

# A qualitative investigation of breast cancer survivors' experiences with breastfeeding

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## Abstract

**Introduction** This is an exploratory, qualitative investigation of breast cancer survivors' experiences with breastfeeding. Previous studies have focused on the physiology of lactation after surgery and treatment, but have not explored factors influencing breastfeeding decisions and behavior.

**Methods** We used purposeful sampling to identify 11 breast cancer survivors who had a child after their diagnosis and treatment. Participants were recruited from among those in the Women's Healthy Eating and Living (WHEL) study and a Young Survival Coalition (YSC) affiliate. We conducted semi-structured, open-ended telephone interviews lasting 45–75 min. We used social cognitive theory (SCT) to structure questions regarding influences on breastfeeding behavior. We transcribed interviews and used cross-case, inductive analysis to identify themes.

**Results** Ten of 11 participants initiated breastfeeding. The following main themes emerged: 1) Cautiously hopeful, 2) Exhausting to rely on one breast, 3) Motivated despite challenges, 4) Support and lack of support, and 5) Encouraging to others.

**Discussion/Conclusions** Study participants were highly motivated to breastfeed but faced considerable challenges. Participants described problems that are not unique to women with breast cancer, but experienced these to a much greater degree because they relied mostly or entirely on one

lactating breast. This study revealed a need for improved access to information and support and greater sensitivity to the obstacles faced by breast cancer survivors.

**Implications for cancer survivors** Results of this qualitative analysis indicate that interventions to support the efforts of breast cancer survivors who are interested in breastfeeding are warranted. Additional research would aid in the development of such interventions.

**Keywords** Breast cancer survivors · Breastfeeding experience

## Introduction

Personal, cultural, social and environmental factors influence women's decisions regarding initiation and duration of breastfeeding [1]. Women previously treated for breast cancer face a unique set of physical and emotional factors that might impact their decisions and ability to breastfeed. Breastfeeding after breast cancer treatment might be possible, although some surgeries and treatments can eliminate or reduce the chances of lactation [2–5]. Breastfeeding can be fraught with anxiety and breast cancer survivors, like many other women, need information and support to help them succeed [6, 7].

Even though breastfeeding might be possible for many breast cancer survivors, lactation can be restricted. Several studies have reported on the ability to lactate after breast cancer surgery and treatment [3, 4, 8–10]. Surgical characteristics, such as proximity of the incision to the areola and nipple, and dose and type of radiotherapy might affect lactation [5]. In an early study of breastfeeding behavior among breast cancer survivors, 1 of 11 patients successfully breastfed from the treated breast after surgery and radiotherapy and most women successfully breastfed

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from the untreated breast [3]. In another, 34% of women who had a child after radiation therapy lactated and about a quarter successfully breastfed from the treated breast [4]. In a more recent retrospective study of 21 patients where 22 breasts were analyzed, lactation occurred in about half of breasts, did not occur in about 40% and was unknown in the remainder [8].

Beyond the physiological ability to lactate, research on breast cancer survivors' experiences with breastfeeding is sparse. In one qualitative study, young breast cancer survivors wanted to breastfeed, but had anxiety and concerns about doing so [7]. In particular, participants were worried about the potential difficulty of detecting breast cancer recurrence [7]. Other researchers have also noted this [11, 12]. Other influences included social expectations about breastfeeding, convenience, desire to experience breastfeeding, and benefits for the infant. Social expectations about breastfeeding might also lead women to feel conflicted if they are unable or choose not to breastfeed [7].

There is evidence that breastfeeding is protective against incident breast cancer [13–15]. However, there are no epidemiological data regarding breastfeeding after breast cancer. The relationship between prior duration of breastfeeding and risk of second primary cancer is not significant [16]. Although there is no evidence that breastfeeding after breast cancer is either harmful or beneficial with regard to breast cancer risk, the benefits of breastfeeding to the newborn and mother are well-established [17]. Current research suggests that breast cancer survivors who wish to breastfeed should be encouraged and supported in their efforts [6, 18–20].

