Young Women with Breast Cancer: A Focus Group Study of Unmet Needs

Kathryn J. Ruddy, MD, MPH,¹ Mary L. Greaney, PhD,² Kim Sprunck-Harrild, MSW, MPH,³
Meghan E. Meyer,¹ Karen M. Emmons, PhD,³ and Ann H. Partridge, MD, MPH¹

Purpose: Young women with breast cancer suffer distress both at the time of diagnosis and afterwards. This study aimed to elucidate which issues are most disturbing to this population and which might be amenable to intervention.

Methods: English-speaking women treated or involved in research at the Dana–Farber Cancer Institute for stage I–III breast cancer while aged 18–42 years were invited to participate in one of four focus groups. A trained moderator led each 90-minute audio-recorded group using a semi-structured interview guide. All transcripts were coded using thematic content analysis with NVivo software.

Results: Thirty-six women participated. Three major themes emerged from the analyses of these focus groups' data: (1) participants felt different from older breast cancer patients with regard to relationships, fertility, menopausal symptoms, treatment side effects, and work/finances; (2) participants faced unique challenges transitioning into the survivorship phase of care; and (3) participants desired assistance, including connections with other young patients, help navigating the healthcare system, educational materials, and lists of appropriate counselors.

Conclusion: Young women with breast cancer have unmet needs for psychosocial support, education, and symptom management, and can identify potential support that may help meet these needs.

Keywords: breast cancer, survivorship, oncofertility, social support

EACH YEAR, APPROXIMATELY 14,000 women in the United States aged 40 or younger are diagnosed with breast cancer.¹ Younger women are at higher risk of distress both at diagnosis and during follow-up.^{2–7} Previous studies showed that young patients with cancer often face unique challenges, including treatment-related infertility, interruption of work/school at a critical time, and responsibilities for young children.⁵ Decreased energy and sex drive and the associated strains on relationships have been identified as substantial stressors in mixed-age survivors.⁶ In a qualitative evaluation of interviews, focus groups, and surveys from a total of 23 breast cancer patients aged 31–47 years at the time of the study, with a median time since treatment of less than 2 years, key issues included thinking they were too young to get cancer, feeling different from others their age, worrying they would not see their children grow up, and infertility.⁷ A systematic review of 28 studies of survivors ≤50 years of age found that anxiety, depression, and impaired quality of life

were common, as were concerns about weight gain, premature menopause, menopausal symptoms, and infertility.⁴ However, little previous research has focused on how to relieve distress and improve quality of life for young women with breast cancer. Consequently, in 2010, the United States' Centers for Disease Control and Prevention convened an Advisory Committee on Breast Cancer in Young Women (www.cdc.gov/cancer/breast/what_cdc_is_doing/young_women.htm), established by the Education and Awareness Requires Learning Young (EARLY) Act (Public Law 111-148),⁸ to commit national resources to this issue.

In light of currently inadequate information regarding *how* to begin addressing the needs of young women with breast cancer, this study was developed to elucidate potential targets and mechanisms for intervention. Focus groups were used to encourage interactive conversations and to empower these women to speak openly in a safe environment about emotionally sensitive topics.⁹

¹Department of Medical Oncology; ³Center for Community-Based Research; Dana–Farber Cancer Institute, Boston, Massachusetts.

²Department of Kinesiology, University of Rhode Island, Kingston, Rhode Island.

Methods

Recruitment

Participants were recruited through the Dana–Farber Cancer Institute (DFCI). Young women diagnosed with breast cancer who were either enrolled in the DFCI cohort study “The Young Women’s Breast Cancer Study” or participated in clinical or educational programming for young women at DFCI¹⁰ were invited to participate via an associated internet listserve. Interested persons contacted study staff by email or telephone; staff confirmed eligibility by phone. Eligibility requirements included: able to read English, no known metastatic disease, and diagnosis during the 4-year period prior to study recruitment (2007–2011) of stage I–III invasive breast cancer while aged 18–42 years.

