Published in final edited form as:

Qual Health Res. 2020 November ; 30(13): 2019–2032. doi:10.1177/1049732320929649.

The Other Side of Through: Young Breast Cancer Survivors' Spectrum of Sexual and Reproductive Health Needs

Kristin Z. Black[1], **Eugenia Eng**[2], **Jennifer C. Schaal**[3], **La-Shell Johnson**[2], **Hazel B. Nichols**[2], **Katrina R. Ellis**[4], **Diane L. Rowley**[2]

[1]East Carolina University, Greenville, North Carolina, USA

[2]The University of North Carolina at Chapel Hill, North Carolina, USA

[3]The Partnership Project, Greensboro, North Carolina, USA

[4]University of Michigan, Ann Arbor, Michigan, USA

Abstract

The long-term reproductive health impact of cancer treatments is a concern for premenopausal women with a history of breast cancer. This study examined the unmet sexual and reproductive health needs of breast cancer survivors, as well as concordances and discordances in needs by childbearing status and race. We interviewed 17 women diagnosed with breast cancer between the ages of 18 and 45 years and living in North Carolina. To analyze these data, we used the *Sort and Sift, Think and Shift©* method, a multidimensional qualitative analysis approach. We learned that breast cancer survivors (a) received limited reproductive health information, (b) desired realistic expectations of conceiving postcancer, (c) struggled with adjusting to their altered physical appearance, and (d) had menopause symptoms that led to sexual health and quality of life issues. Breast cancer survivors are in need of and desire more education and resources to address their sexual and reproductive health concerns.

Keywords

breast cancer; premenopausal; survivorship; sexual health; reproductive health; qualitative; interviews; North Carolina; United States of America

Introduction

An estimated 252,710 women were diagnosed with invasive breast cancer in 2017, and a significant proportion of these women (19%) were diagnosed before the age of 50 (American Cancer Society, 2017). Breast cancer among premenopausal women is often more advanced and has a poorer prognosis compared with postmenopausal women (Nichols

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Corresponding Author: Kristin Z. Black, Department of Health Education and Promotion, College of Health and Human Performance, East Carolina University, 2308 Carol G. Belk Building, Greenville, NC 27858-4353, USA. blackkr18@ecu.edu.

Declaration of Conflicting Interests
The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

et al., 2017). Premenopausal women who desire to conceive after a breast cancer diagnosis may face declines in reproductive function because of cancer treatment (Bouchlariotou et al., 2012; Camp-Sorrell, 2009; Friedlander & Thewes, 2003; Hickey et al., 2009) and recommendations to delay childbearing (Camp-Sorrell, 2009; Hickey et al., 2009). Whether or not women desire to conceive after breast cancer treatment, premenopausal women may experience treatment-related sexual or reproductive health issues that have the potential to affect their quality of life in survivorship (Cho et al., 2014). However, less is known about the sexual and reproductive health supportive care needs of premenopausal women with a history of breast cancer.

Chemotherapy can be directly toxic to ovarian follicles and result in temporary or permanent absence of menstrual cycles, depleted ovarian reserve, and a shorter reproductive window (Bouchlariotou et al., 2012; Camp-Sorrell, 2009; Friedlander & Thewes, 2003; Hickey et al., 2009). Chemotherapy and adjuvant endocrine therapy may also cause changes in sexual function and earlier onset of menopause (Barton & Ganz, 2015; Marino et al., 2016). Potential side effects of menopause brought on by these treatments, including vaginal dryness and low libido, may restrict women’s desire or ability to be sexually intimate with their partners (Crowley et al., 2016; Herbenick et al., 2008).

Indirectly, delays in childbearing plans can contribute to an age-related decline in fertility (Hickey et al., 2009). Breast cancer patients are often encouraged to delay pregnancy for at least 2 to 3 years after diagnosis (Camp-Sorrell, 2009; Hickey et al., 2009) and not become pregnant during adjuvant endocrine therapy, which may be prescribed for 5 years or more. This recommendation stems in large part from concerns about the lingering toxic effects of cancer treatment on growing oocytes, and the risk of cancer recurrence is highest during this period (Camp-Sorrell, 2009). However, limited evidence exists to support waiting more than 2 years after diagnosis to become pregnant, especially if the woman has a good prognosis and localized disease (Ives et al., 2007) and the risk of recurrence is low (Camp-Sorrell, 2009; Mueller et al., 2003; Pagani et al., 2011). Compared with women who do not become pregnant after a breast cancer diagnosis, women who become pregnant tend to have the same, if not better survival rates (Gelber et al., 2001; Kroman et al., 2008; Mueller et al., 2003), and are less likely to experience a recurrence (Azim et al., 2011).

Preconception health interventions aim to improve the health status and behaviors of women (and men) prior to conceiving a child with the ultimate goal of decreasing the risk of adverse pregnancy-related outcomes (Johnson et al., 2006). As a majority of pregnancies in the general population are unplanned, there has been a growing emphasis on promoting healthy behaviors throughout the reproductive age period (e.g., smoking cessation, maintaining a healthy weight) and not just during the prenatal period (Moos, 2010). The preconception health care needs of women diagnosed with and treated for breast cancer may differ from the general reproductive age population. For example, having information on the potential effects of cancer treatment options on sexual and reproductive function allows breast cancer patients to make informed decisions about their cancer treatment regimen and determine whether they should receive fertility preservation treatment prior to the onset of cancer treatment.

Furthermore, known racial disparities in breast cancer incidence rates and birth outcomes raise concerns about potential disparities in the sexual and reproductive health outcomes of premenopausal breast cancer survivors. Black women are more likely than their White counterparts to be diagnosed with breast cancer during their reproductive years (American Cancer Society, 2017) and experience adverse birth outcomes (Hamilton et al., 2016). Therefore, it is important to learn about the health status and behaviors of special populations (and their subgroups), so that preconception health services can be developed to meet their specific reproductive health concerns.

Purpose and Theoretical Foundation

This study aimed to determine the concordances and discordances in premenopausal breast cancer survivors' identified sexual and reproductive health needs between (a) women who did/desired and did not have a child after their breast cancer diagnosis and (b) women of color and White women.