There are an estimated 250,000 women under the age of 40 currently living with breast cancer [21]. Women in this younger group are more likely than older survivors to be interested in having children and possibly breastfeeding [22]. Previous studies suggest that lactation after breast cancer treatment is possible but do not explore the factors influencing breastfeeding decisions and behavior. Given the established benefits of breastfeeding for all women, it is important to learn more about the factors that support breastfeeding as well as potential challenges faced by breast cancer survivors. This information will benefit practitioners as well as researchers interested in developing interventions to support the efforts of women who wish to breastfeed after breast cancer.

## Methods

### Study design

We used an exploratory, qualitative research approach to investigate breast cancer survivors' experiences with

breastfeeding. Qualitative research provides in-depth and contextual information that cannot be obtained from quantitative research alone [23]. This approach allowed us to explore the context and meaning of women's experiences and motivations around breastfeeding. The study protocol was approved by both the University of California San Diego and San Diego State University.

### Sampling and eligibility criteria

Participants were recruited from the Women's Healthy Eating and Living (WHEL) study ( $N=3088$ ). The WHEL study is a multi-site randomized controlled trial to evaluate the effectiveness of a high-vegetable, low-fat diet to reduce recurrence of breast cancer and early death. Participants included those diagnosed with Stage I, II or IIIA invasive breast cancer within the previous 4 years. Participants were enrolled between 1995 and 2000. The average age at study entry was 53.3 years and 376 (12.2%) of participants were 40 or younger at diagnosis. Over 85% of the study population was Caucasian. Approximately 45% of the sample was diagnosed with Stage II breast cancer, 40% with Stage I, and less than 15% with Stage IIIA disease. Women who were pregnant were excluded. Other inclusion and exclusion criteria for WHEL are extensive and described elsewhere [24]. From among all WHEL study participants, we identified 28 survivors who: 1) had a live birth after the time of their diagnosis and treatment and 2) agreed to be contacted in the future during their exit interview. All women were age 40 or younger at the time of diagnosis. To broaden the study population, we made an announcement through the local YSC affiliate. Five women agreed to participate and one of those had a child after breast cancer and provided information about breastfeeding.

We used purposeful sampling to identify breast cancer survivors who had a child after their diagnosis and treatment. Among WHEL participants, we aimed to include those who had a lumpectomy as well as those who had a mastectomy involving one breast. This strategy was chosen to identify a representative group of young breast cancer survivors who would be able to provide rich, in-depth information on the interview topics, including their unique experiences with breastfeeding. The final sample size was determined by informational considerations; the sampling ended when saturation had been reached and no new information was provided by participants [25]. The final sample included 11 participants. Table 1 outlines participant characteristics.

### Interviewing and data collection

The interviewer first contacted potential WHEL study participants via telephone. We attempted to contact 15

**Table 1** Characteristics of study participants ( $N=11$ )

Characteristics	Breast cancer survivors
<b>Age at diagnosis (years)</b>	
30 or younger	5
31–34	4
35–40	2
<b>Education</b>	
Some college	4
College graduate or higher	7
<b>Ethnicity</b>	
White	11
<b>Cancer stage at diagnosis</b>	
Stage I	3
Stage II	8
<b>Surgery</b>	
Lumpectomy	7
Mastectomy	4
<b>Treatment</b>	
Adjuvant chemotherapy	9
Radiation	8
Antiestrogen use	4

participants who had a child after their cancer diagnosis and were able to reach 11 of those. Ten agreed and completed the interview and one declined. The interviewer described the study briefly and completed oral informed consent for those who were interested. The participant from the YSC contacted the study directly to participate. All participants completed one telephone interview between February and March, 2008. Interviews lasted 45 to 75 min. With participants' permission, we recorded the telephone interview.

We used a semi-structured interview guide, which included questions about fertility after breast cancer, experiences with pregnancy and postpartum, and experiences with breastfeeding, including facilitators and barriers. The interview guide was informed by existing research on factors influencing breastfeeding behavior, including sources of support [1]. We used social cognitive theory (SCT) to structure questions regarding individual- and environmental-level factors that might have influenced breastfeeding behavior. SCT provides a framework for understanding the reciprocal influence between individual factors (e.g. cognitive and physiological), environmental factors, and individual behavior [26, 27]. In particular, we focused on two environmental-level factors, health care providers and partner/spouse, and two individual-level factors, outcome expectations and outcome expectancies. Outcome expectancies refer to the values placed on a

particular outcome, such as the value of breastfeeding. Individuals are expected to behave in a way that maximizes the valued outcome. Outcome expectations refer to the anticipated outcomes that guide a person's behavior [26, 27]. Breastfeeding specific questions from the interview guide are outlined in Table 2.