Procedures

Four focus groups were held at a satellite building of DFCI in Boston, Massachusetts. Participants provided signed informed consent and completed a brief initial demographic survey. A moderator trained in qualitative research methods conducted the focus groups using a semi-structured interview guide developed utilizing the existing literature. Questions were designed to explore the experiences of young women with breast cancer at the time of diagnosis and during follow-up. The interview guide format allowed the moderator to use probes to explore participants’ responses further while maintaining consistency across the focus groups.¹¹ During the focus groups, the moderator summarized major discussion points between questions, which provided participants with an opportunity to share any final thoughts and to clarify anything they felt was misunderstood by the moderator.

Focus groups lasted approximately 90 minutes each. Study staff took handwritten notes during each group, and sessions also were audio recorded for transcription. Participants were served a meal and received \$40 as compensation. The DFCI Institutional Review Board approved this research.

Analysis

The focus group audio recordings were professionally transcribed with all identifiers removed. Using steps outlined by Strauss and Corbin,¹² analysis was a multistage process. First, a codebook was developed by examining the transcripts to identify themes and create initial coding categories. Second, all transcripts were coded using thematic content analysis using NVivo software v2 (QSR International, Burlington, MA). Finally, initial codes were classified into broader categories and examined for emerging themes.¹³ Frequencies and means for demographic data were obtained using SAS v9.3 (SAS Institute, Inc., Cary, NC).

Results

A total of 36 women participated in the four focus groups. Participants’ mean age at the time of the study was 37.8 years (standard deviation [SD]=4.7; range: 26–44), and the mean time since diagnosis was 22.3 months (SD=14.6; range: 3–53). The number of participants and their age range at study varied slightly between the four focus groups: the first focus group consisted of nine women aged 34–42 years, the second had eight women aged 26–38 years, the third group had 10

TABLE 1. FOCUS GROUP PARTICIPANTS’ DEMOGRAPHIC, CANCER, AND TREATMENT CHARACTERISTICS

	Mean (SD) or n (%)
<i>Demographic characteristics</i>	
Age at study, in years	37.8 (SD=4.7)
White, non-Hispanic	34 (94%)
Ashkenazi Jewish	5 (14%)
College degree or higher	33 (92%)
Married or living as married	27 (75%)
<i>Financial situation</i>	
Family income <\$50,000	6 (18%)
Family income \$50,000–\$100,000	10 (29%)
Family income >\$100,000	18 (53%)
Has health insurance at time of study	35 (97%)
Insurance covered all treatment costs	23 (68%)
<i>Cancer and treatment characteristics</i>	
Months since diagnosis	22.3 (SD=14.6)
Stage	
I	15 (42%)
II	18 (50%)
III	3 (8%)
Breast surgery	36 (100%)
Chemotherapy	31 (86%)
Radiation	23 (64%)
Hormonal therapy (current or past)	16 (44%)

SD, standard deviation.

women aged 26–42 years, and the final group contained nine women aged 25–41 years. See Table 1 for additional participant characteristic data.

Three major themes emerged during analyses: (1) participants felt different from older breast cancer patients; (2) participants faced unique challenges transitioning into the survivorship phase of care; and (3) participants desired assistance, including connections with other young patients, help navigating the healthcare system, educational materials, and lists of appropriate clinicians. These themes are presented below, with representative quotes shown in Tables 2–4 as indicated.

Theme 1: Feeling Different from Older Breast Cancer Patients (Table 2)

Across all four focus groups, participants repeatedly expressed a perception of themselves as distinctly different from most other women they knew who had breast cancer because of their young age. Analysis revealed five domains that participants viewed as being most substantially impacted by breast cancer at a young age.

