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*Corresponding author: Jenna Ratcliffe, Department of Oncology, Juravinski Cancer Centre, McMaster University/Hamilton Health Sciences, 699 Concession Street, Suite 4-214, Hamilton, Ontario, Canada L8V 5C2
E-mail: ratclifj@hhsc.ca

Reviewing editor:
Udo Schumacher, University Medical Center Hamburg-Eppendorf, Germany

Additional information is available at the end of the article

ONCOLOGY | RESEARCH ARTICLE

Young women with breast cancer: Needs and experiences

Punam Rana¹, Jenna Ratcliffe^{1*}, Jonathan Sussman¹, Margaret Forbes¹, Mark Levine¹ and Nicole Hodgson¹

Abstract: *Background:* Approximately 20% of all newly diagnosed breast cancer cases in Canada occur in women less than 50 years of age. Young women diagnosed with breast cancer (YWBC) may experience unique physical and psycho-social issues. There is a lack of data outlining the specific needs and experiences across the trajectory of care in YWBC. This study aimed to gather and analyze the physical, psycho-social and informational needs of YWBC at a regional cancer centre. *Methods:* Participants attended either a focus group or interview that was moderated by following a semi-structured interview format. Transcripts were reviewed independently and then compiled by themes and recurring responses by two reviewers using constant comparative method. Discrepancies were resolved via consensus and definitions were revised. *Results:* Focus groups and interviews were conducted with a total of 16 women, 40 years of age or less, diagnosed with breast cancer within the last year. Several themes arose from the data which included the need for: age appropriate information; timely referral to fertility services and supportive care services. Most participants reported experiencing a timely work-up and diagnosis. All participants expressed distress. The most common triggers were telling their children of their diagnosis, waiting for biopsy results and fear of recurrence. *Conclusion:* Most YWBC reported they were provided with adequate medical information for

ABOUT THE AUTHOR

Dr Punam Rana trained in medical oncology at the University of Toronto followed by a research fellowship at the Juravinski Cancer Centre. She recently completed a Masters of Science in Health Research Methodology at McMaster University. Her research interests include improving the patient experience, with a focus on the AYA population (adolescents and young adults) population. She worked to create informational resources for young adults diagnosed with cancer and is a Medical Advisor for the Pink Pearl, a non-profit charity for young women diagnosed with cancer. Dr Rana has been the co-principal investigator on studies looking at the supportive care needs of young women diagnosed with breast cancer at the Juravinski Cancer Centre in Hamilton, Ontario, Canada.

PUBLIC INTEREST STATEMENT

Approximately 20% of all newly diagnosed breast cancer cases in Canada occur in women less than 50 years of age. Young women diagnosed with breast cancer may face unique challenges during and after their cancer treatment. The current study was designed to explore the physical and psycho-social needs of young women diagnosed with breast cancer in southern Ontario with respect to fertility, breast reconstruction, mastectomy, sexuality and emotional counseling. Authors conducted focus groups and interviews with women recently diagnosed with breast cancer, 40 years of age or less. Common themes generated from these discussions included the need for: age appropriate information; timely referral to fertility services and supportive care. All participants expressed distress. Further research is needed to understand how changes could be implemented to better meet the needs of young women diagnosed with breast cancer.

decision-making. However gaps were found in supports for psycho-social, fertility, and sexuality needs. Further research is needed to understand how changes could be implemented to help better meet the needs of YWBC.

Subjects: Qualitative Methods; Cancer; Medical Social Work; Social Work Research

Keywords: young women with breast cancer; supportive care needs

1. Introduction

It is estimated that 9,100 women are diagnosed with breast cancer in Ontario, Canada each year (Canadian Cancer Society, 2012). In 2012, 110 cases (0.5%) occurred in women 20–29 years of age and 850 (3.7%) in women 30–39 years of age (Canadian Cancer Society, 2012) breast cancer diagnosed in young women is associated with a poorer prognosis (Canadian Breast Cancer Foundation, 2014). In part, this is as a result of an inherently more aggressive biology. In addition, breast cancer in younger women tends to be diagnosed at a more advanced stage (Gajdos, Tartter, Bleiweiss, Bodian, & Brower, 2000).