## Analysis

We transcribed all interviews verbatim and used cross-case analysis to identify themes, combining answers from all participants and using these grouped answers to analyze responses [23]. First, we examined data by theme/topic following the interview guide to identify facilitators and challenges to breastfeeding. We then used inductive analysis to identify themes, sub-themes, and patterns in the data. Although SCT helped identify internal and external influences on breastfeeding behavior, we did not restrict our analysis to SCT constructs. We used the following steps for qualitative data analysis: 1) Reading and re-reading qualitative data to become familiar with the text and begin developing codes; 2) Coding data to begin developing themes and sub-themes; 3) Displaying details of categories and themes (e.g. identifying variations of each theme, noting differences between individuals and among sub-groups, exploring nuances in text); 4) Reducing data to essential points; and 5) Developing an overall interpretation based on this process [25]. This process was iterative and continued as we collected data. We imported the transcripts into the QSR NVivo 8 software package [28] to code, sort and analyze the data.

The PI conducted all interviews and was responsible for coding and identification of themes, using continuous coding as new data were collected in order to identify and resolve potential gaps in questions as well as potential biases. Through this process, several consistent themes emerged. In the final step, the PI re-read the interviews and evaluated the coding categories to ensure that the meaning and intent of the participant comments was captured accurately.

## Results

### Study participants

This study includes 11 younger breast cancer survivors who had at least one child after their breast cancer treatment and did not have a bilateral mastectomy. Participants were diagnosed at Stage I (27%) or Stage II (73%) breast cancer between the ages of 27 and 36 (average age 31.7 years). Prior to diagnosis, four participants (36%) had one or more

**Table 2** Semi-structured interview guide on breastfeeding**Breastfeeding prior to breast cancer**

1. Were any of the children that you had before your breast cancer diagnosis breastfed or fed breast milk? If yes, how many?
2. How old was the (first/second/third...) child when he/she completely stopped breastfeeding or being fed breast milk?
3. How old was the (first/ second/third...) child when he/she was first fed anything besides breast milk?

**Breastfeeding as a breast cancer survivor**

1. What can you tell me about breastfeeding for women who are breast cancer survivors?
2. Did you talk to your doctor about the possibility of breastfeeding after breast cancer?  
Probes:  
What did your doctor tell you?
3. What were your expectations about breastfeeding?
4. Was breastfeeding a possibility for you?  
Probes:  
Did you try to breastfeed?  
What motivated you to try to breastfeed?  
Can you tell me about your experiences with breastfeeding?  
What was the best part?  
What was the most difficult part?
5. How old was your (first/second/third...) child [born after breast cancer] when he/she completely stopped breastfeeding or being fed breast milk?
6. How old was your (first/second/third...) child [born after breast cancer] when he/she was first fed anything besides breast milk?
7. Where did you go for information about breastfeeding?
8. Where did you go for support?
9. Did you feel supported in your decision about breastfeeding?  
Probes:  
What made you feel most supported?  
Least supported?
10. What would you say to other breast cancer survivors who are interested in breastfeeding?  
Probes:  
What advice would you give them?
11. Is there anything else you would like to tell me about your experiences that we haven't covered?

child and three of those had breastfed. Participants became pregnant between less than 1 year and 6 years post-diagnosis. Compared to other WHEL participants, the 10 women who participated in this study were younger, more likely to be White, more likely to be college graduates or higher, more likely to have been Stage II and less likely to have been Stage I at diagnosis, more likely to have had a lumpectomy, and less likely to have ever used antiestrogens. Participants had a total of 19 children after breast cancer, with a range of one to three children each. One participant chose not to breastfeed and two were unable to breastfeed all of their children post-cancer; one had difficulty breastfeeding her twins and another was taking medication contraindicated during breastfeeding. Ten women did breastfeed a total of 15 children. These women were able to provide breast milk to their children for between 6 weeks and three and a half years, for an average of

8 months. The majority of participants supplemented with formula either immediately or after a short time, between 1 and 4 months after initiating breastfeeding. Participant characteristics are outlined in Table 1.

