59% of young women (compared to 42% of older women) had a difficult time transitioning from regular medical monitoring to occasional medical monitoring, leading some women to feel abandoned by the healthcare system once they completed treatment. Among women 20-29, 71% had a hard time with the transition.

Once your treatment is over, the doctors seem to lose interest and are not as supportive of your needs. 30-39, Ontario, Urban

Support from my medical team has been wonderful; however, after all active treatment is completed, it does leave you with the sense of being very much on your own after such intense medical monitoring. 30-39, Ontario, Urban

Once radiation was finished the cancer centre “set me free” and only wants follow-ups with my family doctor. This was an enormously difficult transition because the fear takes over and as a patient I felt somewhat abandoned. My fears and questions about recurrence were dismissed without much sensitivity. 30-39, Ontario, Urban

Furthermore, the survey found there were fewer sources of emotional support and understanding for young women after treatment than during treatment. Several young women reported that the emotional impact of going through treatment caught up with them only after the treatment was finished. This made the scarcity of post-treatment support even more difficult.

It's just hard to go from so many people being with you, working with you, supporting you, to nothing - fast. Once it's over, it's over. You feel lonely after. I had soooo much love and attention while I went through it. It was hard to handle the change after. 40-45, Quebec, Urban

I feel that some people think that once treatment is over you should be better and just move on with your life. They don't understand the long-term effects, the effect on your body image, the fear you live with wondering if/when the cancer will return. 30-39, Atlantic, Urban

During and just after treatment, I was appreciative of the support I asked for and received. It helped me to get through it. But now I feel I need emotional support more than ever, and am ashamed and embarrassed to ask for it. I find it strange that I am experiencing strong emotions about the cancer now. 30-39, British Columbia, Urban

People need to realize that just because you are finished treatment doesn't mean that you are better and that you should just move on. It takes a while to mentally process everything you went through. Sometimes during treatment you have

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your head down and are just trying to get through it all. When you start feeling better physically, it is then you are worse mentally because you finally get a chance to process it and deal with the body image and relationship issues that you put aside when you were sick. Breast cancer is such a complex disease that affects you both mentally and physically. 30-39, Atlantic, Urban

EMOTIONAL STRESS

CONCERNS ABOUT CHANGES in physical appearance due to treatment, long-term effects of treatment and maintaining a healthy body weight were among the chief health and body challenges young women faced after treatment. The effect of treatment on fertility, especially for the women 20-29, remained an ongoing issue.

Breast reconstruction can take place during treatment (at the same time as a mastectomy) or months, or even years later. A little less than one-third of young women chose breast reconstruction and most were somewhat or very satisfied with the results. However, only the younger women surveyed expressed dissatisfaction, with 19% indicating that they were somewhat or very unhappy with the results.

Dealing with the long-term effects of treatment was an unexpected issue for many young women.

I don't feel healthcare practitioners explain the short-term and especially long-term side effects of treatment. After treatment was complete I wasn't sure who to talk to for this information. 20-29, Ontario, Urban

The long-term side effects from chemo and radiation are not shared with the patient as much as the immediate side effects. I'm now

suffering from long-term side effects. 40-45, Prairies, Urban

One of the long term side effects of lymph node removal is lymphedema, which can cause painful and debilitating swelling of the arm. It can be hard to find resources to deal with this long-term side effect.

There is not a lot of information readily available about lymphedema. Oncologist, nurses, radiologists and family physicians are not well informed. It is hard to access appropriate resources and treatments when you have lymphedema. 30-39, Quebec, Urban

RE-ENTRY TO CAREER AND EVERYDAY LIFE

ONCE TREATMENT IS completed, most young women want to resume their career and other activities. A strong concern at this stage was coping with changes in their lives due to having had breast cancer. A changed body image, fatigue and the pressure to make up for lost time in one's career, can take its toll on a young woman's self-confidence. An important concern, particularly among women ages 40-45, was a diminished ability to concentrate and remember. This can have an impact on the return to everyday life, especially at work.