The clinical care of young women diagnosed with breast cancer (YWBC) tends to be more complex than older women with breast cancer. They can experience similar physical and emotional issues as older women (e.g. nausea, vomiting, hair loss, altered body image, and uncertainty about the future) (Thewes, Butow, Girgis, & Pendlebury, 2004). In addition, YWBC may experience unique physical and psychosocial problems including: premature menopause (Thewes, Meiser, Rickard, & Friedlander, 2003), infertility (Duffy, Allen, & Clark, 2005), strain in relationships (Fergus & Gray, 2009) and decisions for bilateral mastectomy (Metcalfe et al., 2012).

The current study was designed to explore the physical and psycho-social needs of YWBC in our region of southern Ontario with respect to fertility, breast reconstruction, mastectomy, sexuality and emotional counseling.

2. Methods

2.1. Study design

A qualitative research design was utilized for addressing our research objectives. Qualitative research is useful in “reach[ing] aspects of complex behaviors, attitudes, and interactions which quantitative methods cannot” (Gilchrist & Engel, 1995). It can be particularly beneficial at answering questions about individuals’ motivations, perceptions, expectations, and meaning (Patton, 2005).

Figure 1. Moderator’s guide for the young women with breast ca study.

Moderator’s Guide for the Young Women with Breast Ca Study

Thanks for taking the time to meet with me today. Please read through the consent form and let me know if you have any questions. If you agree to participate, please sign and date the last page of the form.

We are meeting today to discuss the needs and experiences of young women with breast cancer specifically so that the information shared today will help us to improve the health care experiences of younger women with breast cancer. I will start by asking what you remember during the initial period of your diagnosis:

1. Do you remember what seemed to go as well as it could during the period of initial diagnosis?
2. How well informed did you feel when making decisions about treatment?
3. Often the topic of sexuality is one that is not well addressed before or during cancer treatments. Would you say this is a topic you would have liked or would like more information about now? If so, who would you like to have this information from?”
4. Did you feel you needed support from the treatment team between appointments?
5. Did you feel you needed support beyond that provided by the treatment teams during your treatments?
6. What was the most distressing aspect of your cancer treatment period?
7. For those of you whose treatment is over, getting back on track can take time and can be challenging. How has it been like for you?

A semi-structured guide was used by a trained facilitator (JR) who conducted focus groups and individual interviews. Each of these followed an identical format including a brief introduction of the project and discussion covering topics of interest: treatment experiences; needs during and after treatment; and supports sought and received. The moderator's guide was developed from a literature review examining common topics relating to YWBC as well as input from the research study team which includes surgical, medical, radiation oncologists and an advanced practice nurse, all specializing in breast cancer (see Figure 1 Moderator's Guide). The guide was organized to follow the usual trajectory of cancer care (Cancer Care Ontario, 2013).

Not all participants were able to attend scheduled focus groups; therefore interviews were conducted to allow participants an opportunity to take part in the study outside of focus group times.

3. Setting

The Juravinski Cancer Centre (JCC) located in Hamilton, Ontario, Canada reported 613 new cases of breast cancer in the year 2012–2013. The JCC has many resources that are available for all women diagnosed with breast cancer including: oncology nursing and oncologist teams; surgical oncologists with special expertise in breast cancer surgery; plastic surgeons with expertise in breast reconstruction; a nurse practitioner who runs a well follow-up survivor clinic; genetic counselors; and a robust supportive care program with social workers, dieticians and a psychiatric clinical nurse specialist.

4. Participants

Women were eligible if they were diagnosed with early stage breast cancer (stages I, II, III) and were seen at one of the sites in the Local Health Integration Network (Hamilton, Halton, Niagara, Haldimand, Brant) in Ontario, Canada. Inclusion criteria were women who were 40 years of age or less with histologically diagnosed breast cancer within the last 12 months. Women were excluded if they met one of the following criteria: diagnosed with metastatic breast cancer; unable to speak English; the time from diagnosis for biopsy-proven breast cancer to entry in the study was greater than 12 months. This study received full Research Ethics approval from the Hamilton Integrated Research Ethics Board (HiREB) prior to study commencement.

5. Recruitment

The Health Informatics team at the JCC provided the research coordinator with a list of eligible patients. The coordinator notified the oncology teams about potentially eligible patients and a permission to contact form was placed in patients' charts. The primary oncology team would approach the identified patients in order to maintain the integrity of the circle of care.