Lu and Halfon's (2003) life course health development model is useful for investigating the life trajectories of young breast cancer survivors from diagnosis to a subsequent pregnancy. This theoretical model, which is grounded in the life course perspective, depicts how Black women have more cumulative exposure to risk factors and less protective factors than their White counterparts, which results in Black women having lower reproductive potential over their life course. Applying this model to young women with a breast cancer history highlights the need to consider the periods when they complete chemotherapy and adjuvant endocrine therapy. Both Black and White women's reproductive potential exponentially declines during these treatment periods, but a life course perspective underscores that declines would likely be more dramatic for Black women than White women based on cumulative exposures. Moreover, the healthy mother effect bias (Ives et al., 2007; Sankila et al., 1994; Valachis et al., 2010) signals that compared with survivors who choose not to or are not able to become pregnant, women who choose to and are able to become pregnant after breast cancer may be healthier, have a more positive breast cancer prognosis, experience less sexual health challenges, and have higher reproductive potential (Hickey et al., 2009; Valachis et al., 2010). In this study, Lu and Halfon's model was used to identify key events during the cancer journey that may have influenced the sexual and reproductive well-being of young breast cancer survivors and the healthy mother effect bias theory assisted with examining key characteristics and experiences of breast cancer survivors who have experienced pregnancy or childbirth post-treatment.

Method

Study Design and Approach

We explored the reproductive health needs of premenopausal breast cancer survivors from a life course perspective via in-depth semi-structured interviews. As sexual/reproductive health and breast cancer are sensitive topics and we wanted to explore similarities and differences between each woman's distinct personal experience, in-depth interviews were an ideal data collection method (Creswell, 2015; Miles et al., 2014). The study's principal investigator (PI) conducted all the interviews. An advisory committee of two breast cancer survivors and two advocates who belonged to breast cancer organizations (but were not survivors themselves) provided a community perspective for the study, including feedback on study design, implementation, and data interpretation.[1]

Study Population and Recruitment

The University of North Carolina at Chapel Hill's Institutional Review Board (IRB) and Office of Human Research Ethics reviewed and approved this study (14–1394). From October 2015 to March 2016, the PI recruited women with a breast cancer history, diagnosed between the ages of 18 and 45, and living in North Carolina (NC). We recruited a racially diverse sample who identified with one the following: (a) live birth after breast cancer diagnosis; (b) desire for child(ren) after breast cancer diagnosis, but inability to become pregnant; (c) never desired to have child(ren); or (d) decided not to have child(ren) once diagnosed with breast cancer. The PI recruited women through community-based and cancer center-based breast cancer support group meetings, cancer center–based listservs for young breast cancer survivors, and referrals from the advisory committee.

Data Collection

We used an in-depth, semi-structured two-part interview guide. Each participant was interviewed by the PI at a private location that was convenient for the participant (e.g., local library, home). Participants provided written consent before the interview. To build rapport, the interview was designed to occur over two sessions; however, three women requested to complete the entire interview in one session for convenience. As discussing breast cancer diagnosis and treatment, as well as sexual/reproductive health may be sensitive topics, we made efforts to ensure that the interview questions would cause minimal emotional trauma to participants. In addition, participants were asked whether they desired to pause or stop the interview when they appeared to be emotionally distressed. All women completed the interview(s).

The life course health development model and healthy mother effect bias informed the development of our interview guide. Part 1 of the interview covered topics such as reproductive history, breast cancer diagnosis and treatment story, and sexual/reproductive health experiences around the time of diagnosis. Part 2 covered experiences that occurred around the time of diagnosis and treatment, including sexual/reproductive health information received or desired, unmet or met reproductive health needs or concerns, reproductive or fertility issues, and life experiences that affected their health. Each interview was audio recorded and transcribed.

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[1] The principal investigator (PI) was cognizant that her positionality as a researcher was influenced by her race/ethnicity (non-Hispanic black), sex (female), educational status (PhD graduate), health status (non-breast cancer patient), and other factors. Consequently, she used rigorous qualitative methods, including consultations with a community advisory committee and member-checking with participants, to increase awareness of how her positionality influenced the research process. Three community advisory committee members (one breast cancer survivor and two advocates) were people the PI was connected to via previous breast cancer research she was involved in, and the fourth member, a breast cancer survivor, was recommended to the PI by one of the other three committee members. The committee met during the initial stages of study development and provided feedback on the interview guide, recruitment materials, and sources. The committee met a second time to discuss and refine the preliminary themes. Two committee members attended member-checking group sessions with interview participants and two serve as co-authors on this article. The community advisory committee's involvement greatly enhanced the overall quality of the study.

At the conclusion of the first interview, participants received US$25 cash, a resource guide of relevant cancer, emotional, and reproductive health support services, and a thank you card. After completing the second interview, each participant received US$35 cash. Participant recruitment continued until a saturation point was reached where the interviewees' responses addressed the questions and began to overlap to the point where new insights ceased to surface.

Analysis Approach

To ground the findings in the data, the PI utilized ResearchTalk's *Sort and Sift, Think and Shift*© method (Maietta, 2006), a multidimensional qualitative analysis approach that is informed by phenomenology, grounded theory, narrative research, and case study (Maietta et al., 2020). The *Sort and Sift* approach includes a variety of methods, such as writing memos, monitoring topics in the data, inventorying quotations, and diagramming quotations and topics. It is an iterative process of diving in and familiarizing oneself with the data, stepping back to reflect on what was learned, and then deciding how to move forward with the analysis. The main emphasis is on comparing the experiences of different participants and analyzing each participant's lived experience in relation to the research topic. This allows for monitoring topics vertically by participant and horizontally across participants.

Prior to reviewing the data, the PI first composed a memo to reflect on the interviews and initial lessons learned. Second, she reviewed each transcript, identified pulse quotations (i.e., quotations that highlighted key life experiences and reflections), and wrote a memo regarding each pulse quotation. Third, the PI wrote a memo about each transcript that addressed two questions: (a) What did we learn from this data collection episode? and (b) Why is this episode important to this study? Under the first question, she composed statements that captured the main topics discussed and exemplary quotations for each statement. Under the second question, she described the importance of topics discussed in the transcript and how the topics addressed the study aims. Fourth, she grouped statements from the memos written about each transcript into key topics. Fifth, from the grouped key topics and associated quotations, she developed a uniting theme. Finally, using matrices, she explored the grouped key topics to compare the sexual and reproductive health needs and concerns between women who did have/desired children and did not have a child after their breast cancer diagnosis and women of color and White women. The PI used ATLAS.ti version 7 to manage these data.