Domain 1.1: Relationships

Partners. Most partnered women spoke of how supportive their spouses/partners were during their treatment, and perceived their relationships as strengthened by this experience. However, others reported that breast cancer strained their sexual and emotional connections and caused communication rifts with their partners. Many expressed regret about the trauma that the cancer caused their partners, and were dismayed at their perceived lack of adequate support to help their partners deal with the burden of suddenly becoming a caregiver. Focusing on aspects of their lives other

TABLE 2. QUOTATIONS REPRESENTATIVE OF THE DOMAINS OF THEME 1:
FEELING DIFFERENT FROM OLDER BREAST CANCER PATIENTS

Domain	Quote
1.1 Relationships	
Partners	<p>"I feel like, through this war, he and I have become a stronger unit."</p> <p>"My husband was working so late—he's a lawyer—and I was never seeing him, and that was taking a huge toll on our relationship. And then, when I was diagnosed with cancer, he just pulled through. We live an hour and a half away and he would just come to every single test with me! We became best friends again, and we've stayed that way. So, it saved our relationship in a way."</p> <p>"...We had a change, and I think the change was made because I wanted nothing to do with romance...I was bald, I was fat, and...not feeling well, and my husband who was probably trying to...act like it didn't bother him that I looked like that, so he kept on pursuing, and I kept on pushing him away, so that caused a lot of conflict."</p> <p>"We both felt very, very alone, because we were both so busy, trying to be strong for each other, that we didn't open up as much as we probably should have, and we each felt like we had gone through it very separately. Despite, like, giving outward support and everything, we each felt like, 'If I tell you how scared I am and how I'm about to lose my %#\$, you might lose your %#\$, too,' and you know, he felt like he couldn't do that to me because I was sick; and I felt like I couldn't do that to him, because I knew he was suffering."</p> <p>"I think that's part of why my marriage fell apart...he listened, he took notes, he asked questions, he did all the right things on the surface. But then, you know, we'd get home and he'd be like, 'When are you going to get better? When is it going to be my turn? When are we going to have sex again? When can my life get back to normal?'"</p> <p>"A couple months after the treatment ended, we were like, 'Where the hell's our life going now?' Like, we can't make plans. I don't know if I'm going to be dead in a year."</p> <p>"A lot of the focus is on, you know, the person going through the cancer and not the caregiver. You know, the husband, or whoever's helping out. And I'm sure that there was a lot that they were going through at the same time, but, you're not really paying attention to that side of it."</p>
Dating	"I'm hesitant to start dating. I'm hesitant to have to explain this to someone...how do I start?... 'Hi, my name is Sarah. I have an implant.'...I mean, how do you go about that?"
Children	<p>"My biggest fear was...I'm going to die, and my daughter's going to grow up without a mom. And I won't have a chance to...teach her and show her everything that I wanted her to have and to know.' And I could cry, just thinking about it now."</p> <p>"The BRCA1 gene, I have it, and my sister was diagnosed with breast cancer right when we were figuring that out (and she had the gene as well). And then, suddenly, the light bulb went off in my daughter's head, my fifteen-year old, and she said, 'Mommy, what am I to expect?' I had to be upfront with her and just say, 'When you get to your twenties...they're going to keep an eye on you a little bit more than they would somebody that doesn't have this risk'...for a fifteen-year old to really understand that is hard."</p> <p>"I did feel guilty. I'd make myself go to bed at 8:00...they were doing homework, and you could hear stuff going on, and I was doing what I could to stay as normal as possible, but I definitely had to make that time for myself."</p> <p>"I remember...not being able to pick up my son, and then, when I did, I couldn't feel him anymore on my chest."</p> <p>"My little one didn't like me to go without my hat on...should she...see me without it, it would upset her."</p>
Parents	<p>"I got the results from the biopsy. And I remember, the first thing I said to my mom when we got into the car so she could take me home was, 'I don't have life insurance.' And that scared the heck out of me, because who's going to take my student loans, my car payment, and all these other things? I was thinking, 'I'm going to die, and I'm going to leave my parents with \$40,000 in debt!'"</p> <p>"I would say that it was hardest for my parents...that a child in her thirties has cancer, and my dad thinking, 'We're the ones who are supposed to [get sick first].'"</p>
1.2 Fertility	<p>"I didn't have a lot of time to make a choice because I had to enroll in a study to get chemo...I felt very, very rushed even though I did a lot of research to educate myself. My insurance wouldn't cover it, and I couldn't afford \$15,000 to harvest eggs. So I just had to take a chance."</p> <p>"The fertility issue is a big issue, and to have to make a decision on that...in that head space, I think, is really challenging...there's so much pressure...'Oh, my God, I have to decide if I want to have kids in 5 years, right this minute!' Which is a really weird place to be in where you're thinking about your own mortality."</p>