6. Analysis

Each focus group and interview was recorded and transcribed verbatim. Two independent coders, PR and JR, reviewed the transcripts and coded them using the constant comparative method to identify emerging themes. The initial transcripts provided a hierarchical thematic framework that was developed by identifying recurring themes and comparing them to subsequent transcripts—constant comparative method. This framework was applied to all the transcripts until we reached saturation of themes (no new themes emerged). This was reached at 16 participants. The constant comparative method is an inductive data coding process used for categorizing and comparing qualitative data for analysis purposes (Strauss & Corbin, 1990). Constant comparative method is usually associated with the grounded theory method to identify issues experienced by the representative groups without a priori hypotheses (Strauss & Corbin, 1990). Once the thematic framework was developed, members of the research team (PR, JR, JS, and MF) met to identify discrepancies and resolve them via consensus (Patton, 2005). Table 1 summarizes recurring themes from participants across all focus groups and interviews.

Table 1. Participant recurrent theme table

Recurring themes	Focus group 1			Focus group 2				Focus group 3			Individual interviews					
	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	R11	R12	R13	R14	R15	R16
Initial diagnosis—what went well, what didn't?																
<i>Delayed</i>						
<i>Timely</i>
<i>Poorly communicated</i>										
Treatment: Informed decision making																
How well informed did you feel by your oncology team when making decision about your treatment?																
<i>Well-informed</i>	
<i>Not well-informed</i>		
Bilateral mastectomy: Did you have, or do you plan to have, bilateral mastectomy?																
<i>Yes</i>				
Breast reconstruction: Did you decide to do reconstruction? If so, was it immediate or delayed?																
<i>Immediate</i>						
<i>Delayed</i>		.		.												
Fertility information: (effects of cancer treatment on fertility, options for birth control, family planning)																
<i>Needs unmet</i>					
Sexuality information: (the effect of cancer treatment on intimate relationship, libido, vaginal dryness)																
<i>Needs unmet</i>	
Support: Did you seek support from the treatment team between appointments?																
<i>Yes</i>
Were you provided information about additional supports like Social Work or Community Services?																
<i>No</i>			
Yes, information was provided about:																
<i>Social worker</i>			
<i>Comm. services</i>			
Did you utilize supports from additional services?																
<i>No</i>			
Yes, I utilized supports from:																
<i>Social worker</i>			
<i>Comm. services</i>				
Distress: What has been the most distressing aspect of your cancer treatment																
<i>Telling kids</i>			
<i>Telling parents</i>			.			.							.			
<i>Waiting for biopsy results</i>						
<i>Having surgery</i>			.	.												
<i>Fear of recurrence</i>		

7. Results

Sixteen out of 20 potential participants agreed to participate in the study. Three focus groups and six interviews were conducted with ($n = 16$) participants whose ages ranged from 30 to 40 (see Table 2). The average age of the participants was 37. Certain themes emerged that could be common to women diagnosed with breast cancer of all ages e.g. double mastectomy, breast reconstruction, distress and life after breast cancer treatment (Thewes et al., 2004). While other themes were specific to a younger age, e.g. experiences of delayed initial diagnosis, pregnancy, fertility, needs for age-appropriate informational support.

Table 2. Participant demographics

Focus group/interview	Respondent (R#)	Age	Stage	Time from diagnosis (months)
Focus group 1	R1	39	2	10
	R2	36	3	11
	R3	40	1	3
Focus group 2	R4	34	3	6
	R5	40	2	5
	R6	30	2	11
	R7	39	2	12
Focus group 3	R8	31	3	4
	R9	36	2	3
	R10	40	1	3
Interview	R11	37	2	11
Interview	R12	33	1	7
Interview	R13	35	3	11
Interview	R14	40	0	12
Interview	R15	40	3	12
Interview	R16	37	2	3

7.1. Initial diagnosis

To begin the discussion, patients were asked about their initial diagnosis. A quarter of participants reported a delayed diagnosis where a significant period of time had elapsed before their breast lump was worked up for malignancy because it was felt unlikely to be breast cancer due to their age.

I found it about two years ago and told my family doctor ... he dismissed it because I have no family history and I'm really young. (R3)

However the majority of participants felt they had an especially timely work up.

So I went in, had the ultrasound, the mammogram ... and I was having surgery within two weeks. (R5)

7.2. Breast cancer during pregnancy

When asked about their initial diagnosis, four of the 16 study participants had their breast cancer diagnosis occur during pregnancy. This is likely due to the reproductive age group for which this study exclusively examined. This participant shared:

I was 34 weeks pregnant ... within five days of having the biopsy it came back that it was cancer So this ultimate high and ultimate low, crazy roller coaster ride ... it was really overwhelming ... being a first time mom and trying to comprehend everything that was going on ... (R6)

7.3. Medical treatment and decision-making

Participants were asked about their decision-making regarding their surgical treatment e.g. lumpectomy, mastectomy, double mastectomy, breast reconstruction. A third of the participants underwent, or were planning to undergo, a double mastectomy. The primary reason reported for this was for cancer prevention and secondarily, for cosmetic results.