After establishing preliminary themes, the community advisory committee and all 17 interview participants were invited to separate sessions to discuss the findings. In the first group session with the community advisory committee, we reviewed 12 sexual and reproductive health-related themes and determined the four most relevant themes to explore further that aligned with the original intent of the study. The second group session was with the interview participants; four of the 17 attended, as well as two community advisory committee members. Participants' provided feedback on the phrasing of emergent themes confirmed by the community advisory committee and exemplary quotes, as well as shared additional insights on how the shared key findings resonated with their lives. The PI used the combined feedback to determine which themes resonated most and enhance the phrasing of the themes in order for the presented findings to be in alignment with what the participants identified as most important.

Findings

Details regarding the characteristics of the 17 study participants are provided in Table 1. The mean age at first breast cancer diagnosis was 38.6 years and mean age at the time of the interview was 45.8 years. All women had at least some college education. A majority were married or engaged ($n = 13$), had two or more children ($n = 11$), and never smoked ($n = 14$). Twelve women gave birth to all of their children prior to their breast cancer diagnosis, one had all of her children after diagnosis, two had children before and after their diagnoses, and two did not have any children. Ten women identified as White, non-Hispanic and seven women identified as women of color (i.e., five Black/non-Hispanic, one Asian, one Latina). Fourteen had invasive (Stages 1–3) breast cancer. Most women had a lumpectomy ($n = 12$), received chemotherapy ($n = 11$), did not receive breast reconstruction ($n = 12$), and received adjuvant endocrine therapy ($n = 14$). Two women experienced a breast cancer recurrence.

Four overarching themes emerged from these data highlighting the spectrum of un/met sexual and reproductive health needs identified by breast cancer survivors during a specific time in their life course (i.e., their postdiagnosis reproductive years). Despite commonalities, there were differences between women who did have/desired children and did not have a child after their breast cancer diagnosis, and between women of color and White women.

Theme 1: Limited Reproductive Health Information Received From Cancer Care Providers

Concordances.—The reproductive health information that a majority of the women received from their cancer care providers was limited and did not comprehensively address their concerns. Most women learned from providers that chemotherapy and adjuvant endocrine therapy treatment might impair their fertility or cause the early onset of menopause and were urged to avoid becoming pregnant. Although the women learned about what not to do, they did not receive sufficient advice about how to prevent pregnancy or manage menopause symptoms.

Pregnancy prevention.—Pregnancy prevention during breast cancer treatment was a particularly challenging issue for women who used hormone-based contraception methods prior to their breast cancer diagnosis. Their providers advised them against becoming pregnant at all or not during treatment. Yet, many of the women did not receive recommendations on which contraception methods to utilize, and there seemed to be an underlining assumption that their only option was condoms. When asked whether her cancer care providers recommended she use contraception, a survivor of color (age 45 at diagnosis; no children) responded, “No, the only thing he said was just don’t get pregnant right now.” When asked what type of contraception she uses, she said, “None really.” This woman was actively going through treatment, and other women had similar responses when asked about their contraception usage during and after treatment. Only one survivor who was White (age 40 at diagnosis; two children prediagnosis) shared that her provider suggested her husband receive a vasectomy. This was viewed as a suitable option for this woman as she had reached her ideal family size.

Alternative sources of information.—As reproductive health-related issues arose during their breast cancer journeys, the women felt their cancer care providers offered limited information and did not address their concerns. They relied on their obstetricians/gynecologists (OB/GYNs), support groups, Dr. Susan Love's Breast Book (Love & Lindsey, 2010), other breast cancer survivors, books on breast cancer, and the internet to fill the gaps in their breast cancer-related reproductive health education. The women felt that their OB/GYNs were better equipped to address their concerns that ranged from vaginal dryness to the pros and cons of hysterectomies. In addition, they valued conversations they had with other survivors as they directly experienced and understood their challenges. A White survivor (age 40 at diagnosis; two children prediagnosis) shared that her favorite resource was her support group:

> I guess because you're talking to people that have actually gone through it. Talking to a male doctor about hot flashes, it's not really—he's like, "Oh, yeah, it could happen 10 to 20 times a day," And I thought, "Oh, yeah, 'cause that's no big deal." Easy for him to say, 'cause he'll never experience anything like that. I find it more comforting to talk to other women that have been through it.

Although many women received advice to not conduct internet searches, some women felt that the internet was a more readily available resource than their cancer care providers. A White survivor (age 39 at diagnosis; one child prediagnosis) discussed her disagreement with discouraging breast cancer patients from using the internet:

> There wasn't just a ton of resources around … reproductive health in general, either on the fertility side or the sexual functioning side … So, I did a lot of my own research. And one of the things that I think has been so weird to me, … all the women are in the support groups, telling each other to stay off the Internet. I'm like, "Why are we telling each other to stay off the Internet?" Like that's where all the great information is. Yes, there's crap out there, but if you're a reasonably intelligent adult, you can filter through what's crap, what is one person's experience versus what is more valuable information I think. Anyway, so that drives me a little crazy about the culture of breast cancer; we're not supposed to be on the Internet. But going on the Internet helped me get a more balanced picture from different resources of what I might be looking at … More of the spectrum of that experience rather than, "Here's all the awful things that are probably gonna happen to you, so get ready."

In light of the limited reproductive health information from their cancer care providers, the internet became an accessible resource the women used to address their concerns.

Discordances.—There was some discordance by postdiagnosis birth status and race regarding fertility preservation options, cancer treatment decision-making, reproductive health information sources, and comfort level discussing reproductive health issues with providers.

Differences in fertility preservation and cancer treatment.—Women who desired to have children after completing cancer treatment, particularly women of color, more often chose the least invasive treatment options to preserve their fertility options post-treatment. One survivor of color (age 37 at diagnosis; two children postdiagnosis) received a Lupron shot to suppress her ovaries during treatment. Another survivor of color (age 45 at diagnosis; no children) sought out treatment from a cancer center that offered her the least invasive treatment route, so that she could preserve her fertility after the cancer center where she was diagnosed insisted on a more aggressive treatment approach. When asked about what she had learned about the potential effect of cancer treatment on her reproductive health, a survivor of color (age 40 at diagnosis; two children prediagnosis) responded,

> Overall is that it could kill your fertility issues. There were things that you could do definitely to preserve your fertility, but it just seemed like it would take away from—at the time your main focus is just taking care of the cancer, and it seemed like preserving your fertility just took time away from that in my mind. That’s why it kind of pushed it to the back burner.