Fighting fatigue every day is hard. I realize that my ability to concentrate is limited, but I can't talk about this openly, which adds a lot of anxiety to my workday. I don't want to do this work – I'd rather do something else, but I don't have the strength. 40-45, Quebec, Urban

In addition to feeling abandoned by the medical system, many women felt the loss of psycho-social supports that

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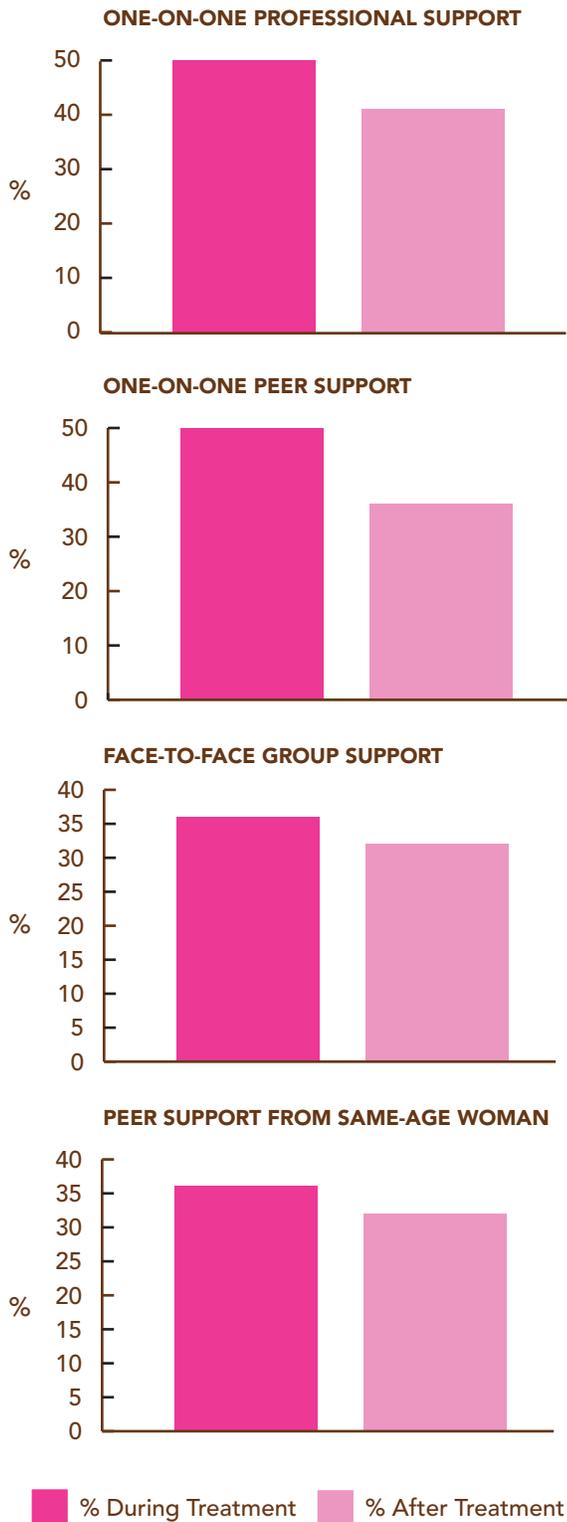


Fig. 7 Younger women are less likely to access support after treatment compared to the support they received during treatment.

were available to them in the treatment phase. Young women were less likely to find peer support, group support and professional support following treatment than during treatment (Fig. 7). Some of the women were not aware that support existed. Others doubted that it would help or wanted support geared to their age and life-stage, but could not find it. The post-treatment support young women were least likely to find and which they most wished were available are face-to-face group support and one-on-one peer support with a woman their age.

Women who returned to work often experienced fatigue and other difficulties. Some expressed the wish for part-time work or the opportunity to gradually return.

I had a mastectomy but prostheses don't replace a breast. My body is learning to function again after all the treatments. Three months after I finished treatment, I went back to work and I was very tired. I'm slowly getting back to normal, but that doesn't happen overnight. 30-39, Quebec, Urban

I am now a single mother; my little boy will soon be 5 and lives with me six days a week. I have to work full-time to pay the bills and I'm exhausted. The fear of cancer recurring is always there but it also makes me live and appreciate each day to the fullest. I've worked hard to rebuild my life post-cancer. It's hard to find a man to share my life with. But cancer has not been totally negative because I try now to be calmer and enjoy every moment with the people I love. In spite of everything, I feel I've been given a "suspended sentence", but isn't that true for everyone? 30-39, Quebec, Rural