I had both removed ... I'm not going through this three years from now ... I'm not taking any chances. I also wanted both to look the same. (R2)

In some cases the decision for a double mastectomy was in contrast to their oncologists' recommendation.

I asked for the double mastectomy originally and they said “no”. He said ... it was not worth it. It is too much. It is overkill. All you need is a mastectomy ... (R9)

Several of the women in our study underwent breast reconstruction and expressed improved self image as a result.

I did the breast reconstruction. It's something I did want ... He (plastic surgeon) made me, in a way ... sexy again. I can wear a bikini and stuff like that, so it was really nice. (R2)

Most of our study participants who had undergone mastectomy had immediate reconstruction although their oncology teams did not always agree with the decision to do it immediately. There were cases of conflicting recommendations between health care providers which affected patient care experience:

I met with my oncologist and told her ... that I wanted to have [immediate reconstruction] ... she was very clear that that's not what we do ... She didn't give me any options ... So, I went to my family doctor and ... she said ... “(name of plastic surgeon) does it, I'll send you to see him”. He said, “There's no reason to delay reconstruction.” I came to the decision on my own that I wanted to have the reconstruction done immediately. (R14)

... That was probably the lowest point that I just really felt like there was nobody communicating about my care. (R14)

7.4. Fertility

Participants were asked how well informed they were regarding the side effects of cancer treatment. A recurring theme was cancer treatment's side effects on fertility. In some cases, women indicated that fertility was not discussed in a timely fashion while in other cases, the issue of fertility was not raised by the primary oncology healthcare team altogether.

I think, being young, no one said, do you want to freeze your eggs? It wasn't even brought up. (R9)

7.5. Sexuality

Study participants were asked if the topic of sexuality was adequately addressed during their cancer journey. Over a third of this study's participants felt that information pertaining to the sexual effects of cancer treatments was not addressed by their treatment team:

The one thing that was never addressed ... is how all of this affects or can affect a woman's sex drive ... It's a domino effect. Physical, mental, hormones, self esteem and so on. (R2)

It has been previously reported that most healthcare professionals fail to address sexuality and patients rarely ask for information about the effects of cancer treatment on their sexuality and intimacy (Gould, Grassau, Manthorne, Gray, & Fitch, 2006; McLachlan, 2009). Failure to address this issue can adversely affect a woman's quality of life (McLachlan, 2009; Partridge et al., 2004).

7.6. Support

Participants were asked if they felt they needed support beyond that provided by the treatment team. Over one third of the women in this study did not receive any information about access to support and community services.

I didn't even know this place [Wellwood] was here, no one has ever mentioned, all my trips to Juravinski. They just tell you, oh, there's support. (R5)

Those that did see a social worker felt that it was helpful.

... when you go and sit down with a social worker, and you lay it all out and say, here are my challenges, here's what I'm dealing with, anything that they can do to help you, they will. (R7)

When asked, other participants felt that additional resources which were identified by their treatment team were helpful. These included website links for wig and post-operative camisole donation and breast cancer support groups. Wellspring, a local community wellness center which provides free services for people affected by cancer, was identified as a source of camaraderie and support.

I found when I went to Wellspring, the second I walked in, I just felt this click and I felt like I just completely fit in there. (R12)

Whereas older women with breast cancer often face life transitions such as entering into retirement, young women may have children at home, may be entering the work force or working on developing their career. These different life stages may contribute to YWBC feeling distressed and isolated:

It was hard for me I think walking into the JCC ... everyone is in their 70s. And not to downplay because it's horrible for anyone but I'm like you can't relate to me with a seven-year-old at home. (R1)

Many of the JCC breast cancer resources are geared to older women's needs. This patient noticed:

When they're talking about certain things it's geared towards geriatrics, like elderly people and not necessarily us. (R2)

7.7. Distress

Study participants were asked to indicate their most distressing aspect of their cancer diagnosis and treatment experience. Over a third of the participants felt the most distressing aspect was uniquely related to their young age such as sharing the diagnosis with their children.