She had undergone multiple fertility treatments prior to being diagnosed, knew the time and effort required, and therefore prioritized her cancer treatment over fertility preservation. Although some of the White survivors believed that young women should be presented with treatment options to preserve their fertility, none of these women personally chose less-invasive treatment options with the intent of preserving their fertility.

Sources and satisfaction with health information.—White women mentioned more often that they attended cancer center-sponsored support groups and workshops that shared sexual and reproductive health information. They also expressed a different level of dissatisfaction with this information. A White survivor (age 42 at diagnosis; two children prediagnosis) shared,

> It was only discussions at group about people that had concerns with intimacy or side effects of some of the drugs. Nothing specific was given to me. I just had exposure from the women around me, not from a doctor or a nurse.

Another White survivor (age 45 at diagnosis; one child prediagnosis) commented,

> I didn’t really have any counseling. The oncologist spoke with me about it, my [obstetrician] has, and then after treatment we had at least one class and they have them on occasion, in the [cancer center workshop series] that kind of talked about maybe not necessarily reproductive, but your intimacy and sexual intercourse after the treatment and that kind of thing. Not necessarily your menopause or ability to have children or any of that, but more of the fun part of it.

None of the survivors of color mentioned utilizing these cancer center resources. The survivors of color were more involved in community-based cancer support groups and one even established a local foundation for young breast cancer survivors. White survivors expressed how their cancer care providers did not seem comfortable discussing reproductive health topics and the sexual health information providers shared was disheartening. A White survivor (age 39 at diagnosis; one child prediagnosis) in active treatment stated,

> They gave me a book at the cancer center, which is a great book. It’s all about treatment and side effects, and there was a section about reproductive health and

> sexuality. And it painted a very dark picture, honestly. It was like, “Your libido is gonna go away. You’re not gonna be interested. You’re not gonna be capable.” I was like, “This is awful.” There was a very negative perspective.

When asked about her concerns regarding the effect of cancer treatment on her reproductive health, she shared,

> Yeah, that was one of my actually biggest concerns about the whole thing … my oncologist … he’s great. He actually draws pictures and writes everything down so you have something to take away. It’s really a wonderful approach. But he’s listing side effects and he’s like, “Hair loss and nausea, but here’s what we’re gonna do.” And I had to actually ask, “Is this gonna kick me into menopause?” … just wasn’t even brought up as a concern, like it was not as important. But I was super concerned about it. Anything that I’ve learned about what kind of impact is this going to have reproductively or sexually has just been independent study … And I just felt like there wasn’t good information about that. It’s hard to get the doctor to talk about it.

Although survivors of color recognized the limitations of the reproductive health information they received, none of them expressed the level of discontent that White survivors openly shared.

Theme 2: Women Desired Realistic Expectations of Conceiving Post-Treatment

Concordances.—The breast cancer journey made several women reflect on childbearing. Women who had completed their families were thankful they had reached their ideal family size prior to their breast cancer diagnosis.

Contentment among women with and without children.—A survivor of color (ages 29 and 37 at diagnosis; four children prediagnosis) reflected on her family size at initial diagnosis:

> Had I not had my tubes tied and had the kids, I definitely would’ve been concerned, and probably doing everything that I could to have kids, ‘cause that’s just something that was very important to me … I read people all the time that’s gone through cancer and still able to have children … I’m just thankful for the time that—you know, of course, I hate that I had to go through cancer, but thankful that I was able to complete my family, with my four, before I had to go through it.

Similarly, when asked whether the negative effects of breast cancer treatment affected her family completion goals, a White survivor (ages 28, 37, and 40 at diagnosis; one child pre-first and one child post-second diagnosis) responded,

> I don’t know. I think I told you last time I may have had another child if I hadn’t gotten cancer again. But like I said, I’m happy with what I have, and I feel blessed to be able to have them. So, I don’t really know how to answer that question, ‘cause it’s possible that I would have had another child, but I try not to think about it too much. You know? And I just, like I say, I’m a glass-half-full kinda girl. So, I’m just as happy, and I feel blessed that I have what I have.

Women who wanted but were not able to have children after their treatment made peace with their circumstances. A survivor of color (age 40 at diagnosis; no children) articulated,

> My journey is an ongoing journey and I don't regret anything that I have been through my journey, even though it is to the point that I will never, ever be able to have children. I am okay with that; I came to an agreement and an understanding and it is okay, because I have other kids that I can love like my nieces and nephews and godchildren.

Even when coming to terms with not being able to bear any more children after completing treatment, some women still felt remorseful of this situation.

Recognizing end of childbearing years.—When asked whether being diagnosed with breast cancer influenced her ideal family goals, a White survivor (age 40 at diagnosis; two children prediagnosis) exclaimed,

> It didn't, but I do remember it making me think I guess. I mean I thought I was done anyway, but you know what I mean? I don't know how to explain it, but at 40 people do have babies in their 40s. So, I mean yeah I guess I thought about it, but luckily I had my two boys, and they were what I wanted. Yeah it just made it more final I guess. It just made me think about the fact that that door was closed, whereas before it wasn't closed. I mean it was closed by me I guess mentally, but it wasn't totally closed. I mean you think about a lot of stuff when you're going through cancer. So it was just one of the things.

A few women remained hopeful that they would be able to conceive after treatment. One survivor of color (age 45 at diagnosis; no children) said,

> Well, ideally I wanted to have two children, a boy and a girl, but I do come from a large family, so my thing was whatever I was blessed with, that's what I would do. But ideally, that was my desire and I still have not totally given up on that. Even though right now while I'm on the Zoladex and Anastrozole, the doctor says not to get pregnant because that could be potentially harmful for a fetus and with all of the other stuff that I'm taking, they don't know. So right now, I'm not actively trying to conceive, but that was one of the things early on that we had talked about that… I wanted to preserve that option because even though I recognize with my age that it presents some health risk for my age… And it has been posed to me to look into adoption, but I won't say it hasn't crossed my mind, but that's not my desire right now. I wanted to at least leave the possibility open to preserve that, so that's my right to choose whether or not to do that.

Some women hoped to conceive after treatment, but the combined reality of their advancing age and potential effect of the treatment on their reproductive health made them face the inevitability of their reproductive years coming to an end even though it was earlier than anticipated.