**Themes**

The following themes were identified from the semi-structured interviews. They include both facilitators and challenges to breastfeeding. The main themes identified were: 1) Cautiously hopeful, 2) Exhausting to rely on one breast, 3) Motivated despite challenges, 4) Support and lack of support, and 5) Encouraging to others. Sub-themes are also discussed within each main theme.

*Theme 1: Cautiously hopeful* The majority of participants expressed hope about their ability to breastfeed and

reported uncertainty about what to expect. Despite their uncertainty, women were hopeful and planned to try to breastfeed and “see what happens”:

*I was just hoping to be able to do it. You know I wanted to try it.... It was I'm gonna try it and if I can do it I'm gonna do it for as long as I can do it and if I can't then I'll have to accept the fact that I can't.* (Mother of 2 after cancer, breastfed 4 months and 2 months)

*I was just hoping I could do it. I was just hoping my milk would come in. I was just praying that it would all work.* (Mother of 1 after cancer, breastfed 14 months)

*I was just going to give my all and try. You know, as much as I could.* (Mother of 1 after cancer, breastfed 6 months)

**Subtheme 1a: Worried about nursing from one side** Women generally expected it to be different than the experience of most other women because they would have to rely mainly or entirely on one breast. All but one participant planned to try to breastfeed, and the majority of those who planned to try expressed concerns about whether or not they would have a sufficient milk supply:

*My biggest thing was I was super nervous about nursing, I wanted to be able to nurse and would I be able to nurse on one side? And would I have enough milk?* (Mother of 1 after cancer, breastfed 14 months)

*My main concern was I wanted to breastfeed, and the one side, the right side where I had the breast cancer wouldn't produce milk like the other side.* (Mother of 3 after cancer, breastfed 7 ½ months, 5 months and 4 months)

**Subtheme 1b: Expected it to be like a mother with twins** Several participants were optimistic about breastfeeding and expected their experience to be similar to that of other women who had twins:

*I basically remember coming up with my own idea that if a woman with twins can nurse two babies with two boobs, basically, I could do it with one with one baby, so you know. So I just figured supply and demand, as long as he can be satisfied, I will nurse him. You know? Because I think it's good for them and good for us, no matter what.* (Mother of 1 after cancer, breastfed 6 months)

*Well I think that for most women it would be like having twins. You know it's sort of supply and demand. So if you, if you know, even though it's only on one side you can still produce enough.*

*Because they're just sucking on that one side, you're still going to produce. You can still make enough to provide for your child.* (Mother of 1 after cancer, breastfed 14 months)

**Subtheme 1c: Didn't stress about it** Although women were generally hopeful about breastfeeding, a few also reflected on the fact that they would not worry too much if they were unable to because, as breast cancer survivors, their situations were different than most other women:

*[Breastfeeding] is a natural thing you want to do it ... it builds up their immunities and it's the perfect thing for babies to drink, but for women like us, who have gone through breast cancer treatment, if we're blessed and fortunate enough to be able to have children... [we] may not be able to breastfeed them.... I guess it goes back to everything I've been through, I just don't stress about it. I can't change it, I have no control over it. So why am I gonna spend any time and energy worrying about it? I'm going to get them on formula and they're going to be fine.* (Mother of 2 after cancer, breastfed 4 months and 2 months)

**Theme 2: Exhausting to rely on one breast** Ten of the study participants breastfed their children and all of them discussed significant challenges to breastfeeding. Primary among these was not having a sufficient milk supply because they relied primarily on one breast. Those who had a mastectomy only had one breast to feed from and those who had a lumpectomy reported little or no milk from the side that had been operated on. Among those who had a lumpectomy, five of seven reported no milk production on the side that was operated on. The remaining two participants reported very little milk on one side.