I did tell her "mommy has breast cancer and I have to have surgery". As soon as she heard cancer, she was like "are you going to die?" So I think for me that was definitely the hardest ... my fear is that I won't be here for her. (R2)

Other distressful experiences included waiting for test results and fear of recurrence. Screening for distress could be one way of mitigating some of these difficult experiences for young women (Bultz & Carlson, 2006; Carlson, Waller, & Mitchell, 2012). Distress screening can be accomplished through the regular use of the revised Edmonton Symptom Assessment Scale (ESAS-r) during a patient's visit with their oncology care team (Cancer, 2012; Watanabe, Nekolaichuk, & Beaumont, 2012).

7.8. Life after cancer treatment

Study participants, whose active treatment was over, were asked about getting back on track after cancer treatment. The uncertainty of "what happens after treatment is over" was a common theme heard from these participants:

Have I done everything I need to do and now am I just crossing my fingers? ... you push through everything you need to and now it's like you're at the end and you go, now what? (R1)

YWBC may benefit from additional information and supportive care that continues after treatment is completed. Ongoing assessment of a young woman's needs after breast cancer treatment and tailoring of resources to meet those needs is important (McLachlan, 2009).

7.9. Patient recommendations

Study participants were then asked to provide suggestions on how the experience of breast cancer diagnosis and treatment could be improved for young women. These fell into two themes: Information about Support Resources and Sexuality.

7.10. Information about support resources

Improving resources specific for younger adults was an overarching theme. One of the challenges faced by YWBC is finding age-appropriate breast cancer support resources (Gould et al., 2006). One participant recommended:

... you need a young social worker out there. Because what they hand you is, here's a Pashmina, here's a book about older women who have been through it. (R7)

Young women with children may require practical support including child care, meal preparation and house cleaning (Bloom, Stewart, Johnston, & Banks, 1998; Gould et al., 2006; Metcalfe et al., 2012).

... you're walking though the cancer centre bald, pushing a baby carriage, red flags should go up, people should flag you and get some help, get a counselor ... social worker, case worker, anything ... Just help take some of that load off, or talk about some options ... financially you can apply for this or there's a program that offers you money ... (R6)

7.11. Sexuality

Another challenge commonly faced by YWBC is issues with sexuality (Burwell, Case, Kaelin, & Avis, 2006; Fobair et al., 2006) Participants recommended that peer support would be helpful when dealing with such issues:

Talking and relating to other women about how they handled this or helped this situation would be helpful. (R2)

8. Discussion

The majority of women in our study reported that the diagnosis of breast cancer and initiation of treatment occurred promptly. They felt that they were provided with sufficient information to make informed decisions about their treatment. However, many of the women indicated that certain aspects of care were not adequately addressed including information about social and community services, managing aspects of distress and available fertility services.

Our study reveals gaps which exist in meeting the needs of this population and in the availability of age appropriate resources. Several themes arose from our data including the need for: information about social and community services; appropriate referral to fertility services; counseling by qualified social workers. These themes will be the focus of future research to improve our understanding of how we can meet the needs of YWBC.

The potential of facing infertility can be devastating for young women. This can be compounded by the fact that young women are now delaying the time until first pregnancy. Previous reports that YWBC are often not provided with adequate information about their fertility options (Duffy et al., 2005; Partridge et al., 2004) was confirmed in our study. Recent guidelines were published by American Society of Clinical Oncology (ASCO) stating that fertility preservation should be discussed as early as possible with all patients of reproductive age if infertility is a potential risk of therapy (Loren et al., 2013). Patients who show an interest in fertility preservation should have a prompt referral to a fertility clinic (Loren et al., 2013).

A quarter of our study's participants were diagnosed with breast cancer during pregnancy. Breast cancer is the most common cancer diagnosed during pregnancy as 1 out of every 3,000 pregnant women is diagnosed with breast cancer (Canadian Cancer Society, 2014). This rate may increase due

to a delay in childbearing (Partridge et al., 2012). Breast cancer in pregnancy is typically diagnosed at a later stage when compared to women who are not pregnant, posing additional challenges in the management of this population (American Cancer Society, 2015). The delay can be due to difficulty detecting the cancer because of lumpy, tender breasts during pregnancy which may mask the cancer, as well as an increased density of the breasts which decreases the sensitivity of mammography detection. There are unique challenges in the treatment of breast cancer in pregnant women because the desire to protect the growing fetus may affect diagnostic testing and treatment options (Ives, Musiello, & Saunders, 2012).