Discordances.—The time of treatment is a crucial decision-making period, particularly for women who desired to conceive after the completion of their treatment. Among the women who desired to conceive or did bear children after treatment, there were distinct differences in how the survivors of color versus the White survivors discussed their challenges conceiving.

Differences in information about pursuing pregnancy.—Survivors of color reported a lack of guidance from their providers on how long they should wait after treatment before trying to conceive. One survivor of color (age 37 at diagnosis; two children postdiagnosis) decided she would try to conceive 6 months after completing treatment, although it is typically recommended that women with breast cancer wait 2 to 3 years after diagnosis to conceive (Camp-Sorrell, 2009; Hickey et al., 2009). Reflecting on the birth of her first child post-treatment, she said,

> I was surprised, actually, how easy I conceived our daughter. ‘Cause I was—I don’t know, I just think that—You know, I wasn’t very young; I was 38. I just thought it was gonna take—it’s going to take a while. But I think—yeah, I think we—I got pregnant after a couple of months.

She had Stage 1 breast cancer and her oncologist did approve of her becoming pregnant but was more concerned about her age than her breast cancer status in regard to her pregnancy outcomes. A different survivor of color (age 40 at diagnosis; no children) was unsuccessful in reaching her childbearing goals after treatment. Although she had in situ breast cancer, her treatment included multiple biopsies and four breast cancer-related surgeries all in 1 year. The following year, she was diagnosed with multiple uterine fibroids, which resulted in a hysterectomy. It was then she knew that her “chances of giving birth [where] no more.” She and other women discussed how they were not emotionally prepared for losing their capability of conceiving after treatment. This reality was particularly challenging for women who did not have any children.

One White survivor (age 33 at diagnosis; one child pre- and one postdiagnosis) experienced both the benefits of provider support and challenges with provider discouragement in regard to becoming pregnant after treatment. She was the only woman to report that her oncologist fully educated her about reproductive health and fertility options even though she told him that she was not planning on having any more children. Regarding the information she received from her oncologist, she stated,

> I think it was great. I mean not useful because we weren’t planning to have children, okay. So, I mean I don’t want to say I used the information. But when I got pregnant, I was like, “Oh my goodness, I remember what he said. This could be really bad.” And so I saw a specialist because of the cancer … and so me and my husband just talked about it. If something was wrong with the baby, what would we do, and that’s ‘cause we remembered everything he said.

What she learned from her oncologist prompted her to seek the proper care during her pregnancy and her oncologist was very supportive and happy for her once she became pregnant. However, once she was under the care of OB/GYN specialists the provider support ceased. She stated,

> Because of my age, cancer, and then right away, like as soon as I found out I was pregnant I went to the doctor. They gave me that gestational diabetes test; I failed

> it right then and there … Like I was diabetic; it was terrible. The lady said to me …, “The chances of this being successful for you and the baby are very small.” She was just like, “By 32 weeks, I expect to have you induced, in the hospital, and having a premature baby … You’ve just gone through cancer treatment, so your body has been chemo-infused. I don’t know how strong your body overall, if it can even carry a baby that long.” And she’s like, “You already have gestational diabetes, which means the baby’s probably going to be fairly large, and I don’t think you’re going to be able to carry.” And so I left that doctor’s office just pure crying my eyes out. I went home, I told my husband …, “I’m just not going to be able to carry this baby. She’s going to die. She’s going to come out sick.” And I made it 39 weeks. Absolutely healthy.

Her OB/GYN team painted a discouraging picture of what to expect during her pregnancy. She hoped these providers learned from her situation that it is possible for breast cancer survivors to have healthy babies. Once she had her child and went back to her cancer providers for check-ups, she experienced additional challenges as a lactating patient. She shared,

> … the whole pregnancy, lactation, breast cancer thing, they had no experience with. “We’ve not had lactation patients in here. This does not happen.” They weren’t against it, but I just think it was so out of—they didn’t know what to do. They were blushing … Like the one doctor, the surgeon, didn’t want to do the mammogram; he just did an ultrasound for the first year … He wouldn’t even touch it. He was, “It’s working.” I mean he was like just, “Cover up. Do you need more paper towels?” … and then when they palpate the breast, they don’t know the difference between a lactating with all the milk ducts full, so to them, it does not feel like an okay breast. And that’s because they’re not used to feeling one that has got the full milk ducts in it. So, I mean the lack of experience on that, and everyone was like, “I don’t know what to do; I’m sorry.”

Her cancer care providers’ lack of comfort examining a lactating patient made for an awkward situation that negatively influenced her relationship with these providers.

Women who desired to have children or were in their prime reproductive years needed support from their cancer care providers and OB/GYNs to successfully attempt and carry out their post-treatment pregnancies. Furthermore, they desired a more comprehensive and balanced depiction of their ability to successfully conceive after treatment. A focus on the potential negative outcomes did not provide a sense of encouragement or hope to women who had already survived breast cancer, but still wanted to bear children.

Theme 3: Women Struggled With Adjusting to Altered Physical Appearance

Concordances.—There was a general consensus among the women’s stories that breast reconstruction did not meet their expectations and they struggled with adjusting to their altered physical appearance.

Dissatisfaction with breast reconstruction.—Many of the women felt that the implants could never be satisfactory replacements for the breast(s) they lost. A White survivor (age 42 at diagnosis; two children prediagnosis) reflected on her breast reconstruction process and stated,

> …you don't feel like yourself there after the implants. You know. And especially during the expander part, it feels very foreign and they're very hard. And every time you breathe, it's a reminder that there's something fake going like this every time you breathe. And then they put the implants in, and it's much better, but it still doesn't feel like you used to.

After undergoing breast reconstruction and living with the results, some women regretted getting implants. A survivor of color (age 34 at diagnosis; one child prediagnosis) shared,

> Sometimes I say if I could go back and change some things about my journey, that may have been one of the things that I would've done, is just kind of let it be … because there's so many prosthesis and apparatuses … Just like you can't look at me today and tell, I don't think anybody would've been able to look at me and tell otherwise either.

The widespread dissatisfaction with breast reconstruction was centered in the women not being well prepared about what to expect from their new implants. It seems they wanted clear expectations to be set by their cancer care providers about the breast reconstruction process. One White survivor (age 42 at diagnosis; two children prediagnosis) even sought out this information from her providers and obtained a picture series of the reconstruction process (from postoperation through the healing process) that a breast cancer patient created and published. However, information of this caliber is not widely available, and some complained that even information on the internet was tilted toward negative experiences of breast reconstruction.