DISCUSSION ● ● ●

ALTHOUGH BREAST CANCER is relatively rare in young women, it is the most common form of cancer in women 45 years and younger and the leading cause of cancer-related deaths for this age group⁹⁻¹⁰. Despite receiving generally more aggressive therapy than their older counterparts, survival rates for younger women are lower than for older women. Moreover, research from the past decade has revealed that the specific practical and psychosocial needs of young women with breast cancer that differentiate them within the broader breast cancer population are often unmet. While the impact of breast cancer is stressful for women of all ages, our survey respondents reinforce that younger women may be particularly vulnerable to the negative effects of the disease. In addition, our survey shows that, unfortunately, despite a growing array of peer-based support interventions and community resources available to young women, many of the concerns of younger breast cancer patients are still not being met by our current healthcare system. Young women continue to have a more difficult experience.

We attribute two key factors to younger women having a more difficult breast cancer experience than older women: aggressiveness of cancer treatment and life-stage. In general, young women have more aggressive forms and stages of breast cancer and are therefore given more aggressive treatments for a longer period of time. In our survey findings, younger women overall were more likely to have been recommended chemotherapy (82% vs 65%), and targeted therapy such as Herceptin, Tykerb and Avastin. In terms of surgical treatments, younger women overall and in particular women aged 20-39 were more likely to be recommended mastectomy, node dissection, breast reconstruction, bilateral mastectomies and oophorectomies versus older women. More aggressive treatment means increased side-effects

and greater chemotherapy toxicity, more difficulty managing daily routines and a longer recovery time for younger women.¹¹

The intense cancer treatment that young women generally receive is compounded by their life-stage. Treatments for breast cancer in younger women may cause premature menopause and enhanced aging, forcing young women to deal with infertility, hot flashes, vaginal dryness and dramatic reductions in their sex drive, osteoporosis, weight gain and inactivity.¹² The harsh treatments and subsequent side-effects are coming at a time in life when young women are adjusting to serving numerous new roles such as starting a family, parenting young children, finishing education and entering the workforce. School, career, wedding and pregnancy plans may be suddenly put on hold for a newly diagnosed young woman—life disruptions which are magnified by the uncertainty of survival. Many young women struggle with bodily disfigurement and consequent challenges to body image and their sense of womanhood.¹³ For example, young women may have difficulty in discussing issues like mastectomy with their boyfriends, some of whom they had only been dating for a short time. These challenges can be particularly difficult for the youngest age group surveyed (ages 20-29) as they worry about how their illness will influence budding or future intimate relationships.

Another challenge for breast cancer patients at this life-stage is juggling treatment with caring for young children. Young mothers in treatment may feel guilty because they do not have the same physical and emotional energy for their kids that they had prior to their diagnosis. They may also have deep fears about death and what will happen to their children if they do not recover. Unfortunately, the practical challenges of having a baby or small children can make it difficult for

⁹ Jamal A, Siegel R, Ward E. et al. (2010) Cancer statistics 2010 CA Cancer J Clin 60 (5)

¹⁰ Canadian Cancer Society (2012) Canadian Cancer Statistics 2012. Breast Cancer is the leading cause of cancer-related deaths of Canadian women 20 to 49.

¹¹ Howard-Anderson J, Ganz PA, Bower JE, Satanton AL. (2012) Quality of Life, Fertility Concerns, and Behavioral Outcomes in Younger Breast Cancer Survivors: A Systematic Review. JNCI J Natl Cancer Inst (2012) 104 (5)

¹² Same as 3

¹³ Avis NE, Crawford S. Manual J (2005) Quality of Life Among Younger Women with Breast Cancer. J Clin Oncol 23

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young mothers to get the emotional and psychosocial support they need. When young mothers are in hospital or recovering from treatment, they may have challenges organizing childcare, adding further stress and worry to an already taxing time. A long wait at a hospital appointment may mean she is running late to pick up her child. Childcare can also pose an additional financial burden to young families struggling with breast cancer.

The combination of having aggressive treatment, increased side-effects and greater chemotherapy toxicity during a hectic and demanding life-stage makes a breast cancer diagnosis traumatically disruptive for a young patient. Instead of our healthcare system providing additional support for this high-needs population, our survey found that younger women overall felt less informed, especially about long-term side-effects and how to manage, and they were more likely to feel that it is difficult to navigate the healthcare system than their older counterparts. Their lack of life-experience and inexperience with the health care system in particular, can make navigating treatment more challenging for younger women than for older women. The younger the woman was at diagnosis, the more difficulty she had navigating treatment and getting information, support and care for her age-specific concerns, with the youngest survey respondents age 20-29 reporting the most difficulty.