*I only had one breast that lactated. The breast that was operated on didn't get the memo that we were pregnant. So I only had one breast that was utilized for breastfeeding.* (Mother of 1 after cancer, breastfed 6 months)

*Depending on what [surgery] you've had, it's really hard afterwards if you try and breastfeed...It was really hard. Doable, but you've got, it was just really hard because the one side produced milk and the other side didn't, so you're feeding just on one side.* (Mother of 1 after cancer, breastfed 2 months)

**Subtheme 2a: Huge commitment** All study participants who breastfed reported that it was physically and emotionally very difficult. The main challenges were related to the fact that women had to rely primarily or entirely on one breast. As a result, breastfeeding was a huge commitment that

included needing to use a breast pump and supplement with formula for the majority of women.

*It's hard, you have to pump, you have to do a lot... you have to be really committed to it.* (Mother of 2 after cancer, breastfed 4 months and 2 months)

*You can't just leave and go take off and go do something, because you have to always be attached to the baby and pumping is just horrible, you definitely feel like a cow. And I had to pump every 3 h to keep up my supply. And that was horrendous and then you're just, everything is about, in the beginning you know, first 6 months about feeding the baby, it's like you nurse every 3 h and you pump every 3 h and then give, I had to give him the supplement because I wasn't making enough, so I'd pump and then give him that supplement.* (Mother of 1 after cancer, breastfed 14 months)

*The hard part was, in addition to breast feeding both of them, I had to pump, so it was like having triplets. So I was constantly attached, which, so that was difficult. So, you know, early on, I breast fed them both, and pumped. As it, as they got bigger, I would bottle feed one, breast feed the other, and then pump.* (Mother of 3 after cancer, including twins, breastfed 5 months and then 4 months with twins)

**Subtheme 2b: Frustrated with milk supply** Several women expressed frustration with the experience of low milk supply, and this was the reason why many either began supplementing or transitioned entirely to formula:

*I thought it was going to be easier than it was. I had thought that side would produce more than it did. So it was kind of frustrating when it didn't.* (Mother of 3 after cancer, breastfed 7 ½ months, 5 months and 4 months)

*I only had my cancer was in my left breast and that breast did not produce any milk... So that one did not produce any milk and I got some out of my right breast so my daughter got, I was only able to breast feed her about 4 months. And then my supply just dwindled down... Even my breast that was making milk wasn't making that much so we would only be able to do it for a few minutes, and then it was drained and so I was having to give her a bottle, you know, anyway. So actually after a, probably with my daughter about a month or so of actually putting her on the breast, I just started pumping... for me, I was so glad when my supply started going down. Because it was more work, than anything, you know it's so much easier to mix up a bottle and give them a bottle and you're done. We probably would have been successful at it if my breast would have been enough*

*nutrition for them. And had filled them up enough, but it wasn't so.* (Mother of 2 after cancer, breastfed 4 months and 2 months)

**Subtheme 2c: Physically difficult** Women also reported many physical challenges from feeding from only one side, including pain and physical appearance:

*[Breastfeeding is] doable, but you've got, it was just really hard because the one side produced milk and the other side didn't, so you're feeding just on one side. So it kind of not only looks kind of awkward, but it's really just hard physically, too, you know.* (Mother of 1 after cancer, breastfed 2 months)

*I remember somebody saying, don't you wish you were a cow? And I'm like, to have like however many? Like they have like six or seven, I'd be happy with two right now, okay? I'd just be really happy with two... this one nipple is killing me! ...And then the hard thing is you've got one huge boob and one regular sized boob. And you look ridiculous!* (Mother of 1 after cancer, breastfed 14 months)

*The experience was difficult at first because it was one side and I could not take a break for the other side. So I had...specifically I had a chapped nipple and a split nipple and it was painful and I actually nursed through it...* (Mother of 1 after cancer, breastfed 3 ½ years)

**Subtheme 2d: Took what I could get** Despite the many physical and emotional challenges that women faced, in the end, they reported that they were happy to have had the experience. Participants who were able to provide breast milk to their child(ren) to whatever degree they were able seemed satisfied:

*And I think under different circumstances I would have breastfed my kids longer, you know? And it would have been different but you know, you take it, I have been, and that's all I can ask for. You know? If I can't breastfeed them, well that's okay.* (Mother of 2 after cancer, breastfed 4 months and 2 months)