(continued)

TABLE 2. CONTINUED

Domain	Quote
1.3 Physical changes and other side effects of treatment	<p>"I didn't lose my eyebrows and eyelashes until like my very last treatment...the hardest time for me is when I lost my eyebrows and eyelashes."</p> <p>"I always looked like I was this upset woman, but I wasn't, it was just because my eyes were just continuously watery, and my face was swollen from the steroids. Although I tried to hide that I had cancer, I wore a wig, I penciled in my eyebrows, people knew."</p> <p>"The weight is brutal, and...and I hate it."</p> <p>"I certainly have had my moments of self-consciousness at the beach, but not having a boob, and trying to manage that is like a whole other level."</p> <p>Regarding sexual dysfunction: "They never discussed anything like that...I'm a pretty open person, in terms of that stuff, but I wish that...that they had been, too. Because I wish I could have been a little bit more prepared for that."</p> <p>Regarding discussing sexual functioning: "Had I never said anything, I think they just would have assumed that everything was fine."</p> <p>"They're telling me these things that happened, and I can't remember...It's just, that chemo brain, or it's just shut everything out...My 5 year old already knows, 'Yeah, you can't remember.'"</p> <p>"I'm almost thinking, 'Should I tell [my kids] that I go to bed at 9:00 now, instead of reading my book till 1:00?'...Because, is that fatigue? Or is that just the new me?"</p>
1.4 Work and finances	<p>"I felt that was the one thing—working full-time through treatment it made me feel like I had some control in my life...Everything else was a question and out of control, and I didn't know what was going to happen. But that was one thing that I [could] control. And my company was great about it. There was an empty office, right down the hall from me, so I brought in my air mattress and my pillow."</p> <p>"I thought I did the responsible thing by going to HR, first and saying, 'Here's my situation, I've just been diagnosed, I don't know what my life is going to look like.' That single meeting at HR was the most horrible part of the entire process. They were awful! I think individual people within my agency were nice...I think the agency itself did a horrendous job."</p> <p>"I was challenged with...navigating through the whole FMLA...you know, kind of making sense of, 'Okay, what is covered? What is considered sick leave?' And it was a lot of phone calls, trying to figure that out. And I just wish that it would just be a lot more seamless, because...I was going through treatment, not sure when am I gonna get my paycheck, how much time should I take off, and such."</p>

FMLA, Family Medical Leave Act.

than cancer was a challenge for many couples. Uncertainty about their health made it difficult for many women to plan for the future with their partners. Some reported that this became most obvious after finishing treatment.

Dating. Partnership issues were also salient for many of those who were not in a relationship at the time of diagnosis. These women noted that trying to date after breast cancer was very challenging due to physical consequences of treatments (e.g., breast surgeries), impaired self-esteem, and discomfort telling new partners about their cancer.

Children. Several participants who already had children when they were diagnosed reported that the most difficult aspect of their diagnosis was the fear that they would die and leave their children motherless. A few also worried that they might have passed on a deleterious genetic predisposition to their children. Women who found out that they carried a BRCA mutation voiced concern about how to deal with the possibility that their children may also be carriers. These women were also concerned about how their illness affected their children, with many feeling guilty that during treatment they did not have the energy to do things they usually did with their children. Mothers reported that physical changes, including hair loss, were disturbing to their children, and that they generally struggled telling their children about their cancer; in fact, some never did.

Parents. Some women described that it was challenging to discuss breast cancer with their own parents and siblings because the diagnosis was so upsetting, especially for their parents. It was stressful to watch their parents suffer due to their illness. One woman reported anxiety about leaving her parents with large bills if she died.

Domain 1.2: Fertility-related issues

Many participants expressed dismay that their breast cancer treatments may have impeded fertility. Participants who did not have children at the time of their diagnosis were most likely to voice concern about their reproductive future. Many of the women were upset they had not had more time to explore fertility preservation techniques. The high cost of these techniques and uncertainties about whether they were needed or would be effective added to distress levels, with some women feeling they had very few realistic options. These women remained worried about their chances of conceiving in the future, and wished they had had more support around fertility-related decisions.