When asked about her satisfaction with her reconstruction results, a White survivor (age 42 at diagnosis; two children prediagnosis) exclaimed, "Well, I'm happy enough. I came to the point where I thought my life, my boobs, and my life was so much more important than the other." Despite having regrets about undergoing breast reconstruction, some women came to terms with their altered physical appearance.

Discordances.—Although both survivors of color and White survivors expressed dissatisfaction with breast reconstruction, there are differences in how they coped with their altered bodies.

Difficulties achieving ideal breast reconstruction.—Both survivors of color and White survivors received follow-up surgeries to repair issues with their breast implants. Yet, only one White survivor (age 42 at diagnosis; two children prediagnosis) went through multiple surgeries to achieve her ideal symmetrical breasts. She was ultimately satisfied because she was able to regain breast sensation despite the plastic surgeon setting low expectations about it. A survivor of color (age 40 at diagnosis; two children prediagnosis) who completed follow-up surgeries to fix issues with her implants drew the line at getting nipples:

> After the last reconstruction, my doctor was like you know … you can come back and we can do nipples and blah, blah, blah. I was like I do not care about nipples. Do not talk to me about nipples; I will not be coming back for nipples. [Laughs] And so you know of course it doesn't look normal, but even with nipples it wouldn't look normal to me because it's so manmade you know.

Several women shared they did not get nipples for similar reasons. They did not want to endure the additional procedure that ultimately would not improve the appearance of their implants.

Post-breast reconstruction body image issues.—Some women struggled with their altered physical appearance. Survivors of color complained the most about scarring and residual pain from stomach or back flaps used to construct their new breasts. In fact, only survivors of color shared that it was difficult for them to look at their undressed bodies in the mirror. A survivor of color (age 34 at diagnosis; one child prediagnosis) shared,

> Nothing is ever like what God gave you. Today I can say that I'm good and I'm happy with it, but initially, I mean it takes some getting used to. Initially I would go in the bathroom and put the towel over the mirror into my shower and this is how I would do. Today I can say I'm good with them, I'm good without them.

Although many of the women reached a point of acceptance of their new physical appearance, it was evident that the implants could never replace the breasts they lost.

Alternatives to breast reconstruction.—Most of the women who had a mastectomy also received breast reconstruction. However, a couple of White survivors shared that they did not undergo reconstruction. When asked why she decided not to have breast reconstruction after her unilateral mastectomy, a White survivor (age 40 at diagnosis; two children prediagnosis) stated,

> I don't want any more major surgeries that I don't have to have. I keep thinking someday there's going to be an easier better solution as things progress. Somebody the other day mentioned the 3D printing, you know how they're printing like ears, and whatever, and they're like why couldn't they do that. That's what I'm going to wait for. You know somebody is going to print a breast. Yeah I'm in no hurry.

Some of the women who did not receive breast reconstruction wore prostheses and others chose not to. They seemed to be more comfortable with their altered physical appearance, and like many of the women, they realized their breasts did not define their womanhood.

Theme 4: Menopause Symptoms Led to Sexual Health and Quality of Life Issues

Concordances.—A majority of the women experienced menopause symptoms induced by chemotherapy, adjuvant endocrine therapy, or postcancer hysterectomies that affected their sexual health and quality of life. The women discussed typical menopause symptoms, such as hot flashes, vaginal dryness, low libido, and weight gain, while others suffered from less common side effects, such as neuropathy, vision impairment, and tear duct damage.

Challenges with menopause symptoms and sexual activity.—Some women welcomed the early onset of menopause and found ways to successfully manage side effects. A survivor of color (age 45 at diagnosis; one child prediagnosis) shared,

> … women say you go through changes. Yes, I had the hot flashes. They weren't fun, but you learn to deal with them. I found out exercising helped some. And doing certain types of exercise, like yoga or breathing exercises—but it's just—you just have to be proactive and find these things and ask questions. And eating. You have to make sure you're eating—eating right.

Finding ways to manage symptoms made it easier for some women to embrace menopause. However, women with partners, especially those who had hormone receptor-positive tumors, found it challenging to find solutions for low libido and vaginal dryness. Many over-the-counter and prescription products available to combat vaginal dryness contain estrogen, which women with hormone receptor-positive tumors are discouraged from using. Furthermore, they found it difficult to engage their providers in discussions about sexual health and intimacy issues. When asked what reproductive health information she wished she had received prior to beginning treatment, a survivor of color (age 40 at diagnosis; two children prediagnosis) responded,

> I guess more so on the effects of treatment on your actual sexuality and desires and what to do. They kept telling me, "Well, there are things we can do. There are things we can do." But I don't feel like I ever got much information on what those things were after the fact. I have since gotten one—or tried one thing and it hasn't worked very well for me, so I just wish that all that had been given.

She and other survivors desired solutions to address their sexual health issues and they did not receive adequate medical counseling or support in this area. Several women feared the challenges ahead with maintaining intimacy with their partners long term as they experienced physical and emotional discomfort when engaging in sexual activity. A White survivor (ages 28, 37, and 40 at diagnosis; one child pre-first and one child post-second diagnosis) shared,

> So, I've had some problems with the dryness and, I guess, the lack of estrogen in my body—it's a problem. You know? So, I do not have sex as much as I used to. But I still do … Thankfully, my fiancé's very understanding about the whole thing.

Fortunately, many women had supportive partners that understood the toll of treatment on their bodies and how their sexual activity may be limited or changed due to menopause symptoms.

Discordances.—Although both survivors of color and White survivors experienced challenges managing treatment side effects, there were differences in their main complaints.

Weight gain and survivors of color.—Survivors of color described their issues with excessive weight gain once they began adjuvant endocrine therapy and started experiencing menopause symptoms. One survivor of color (ages 29 and 37 at diagnosis; four children prediagnosis) stopped taking a medication for menopause symptoms because she felt it was causing her weight gain. She utilized nonpharmaceutical methods to manage her symptoms.

After her providers said there was nothing that could be done about her excess weight, another survivor of color (age 40 at diagnosis; no children) accepted her 30-pound weight gain as a side effect of adjuvant endocrine therapy and remained hopeful she would shed the extra weight once she stopped the treatment in the coming year.