While active treatment causes obvious hardships, transitioning out of treatment presents numerous emotional and physical challenges too. In addition to having more difficulty navigating the healthcare system during treatment, younger women also have a harder time with recovery and transitioning out of active treatment. This may be due to having more aggressive treatment but also could result from feeling unprepared for long-term side-effects, fears of a recurrence and having experienced such a traumatic life disruption at a young age. In addition, since many young women serve

multiple roles not easily filled by others—for example, parenting young children—they may feel pressure from themselves and their loved-ones to return to the level of responsibility and volume of tasks they had before diagnosis. Young women are eager to get back to “normal” after treatment; however, the fatigue resulting from chemotherapy, accumulated effects of treatment and mental changes like memory deficits, word-finding difficulty and lack of concentration makes it frustrating for young women handling busy lives, families and careers to feel “normal.” Younger women also frequently commented that the diagnosis and treatment period is so busy with appointments, processing new information, making decisions and getting through the various treatments, that there is little time to process their emotions. Many were surprised that it was only after treatment ended that the real emotional impact of their diagnosis and treatment experience emerged. We believe that broader awareness that younger women need time, space and support to heal emotionally after treatment may help ease their transition.

Studies show that younger breast cancer patients also experience more isolation, depression and anxiety¹⁴. Many young women admit to having difficulty relating to their general peer group, and even close friends, most of whom have not had such a shocking life disruption. At the same time, most of the other patients young women meet in hospital and support settings are significantly older and are not struggling with the same challenges (i.e. early menopause, infertility, childcare etc.). This generation gap can be a contributor to the higher levels of stress and isolation identified in our survey.

Available evidence from a decade of qualitative studies and literature reviews suggests that there are significant gaps in the care of younger women with breast cancer with potentially serious negative consequences.¹⁵ Our national, quantitative survey findings validate these anecdotal concerns. Young women remain dissatisfied

¹⁴ Partridge AH, Ruddy KJ, Kennedy J, Winer EP. Model Program to Improve Care for a Unique Cancer Population: Young Women With Breast Cancer (2012). *J Oncol Practice* 8 (5)

¹⁵ See above

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with the diagnostic process and struggle to navigate the healthcare system. They continue to have more difficulty accessing treatment to deal with side-effects—less than half of the women in our survey who were concerned about the impact of treatment on their fertility were referred to a fertility specialist. And, despite the increase in psychosocial support programs and resources for young women implemented over the past decade by non-profit breast cancer organizations, psychosocial support is sporadic across the country and young women have difficulty accessing it or are simply not aware of community programs that do exist. As a result, younger women have more negative physical outcomes and psychosocial distress, both during and after treatment, compared to older women, impacting their overall quality of life.¹⁶

We need to ensure that all young women affected by breast cancer have access to the most appropriate and best possible services and treatments. The gaps in support and inconsistency of care point to the need for more standardized care and systematic interventions to be put in place to meet the unique concerns of young women in all corners of the country. Given the situation, Rethink Breast Cancer has identified two key priority areas for immediate action that could significantly assist with the challenges facing young women diagnosed with breast cancer: the development of a Standard of Care for Younger Women with Breast Cancer and a call for nurse navigation services to be available to all Canadian women.

A Standard of Care would ensure that all community and healthcare workers are aware of the unique challenges that young women are confronted with during diagnosis, treatment and recovery. By creating protocols around issues such as fertility, side-effect management, childcare and financial implications, a Standard of Care for Young

Women with Breast Cancer could be an important step towards improving the experience of young breast cancer patients.

In addition, ensuring that nurse navigation services are available to all breast cancer patients would help improve access to tailored information, resources and support services for young women. Much work has been done over the past ten years to create support and information resources geared specifically at young women with breast cancer. Our survey identified that many young women are not accessing the support and information that they desperately need and that we know is available to them through a variety of organizations across Canada (including Rethink Breast Cancer). These “access and distribution” problems could be a result of the small number of young women diagnosed each year (under 1000 Canadian women)¹⁷ that are geographically spread across such a vast country. Extensive research has been done on the positive impact nurse navigators can have on cancer patients. Moreover, our survey revealed that young women in regions with nurse navigators had a much easier time navigating the healthcare system than those in areas without a consistent nurse navigator program. Without a province-wide nurse navigation service, many young breast cancer patients will be faced with the challenge of dealing with their diagnosis, trying to understand tests and treatments, while managing work, childcare, fear of a recurrence, fear of treatment and side-effects without supportive care.