Domain 1.3: Physical changes and other side effects of treatment

Physical changes due to breast cancer treatments caused distress for many participants. While losing the hair on their head was bothersome as expected, some reported that losing

TABLE 3. QUOTES REPRESENTATIVE OF THE DOMAINS OF THEME 2: FACING UNIQUE CHALLENGES TRANSITIONING INTO THE SURVIVORSHIP PHASE OF CARE

Domain	Quote
2.1 Expecting to feel normal	"I think the misconception is... 'Once I get through all this, I want to go back to normal.' Like, that's the goal... to be 'back to what I was, before.' It's not like that. You are completely changed and different and, you know, I kind of just took that expectation off myself, because I felt... you can't go back..."
2.2 Loss of supports	"I felt like you were just set adrift. And, it was sad because, during the whole process, there's so much support, and it almost seems like everyone disappears. It's like this big bandwagon, 'Yay! Here's some meals, here's this, here's all the support groups and the social worker.' But then it's over! And then... you have this expectation that you're supposed to be glad you're alive, and grateful, and it's past you, but it is totally not."

their eyebrows and eyelashes was even more upsetting. Also, many complained about weight gain during treatment, and that they had not been adequately informed about the high likelihood of this. Women also described negative feelings about body contour changes due to surgery. Some also expressed dissatisfaction with the information they received from their doctors about the hormonal side effects of their treatments. They felt that discussions and materials were too

generic (their specific problems were not addressed), and they complained that sexual functioning was seldom proactively discussed by practitioners.

In addition to physical changes, many participants reported that chemotherapy caused substantial changes in their energy and memory. Many reported that becoming accustomed to the changes in their body, energy level, and cognitive ability was a challenge.

TABLE 4. QUOTES REPRESENTATIVE OF THE DOMAINS OF THEME 3: DESIRED ASSISTANCE AND POTENTIAL AIDS

Domain	Quote
3.1 Connections with other young patients	<p>"Right after you're done with chemo, or, the period when you're done with treatment, if people haven't had chemo or radiation or whatever, and then you're just sort of supposed to be normal, but you're not quite normal. My oncologist actually said they used to have support groups just for people during this transition time. I don't know what happened to those support groups..."</p> <p>"I always find myself on the younger side of everything... [with] people that are MUCH older and didn't have kids that are at a similar age, and so, that's been very difficult."</p> <p>"By the end, you feel like you've been beat up and abused. And you're TIRED. And you're like, sort of emotionally raw, and I feel like THAT'S the time when there need to be more supports out there."</p>
3.2 Patient navigator/case manager	"I guess the other thing... which would be really helpful, would have been to have one person who I kind of felt was my case manager... My oncologist is super duper, but because is so super duper I... you know, I get like ten minutes with him and then that's it. And... he's very careful, he's like, 'Any questions...?' but I don't want to pressure him with anything else, all the time... and my nurse practitioner... was like, 'This is more of an OB question,' 'That's more of a surgery question,' so I'd go off and ask the other person... they can ask the other person, but... it's very tiring to do that. So, it would have been very helpful for me to have one person who was my kind of appointed question asking person, rather than this Rolodex of business cards."
3.3 Additional educational materials	<p>"I just wish that there was more information in a nicely... easy-to-read packet, that someone would say, 'Here you are, you've ended treatment and this is where you can go if you need X, Y, and Z'... when you are going through all of this, it is overwhelming, you are focusing on surviving, you're focused on your treatment, and then when the dust settles, then that is when you... start to process everything, and it's overwhelming, and you feel alone, and you feel depressed. And having [materials] right in front of you, ready to go at your... convenience to read, it [would be] invaluable."</p> <p>"You could almost do a pamphlet... head to toe... chemo brain, loss of sensation, sexual functions, joint hurts, real pain... this is stuff that you might experience... because I never knew that."</p> <p>"I think people, generally, are trying to support you, and they don't know that telling you their death stories, you know, makes you think about death."</p>
3.4 Counseling	"[I wish someone had said,] 'Here's a list of therapists. You might want to go down, see if some of them click, you might find them useful to talk to.' I'm like a complete and utter mess... I know that... it's normal... and they didn't really tell me that. It would be helpful for them to say... 'There are going to be issues that are going to come up. You might find it useful to find a therapist.'"