Unexpected side effects and White survivors.—A few White survivors discussed the unexpected side effects of adjuvant endocrine therapy. Two White survivors participated in clinical trials where they consumed double doses of adjuvant endocrine therapy, such as Tamoxifen, for short bouts of time. Both women reported developing a serious health issue that they felt resulted from this intensified treatment. These health issues included benign uterine/ovary growths and long-term tear duct impairment. Other White survivors experienced neuropathy and vision impairment that may have been induced by chemotherapy and adjuvant endocrine therapy. These types of long-term health challenges caused by their cancer treatment ultimately affected their quality of life.

Recommended Services and Resources for Premenopausal Breast Cancer Patients

In addition to exploring their breast cancer experiences and reproductive needs, we asked the women what types of information young breast cancer patients should receive about sexual and reproductive health. The types of information they felt were necessary to deliver to young patients included (a) picture diary of the breast reconstruction process from mastectomy surgery through the postreconstruction healing phase and (b) potential effect of cancer treatment on sexual and reproductive health and pregnancy outcomes. Women with strong family histories of breast cancer felt providers should be more forthcoming about the increased risk of breast cancer associated with birth control use, so young women can make informed decisions about their contraception use. In addition, the women wanted providers to raise breast cancer patients' awareness about the ability for them to conceive after treatment and genuinely support their patients' decisions to pursue pregnancy. They wanted to know the risks associated with bearing children after completing treatment, but they also desired to be given the full spectrum of options for conceiving children and the possible pregnancy and birth outcomes (i.e., not just the potential negative outcomes). Overall, the women felt that sexual and reproductive health information should be reiterated at various time points throughout breast cancer patients' care.

Discussion

In an effort to learn more about the sexual and reproductive health needs of women with a breast cancer history, we interviewed women diagnosed at or before the age of 45 who did and did not have children. This research was guided by Lu and Halfon's (2003) life course health development model and the healthy mother effect bias theory, which helped us identify key aspects of young breast cancer survivors sexual and reproductive health needs from diagnosis into survivorship. Our examination of their expressed needs revealed important information about postdiagnosis birth status and racial concordances and discordances in these women's experiences, and recommendations for improving sexual and reproductive health counseling for young breast cancer patients.

First, women are not receiving sufficient breast cancer treatment-related reproductive health information from their cancer care providers. Women are relying on the internet, their OB/GYNs, and support groups to address their concerns and find it difficult to discuss sexual and reproductive health concerns with male oncologists, in particular. Second, they desire realistic expectations about their ability to conceive after treatment and for providers to support their decisions to become pregnant if they are healthy and able. Third, some women regret undergoing breast reconstruction and struggle with accepting their new bodies, while others found ways to accept the physical changes to their bodies by reevaluating the importance of physical appearance in their lives. Finally, they learned to manage some treatment-induced menopause symptoms, but are not receiving sufficient support in resolving sexual health issues that have resulted from the early onset of menopause.

The experiences shared by these women were more similar than different, yet it is important to acknowledge how various subsets of women may have sexual and reproductive health needs and concerns that diverge from what is considered the norm. A previous study that explored how young breast cancer survivors' values about conceiving after treatment influenced their treatment decisions compared the experiences of subgroups of survivors (e.g., women who did vs. did not have children after treatment), but they did not find any significant differences and only presented the joint findings (Gorman et al., 2011). In contrast to Gorman et al.'s (2011) finding that their participants (85% White) chose more aggressive treatment approaches as they were motivated by survival and preventing recurrence, our study found that women who desired to conceive after treatment were more likely to choose the least invasive treatment route, especially the survivors of color.

A majority of women in these studies (81%–100%) were White breast cancer survivors (Avis et al., 2004; Gorman et al., 2011; Halley et al., 2014; Knobf, 2002), except for one study that included only Black women (Lewis et al., 2012) and another study where 50% of the participants were women of color and 50% were White (Ginter & Braun, 2017). The racially homogeneous populations recruited for most of these studies did not allow for racial differences in experiences to be examined or they did not analyze their data by race. Ginter and Braun (2017) discussed how breast cancer patients who were not in intimate relationships feared that their post-treatment bodies would ultimately influence their future relationship prospects and interactions. This study included a racially diverse group of women, but their findings were not reported by race. Lewis and colleagues (2012) found that Black women seemed to report more severe issues with intimate relationships, distress with their fertility, and more often lacked information on sexual dysfunction after breast cancer compared with White women in other studies. In our study, compared with White survivors, survivors of color were the only ones to report receiving ovary suppression shots to assist in the process of preserving their fertility during their treatment. They also shared more about struggles with body image disturbance and how they had to work on accepting their physical appearance after treatment. Unlike the White survivors, survivors of color discussed weight gain as a major side effect from adjuvant endocrine therapy or menopause. The White survivors felt the information they received painted a bleak picture of their sexual and reproductive health outcomes, which was discouraging. Only White survivors shared that they did not get breast reconstruction, participated in adjuvant endocrine therapy clinical trials, and experienced nonreproductive health-related side effects of breast cancer treatment that affected their quality of life (e.g., neuropathy, vision impairment, tear duct damage).

The literature examining the sexual and reproductive health needs of women with a breast cancer history in the United Studies is limited but has garnered more attention over the past few years. Some of our study findings align with the previous literature and reinforce that young women with a breast cancer history are concerned about sexual dysfunction and body image (Avis et al., 2004); found it difficult to discuss sexual and reproductive health issues with their providers (Sankila et al., 1994); felt that cancer care providers were dismissive of or not knowledgeable about how to address their sexual and reproductive health concerns (Halley et al., 2014; Knobf, 2002); and had to conduct their own research and speak with other breast cancer survivors to learn more about treatment-related reproductive health issues (Gorman et al., 2011). A strength of this study is that we recruited a diverse group of women with a breast cancer history, so that comparisons could be made based on postdiagnosis birth status and race. Our engagement of breast cancer survivors and advocates in various aspects of the study, including the development of recruitment materials and interview guide, as well as feedback on the themes and illustrative quotes prior to disseminating the findings, further strengthened our findings.

The main limitations of this work pertain to the recruitment sources. We recruited a majority of the women via cancer center-supported and community-based breast cancer support groups located in a major metropolitan area in NC and most of these women received care from the same regional cancer center. The resources available at this one facility may vary from other cancer centers in NC. This may explain some of the differences in participants' access to cancer center–sponsored workshops that covered sexual and reproductive health topics. The experiences of the women interviewed did partly depend on the providers and resources available to them at their given cancer centers. Recruiting women from a range of cancer centers in NC may have increased the diversity of women we interviewed. Future studies on this topic would benefit from recruiting from a range of cancer centers and within rural communities. Despite limitations, this study provides a strong methodology that can be replicated and a basis for comparison with a more diverse sample.