Nurse Navigators can play a major role in supporting and implementing a Standard of Care for Young Women with Breast Cancer as well as ensuring that young women are getting the proper medical interventions and practical and psychosocial supports they need. Nurse navigation services also improve management of oncological emergencies, reduction of service duplication and potential improvement in continuity of care.¹⁸

¹⁶ Howard-Anderson J, Ganz PA, Bower JE, Satanton AL. (2012) Quality of Life, Fertility Concerns, and Behavioral Outcomes in Younger Breast Cancer Survivors: A Systematic Review. *JNCI J Natl Cancer Inst* (2012) 104 (5)

¹⁷ Canadian Cancer Society (2012) Canadian Cancer Statistics 2012

¹⁸ Canadian Partnership Against Cancer. (2010) Cancer Journey, Guide to Implementing Navigation.

DISCUSSION

RETHINK BREAST CANCER'S PRIORITY AREAS FOR IMMEDIATE ACTION

Upon completion of the survey, we met with key stakeholders from breast cancer organizations across Canada to present our National Needs Assessment Survey results to better understand the gaps in care for breast cancer patients and how we can all work together to bridge them or help make needed systemic change. The discussion at the one day meeting has helped inform the Discussion section of this report.

Rethink Breast Cancer is currently taking the lead in developing a Standard of Care for Younger Women with Breast Cancer. We are collaborating with younger women with breast cancer and breast cancer specialists, oncology nurses and supportive care providers to form standards for the type of information and support young women with breast cancer should be given access to across Canada. In addition, Rethink Breast Cancer is calling for nurse navigator services to be available to all Canadian women. We are developing a solid and concise position that speaks to this need specifically in Ontario with the intent to work with other provinces to make this a reality across the country.

LIMITATIONS AND DIRECTIONS FOR FUTURE RESEARCH

Our survey set out to understand the issues young women with breast cancer face, and to identify the broad gaps in support and care for this community. We were looking specifically at the role age plays in the breast cancer experience and in this way we did not examine many other important determinants such as socio-economic status, ethnicity, employment etc. Further investigation is needed to understand how these other determinants effect a woman's access to proper information, health care and support.

It is important to note that our survey did not explore the specific and unique issues that young women with metastatic breast cancer face. In 2008, the Metastatic Working Group made up of 16 patient advocates from seven countries compiled a consensus report with the input of more than 30 women living with metastatic breast cancer. The report found that there are not enough information and support services specifically for women with advanced breast cancer, and some patients find it difficult to locate existing materials; and that women with advanced breast cancer feel isolated and marginalized. These needs identified by women with metastatic breast cancer are similar, in a broad sense, to the needs of the young women with breast cancer in our survey. As women diagnosed with breast cancer at a young age are more likely to have a recurrence and metastases, it would be valuable to do further investigation around the unique information, resources and support services that women who are young and metastatic need to make informed decisions that will support them in their breast cancer journey.

CONCLUSION ● ● ●

RETHINK BREAST CANCER is hopeful that the results of this National Needs Assessment will lead to improved experiences for younger women diagnosed with breast cancer by deepening the understanding among Canadian health care professionals about their unique needs of younger women with breast cancer and the current gaps in care; by guiding organizations providing support for younger women with breast cancer (including Rethink Breast Cancer) to best tailor their support programs; by increasing the awareness among the general population that younger women diagnosed with breast cancer face specific challenges; and by showing young women with breast cancer that they are not alone and share experiences with other women their age facing this disease.

We also hope that our initiatives resulting from the survey - developing a National Standard of Care for Young Women with Breast Cancer and the call for nurse navigator services for all Canadian women - will be joined by other initiatives that will improve the care and support for younger women with breast cancer.

Rethink Breast Cancer thanks all of the women who took the time to complete the online survey and shared their experiences with us. We look forward to a future where the needs of younger women with breast cancer are understood and met and that no women facing breast cancer has to suffer unduly due to her age.

For more information about Rethink Breast Cancer and our work, please visit

www.rethinkbreastcancer.com

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