Domain 1.4: Work and finances

For those who were employed at diagnosis, treatment posed unique challenges. Although many participants continued working through treatment, a few stopped entirely during treatment, while some reported that it had been difficult to decide whether or not to continue working. Uncertainties about necessary recovery time often complicated these decisions.

Some participants had supportive work environments and found that continuing to work was beneficial, while others did not. Many reported that it was hard to decide whom (if anyone) at work to tell about their cancer because they were not sure how colleagues would react. Some who elected to tell coworkers said they later wished they had not divulged that information.

Furthermore, participants who took time off from work reported that significant stress resulted from dealing with disability paperwork and figuring out how to use the Family Medical Leave Act, a United States law allowing some eligible employees to take 12 weeks of unpaid, job-protected medical leave without losing their health insurance.¹⁴ Participants explained that it was challenging to learn enough about the financial, insurance, and work leave aspects of treatment while in the throes of a new cancer diagnosis.

Theme 2: Facing Unique Challenges Transitioning into the Survivorship Phase of Care (Table 3)

In addition to the emotional adjustment and trauma they experienced when newly diagnosed with breast cancer, participants also described the difficulties they experienced during the transition to survivorship care.

Domain 2.1: Expecting to feel normal

Participants did not feel adequately informed about chronic survivorship issues such as fatigue, memory problems, anxiety, what to expect from their bodies, and how to differentiate side effects from symptoms of recurrence. Many had incorrectly expected they would be able to resume their pre-treatment lives easily, and were distressed to find they could not.

Domain 2.2: Loss of supports

The emotional toll of the transition into the survivorship phase was compounded by the fact that participants lost many of the supports that had helped them during treatment. Participants explained that once they were no longer receiving treatment, some friends and family stopped calling and visiting as often. Some women missed seeing their healthcare providers as frequently as they had during treatment.

Theme 3: Desired Assistance and Potential Aids (Table 4)

When queried as to what would have been useful for them before, during, and after their cancer treatment, participants described practical sources of support that were or could have been helpful.

Domain 3.1: Connections with other young patients

Many participants wished they were able to talk, both during and after treatment, with other breast cancer survivors

who were of a similar age and life stage, in order to get “straight answers about the ups and downs of treatment” and the transition into survivorship. Participants emphasized the special value of connecting with fellow patients in a similar life stage (e.g., single, starting a career, with young children, or childless) for support regarding the consequences of breast cancer.

Domain 3.2: Patient navigator/case manager

Participants indicated that a relationship with a healthcare professional other than their oncologist would have been appreciated before, during, and after treatment to help answer questions outside of medical appointments, provide support and information to their families, and coordinate follow-up care. They also desired more information on a variety of issues, including how and where to start treatment, the impact of diagnosis and treatment on their personal relationships, side effects from treatment, fertility, nutrition, exercise/weight loss, vitamins, and what to expect physically and emotionally after treatment.

Domain 3.3: Additional educational materials

Women expressed interest in high-quality educational materials for themselves (e.g., pamphlets on nutrition/diet), as well as materials specifically designed for family members and caregivers (including descriptions of treatments and recommendations regarding what to do/not do for patients and when it is okay/not okay to talk about cancer). Some felt that online information about statistics and survivorship care follow-up plans would be particularly reassuring, and they were not aware of existing resources of this type. Participants specifically expressed desire for educational materials at the time of transition into the survivorship phase of care.

Domain 3.4: Counseling

A few participants wished for a list of therapists with experience providing counseling for young women with breast cancer, though none discussed their personal experiences with therapy. A few women were also interested in easier access to therapists (i.e., lists of experienced providers who were accepting new clients) for partners and other family members.