Women with a breast cancer history are in need of and desire more education and resources to address their sexual and reproductive health concerns. Young patients would greatly benefit from receiving reproductive health counseling and access to resources to address their concerns during the breast cancer treatment phase and beyond. Additional resources outside of the services currently offered by cancer care centers are needed. Offering regularly scheduled workshops in the cancer center that cover sexual and reproductive health topics, as well as having designated reproductive health specialists available may be useful resources and safe spaces for women, especially those who are not comfortable discussing such topics with their cancer care providers. In addition, providing trustworthy websites that discuss and provide solutions for breast cancer patients' sexual and reproductive health concerns may be another welcomed resource. It may also be beneficial for cancer centers within larger health care systems to partner with their OB/GYN departments to develop useful approaches for jointly supporting breast cancer patients with sexual and reproductive health concerns or that desire to conceive after completing their treatment.

Furthermore, when implementing sexual and reproductive health-focused interventions for young breast cancer survivors, it is vital to design interventions that meet the specific needs of subpopulations based on race and desire to conceive post-treatment, as indicated by our findings. Overall, the sexual and reproductive health needs and concerns of young breast cancer survivors deserve more attention as an important quality of life and survivorship issue.

Acknowledgments

This study would not have come to fruition without the contributions of several key people and organizations. We will forever be grateful to the wonderful women who shared their time and stories with us and allowed us to interview them about very sensitive topics. We would not have been able to recruit these women without particular organizations in North Carolina that connected us with their members, including Sisters Network, Inc. (Greensboro and Triangle chapters), young breast cancer support groups at local cancer centers, and local foundations for young breast cancer survivors. Thank you for your support!

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the University of North Carolina at Chapel Hill Lineberger Comprehensive Cancer Center University Cancer Research Fund (to K.Z.B.) and Health Resources and Services Administration MCH Epidemiology Training Program (Grant No. 2-T03-MC07643-04 to K.Z.B.).

Biographies

Kristin Z. Black, PhD, MPH, is an Assistant Professor in the Department of Health Education and Promotion at East Carolina University in Greenville, North Carolina. Her career commitment is to utilize community-based participatory research, mixed methods, and racial equity approaches to understand and address inequities in chronic disease and reproductive health outcomes.

Eugenia Eng, DrPH, is Professor of Health Behavior at the Gillings School of Global Public Health, University of North Carolina at Chapel Hill. Her research and teaching focus on the community-based participatory research approach to understand and enhance race-specific equity in health outcomes through system change.

Jennifer C. Schaal, MD, is a trainer and organizer with the Racial Equity Institute based in Greensboro, North Carolina. She is a retired Ob/Gyn who has worked in community-based participatory research based on a racial equity analysis for 17 years.

La-Shell Johnson, MA, is a Faculty Instructor/Program Coordinator for the National Center of Excellence for Eating Disorders (NCEED), housed at the University of North Carolina at Chapel Hill. Her work focuses on providing knowledge and education to healthcare providers and the general public on eating disorders, and her previous research focused on improving cancer survivorship care by providing peer support and information on self-care.

Hazel B. Nichols, PhD, is an Associate Professor of Epidemiology in the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. Her research is focused on improving cancer care by providing epidemiologic evidence to guide personal and medical decision-making around cancer risk and survivorship.

Katrina R. Ellis, PhD, MPH, MSW, is an Assistant Professor at the University of Michigan School of Social Work. Her research centers around supporting the health of families facing multiple, coexisting illnesses, with a specific focus on African Americans, cancer, and chronic disease.

Diane L. Rowley, MD, MPH, is Professor Emeritus in the Department of Maternal and Child Health, Gillings School of Global Public Health at the University of North Carolina at Chapel Hill. She is a medical epidemiologist whose research focuses on disparities and inequities in pregnancy and infant health outcomes, and she collaborated with others to develop a theoretical approach to research and evaluation of health inequities among African American populations.

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Table 1.

Characteristics of 17 Young Women With a Breast Cancer History at Time of Interview.

Demographic Characteristics	***N* or *M (SD)***
Education	
Some or graduated college (13–16 years)	10
Professional/graduate degree (≥17 years)	7
Marital status	
Married/engaged	13
Divorced	3
Single/never married	1
Parity	
Nulliparous (0 births)	2
Primiparous (1 birth)	4
Multiparous (≥2 births)	11
Birth of child(ren) relative to breast cancer diagnosis date	
No births	2
Birth(s) occurred before diagnosis	12
Birth(s) occurred after diagnosis	1
Birth(s) occurred before and after diagnosis	2
Race/ethnicity	
White, non-Hispanic	10
Black, non-Hispanic	5
Other	2
Smoking	
Never smoked	14
Former smoker	3
Stage[a]	
Stage 0 (in situ)	2
Stage 1	4
Stage 2	7
Stage 3	3
Unsure	1
Hormone receptor status[a]	
ER+/PR+	9
ER+/PR−	4
ER−/PR−	1
ER−/PR−/HER2− (triple negative)	3
Treatment type[a,b]	
Lumpectomy	12
Unilateral mastectomy	3
Bilateral mastectomy	4
Chemotherapy	11

Demographic Characteristics	***N* or *M (SD)***
Radiation	12
Breast reconstruction	5
Adjuvant endocrine therapy	14
Breast cancer recurrence	
1 breast cancer diagnosis	15
2 or more breast cancer diagnoses	2
BRCA mutation	
No	12
Yes	1
Variants of unknown significance	1
Not tested	3
Time since diagnosis[a]	
<1 year	2
1 ≤ years < 5	6
5 ≤ years < 10	4
≥ 10 years	5
Age at diagnosis (in years)[a]	38.6 (5.0)
Range	28–45
Age at time of interview (in years)	45.8 (7.2)
Range	37–64

Note. ER = estrogen receptor; PR = progesterone receptor;

HER2 = human epidermal growth factor receptor 2

[a] Refers to participant’s first breast cancer diagnosis.

[b] This column does not add up to 100% since a participant may be included in >1 category based on their treatment regimen.