A third of this study's participants reported undergoing a double mastectomy. Double mastectomy is a controversial issue because the benefits of this procedure are unclear for patients who do not have a genetic mutation (Hordern, 2000). It is often performed in order to reduce a patient's anxiety about a second breast cancer (Schmidt, 2014). Women who undergo a double mastectomy tend to overestimate their risk of a contralateral breast cancer (Burke, Portschy, & Tuttle, 2015; Tracy, Rosenberg, Dominici, & Partridge, 2013).

All participants in this study experienced distress as a result of their breast cancer diagnosis. To manage distress, some patients mobilize their own resources to handle the situation independently whereas others benefit from formal assistance (Cancer, 2012; Watanabe et al., 2012). At our cancer centre, assistance can be provided by a social worker in the Supportive Cancer Care team. Screening for distress could identify those at risk (Bultz & Carlson, 2006). Distress screening can be accomplished through the regular use of tools such as the revised ESAS-r during a patient's visit with their oncology care team (Cancer, 2012; Watanabe et al., 2012). Although ESAS is commonly utilized in clinical oncology in Ontario, it does not necessarily translate into appropriate supportive care referrals (Dudgeon et al., 2012; Pereira et al., 2014)

The current study reinforces previous research that identified similar gaps relating to fertility (Partridge et al., 2004), early menopause (Loren et al., 2013; Partridge et al., 2004) genetic risk (Ruddy et al., 2014), body image (Fobair et al., 2006) sexuality (Burwell et al., 2006; Fobair et al., 2006; Hordern, 2000), depression and anxiety (Thewes et al., 2013). Inadequate attention to supportive care needs has been repeatedly documented in YWBC (Armes et al., 2009; Burwell et al., 2006; Fobair et al., 2006; Partridge et al., 2004). A recent systematic review examined the prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer and found higher levels of needs in patients of a younger age (Fischer, Dolbeault, Sultan, & Brédart, 2014).

Some cancer programs in the US and in Canada have developed breast cancer programs specifically geared for YWBC with success including the Program for YWBC at the Dana-Farber Cancer Institute in Boston, MA and the PYNK program at Sunnybrook hospital in Toronto, ON (Partridge, Ruddy, Kennedy, & Winer, 2012). A key component to both programs is the utilization of a "nurse navigator" who assists patients with referrals to fertility specialists, genetic counseling, plastic surgery and other informational materials and supportive care services throughout treatment and follow-up (Ali & Warner, 2013). Each patient is also automatically referred to a social worker who provides an initial consultation to determine the supportive care needs and depending on the needs of the situation, may refer the patient to other mental health specialists (Partridge et al., 2012). Despite their widespread use, these types of program approaches have not been found to be formally evaluated in the literature. Therefore the need to evaluate the efficacy of these programs specifically geared for YWBC is necessary.

We recruited patients who received their diagnosis within the preceding 12 months in order to minimize any recall bias. The average time from initial diagnosis of breast cancer to participating in our study was 8 months. The average age of women in our study was 37 which is younger than previous studies (Gould et al., 2006). The younger population allowed us to identify the issues pertaining to a more specific group of women. Our recruitment strategy aimed at minimizing self-selection bias

which can often be seen when recruiting through support groups and advertisements. Hospital generated lists were employed and oncology teams approached their eligible patients.

9. Limitations of the study

The needs and experiences of YWBC outside of our region may differ. Our study did not include patients younger than 30 years of age therefore we cannot comment on their needs and experiences. The use of interviews and focus groups could affect results as participants may have felt less inhibited in their responses during a one on one interview rather than in a focus group setting.

10. Conclusion

Young women with breast cancer face unique challenges during and after treatment. Our findings suggest that despite the use of symptom screening there continues to be unmet needs expressed by young women. We have found gaps in support for surgical decision-making, fertility support and social support. Enhanced mechanisms should be formally studied to link early detection of significant unmet need to appropriate supports and services of YWBC.

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Competing Interests

The authors declare no competing interest.

Author details

Punam Rana¹

E-mail: punam.rana@gmail.com

Jenna Ratcliffe¹

E-mail: ratclif@hhsc.ca

Jonathan Sussman¹

E-mail: sussman@hhsc.ca

Margaret Forbes¹

E-mail: mforbes@hhsc.ca

Mark Levine¹

E-mail: mlevine@mcmaster.ca

Nicole Hodgson¹

E-mail: nhodgson@hhsc.ca

¹ Department of Oncology, Juravinski Cancer Centre, McMaster University/Hamilton Health Sciences, 699 Concession Street, Suite 4-214, Hamilton, Ontario, Canada L8V 5C2.

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