Discussion

Findings from these focus groups highlight the importance of counseling and supporting young breast cancer patients with regard to weight gain, fertility, and the potential impact of the disease on relationships, finances, employment, and other aspects of physical and mental functioning. Although this study did not include a validated measure of quality of life, problems with relationships, sexual functioning, and body image were previously shown by other investigators to be associated with poor quality of life for young women with breast cancer.¹⁵

Theme 1: Feeling different from older breast cancer patients

A novel discovery of our study was that women were worried about the stress of their diagnosis not only on their

children and partners, but also on their own parents. Prior to a cancer diagnosis, young women may be providing care to both their parents and their own children, and cancer may interfere with their caregiving abilities. Consistent with prior work by our group and others,^{16–18} fertility was a substantial concern for many participants in this study. Interestingly, no one spoke about adoption or surrogacy.

Another important finding was that navigating employment and insurance issues was extremely stressful for many participants. This was consistent with prior research nationally and internationally in various populations of cancer survivors.¹⁹ Young patients, who may not yet be well established in their jobs, may struggle more with deciding whether to work through treatment. Although most participants in this study were well educated, many described significant difficulties with the paperwork process for the Family Medical Leave Act and disability claims.

Theme 2: Facing unique challenges transitioning into the survivorship phase of care

The transition to the survivorship phase was also identified as a time of high need, confirming prior studies in mixed-age cancer patients.⁶ The young participants in this study felt this transition was challenging in part due to a sudden drop-off at the end of treatment in social support and medical visit frequency. Survivorship care plans given at the transition time that summarize diagnostic and treatment information might provide some of the needed education and support.⁶

Theme 3: Desired assistance and potential aids

Participants clearly articulated their desire for supportive aids to ease anxieties at the time of diagnosis, to manage symptoms and concerns during treatment, and to ensure a smoother and more informed transition to survivorship care. Bloom et al. found that physical, psychological, and social concerns remained problematic for some women diagnosed with breast cancer under the age of 50, even 5 years after diagnosis,²⁰ and that by that late time it was difficult to ameliorate these concerns with educational workshops.²¹ Our study suggested that a more optimal intervention might occur earlier (at diagnosis and/or at transition to survivorship) and might also target patients' family members.

Some participants in our study wished for a non-oncologist healthcare professional to aid in coordinating their cancer care from the time of diagnosis into survivorship, providing "one-stop shopping" for information and symptom management. While it may be unrealistic that any one individual would be able to answer all of a cancer patient's questions, it is possible that a well-educated patient navigator or program nurse could address many patients' symptoms and informational needs either in person or through online communication such as internet-based seminars.

Limitations

This study's findings should be interpreted with an understanding of its limitations. Because participants were required to be within 4 years of diagnosis, this study does not provide information regarding longer-term survivorship issues. Notably, participants were not asked about the timing of their treatments, so some may have still been receiving che-

motherapy and/or radiation therapy; results might differ in women who have completed all of these. Also, we were not able to analyze for differences between participants who had children prior to diagnosis and those who did not, as this data was not collected in our survey. Participants were predominantly white, well educated, and financially comfortable, which may limit generalizability. Sexual orientation was not assessed, though no one openly discussed being in a partnership with another woman. There is some evidence that lesbians may differ from heterosexual women in their level of distress and in the coping mechanisms utilized during and after breast cancer treatment.^{22–24} Also, no woman discussed being a single parent, which may increase the depression and stress associated with breast cancer.²⁵

Conclusion

Participants in these focus groups of young women with breast cancer reported multiple unmet needs and suggested various aids that might meet these needs. Future studies should explore whether these issues are similarly experienced by young female cancer patients with a variety of demographic characteristics, including additional geographic areas, racial/ethnic groups, educational and financial levels, and sexual identities, and whether these findings apply to young patients with other types of cancers.

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Address correspondence to:

Kathryn J. Ruddy, MD, MPH

Department of Medical Oncology, Dana-Farber Cancer Institute

450 Brookline Avenue

Boston, MA 02215

Email: katieiruddy@gmail.com