*There's something very comforting and very soothing about sitting on a breast pump and having the milk being expressed, just knowing that, you know, even though he's not latched on, I'm still doing what I need to do to, you know, supply for my son or my daughter.* (Mother of 2 after cancer, breastfed 14 months and 0 months)

**Theme 3: Motivated despite challenges** Study participants overwhelmingly reported a strong desire to attempt to breastfeed their children. One woman reported going to great lengths to be able to breastfeed her child in the hospital:

“I bugged the heck out of them in the hospital, let me nurse him while he’s in intensive care...they wouldn’t let me nurse him, until they finally did let me, but I had to beg and plead.” (Mother of 1 after cancer, breastfed 6 months)

*Subtheme 3a: Baby’s nutrition and bonding were important* Study participants were highly motivated by the benefits of breast milk for the baby’s health. All of the women who reported breastfeeding stated that their decision was influenced by the benefits of breast milk for their child’s health. As one participant said, “It’s the healthiest thing for a baby...its designed specifically for the baby. That’s why it’s there.” (Mother of 1 after cancer, breastfed 3 ½ years)

The majority of women also commented on the importance of bonding with their child:

*Oh it’s just that bonding with your child, you know? They’re right there you know, you are their sustenance, you’re giving them the food that they need to live. It’s just that whole cliché with, you know just that special, close bonding time. That skin on skin time. I mean it was wonderful, it was wonderful.* (Mother of 2 after cancer, breastfed 4 months and 2 months)  
*It’s just so beautiful I don’t know, it’s so like bonding with your baby. Not that you’re not close when you’re bottle-feeding but it’s just amazing that your body can do it. And I don’t know it’s just really beautiful, I was really happy.* (Mother of 1 after cancer, breastfed 14 months)

*Subtheme 3b: Personal benefits* Additionally, several mothers discussed their beliefs that breastfeeding might be beneficial to their own health, possibly reducing their risk of breast cancer recurrence: “I’ve always heard that breastfeeding, well this is prior to cancer though, but I always heard breastfeeding was good. You know, you’re at a higher risk for breast cancer if you haven’t breastfed.” (Mother of 3 after cancer, breastfed 5 months and 4 months with twins)

A couple of participants also reported that they were motivated by the cost of formula and by the convenience of breastfeeding: “Have you seen how much formula is?... Cost, cost was I think the main thing.” (Mother of 2 after cancer, breastfed 4 months and 2 months)

*Subtheme 3c: Influence of past experience* Another important motivating factor was having a previous positive experience with breastfeeding. One participant discussed how her earlier experiences with breastfeeding helped her to overcome the significant challenges she faced with post-cancer breastfeeding:

*It gave me a better perspective on women that have challenges with breastfeeding because my first two*

*were like it was so easy and it was, I just fell right into it... it really took some perseverance for this one, the third one...And I’m glad that I had had the experience with the other two that I knew that it could eventually work so I didn’t give up easily. Oh yes, absolutely I would have given up, absolutely if I did not have that good...those two good experiences.* (Mother of 1 after cancer, breastfed 3 ½ years)

One participant who had not breastfed her previous child chose not to breastfeed: “[I didn’t breastfeed] because I never breastfed my first child. My mom didn’t breastfeed, my sisters didn’t, you know so I just thought oh I’m not going to breastfeed. So no big reason why I didn’t, I just didn’t.” (Mother of 1 after cancer, breastfed 0 months) All other participants had either breastfed their previous children or had their first child after breast cancer.

*Theme 4: Support and lack of support* Participants reported seeking information and support from a range of sources, including their physicians, lactation consultants, female family members/friends, and spouses/partners. However, several women reported that they did not seek support for breastfeeding and a few reported feeling unsupported by social norms and expectations surrounding breastfeeding.

*Theme 4a: Support from multiple sources* The majority of women reported asking a physician about whether or not they would be able to breastfeed. Women reported talking to their obstetrician, general practitioner, oncologist, or radiation oncologist. Most of those reported that their physicians were very supportive: “They were all for it...whatever my body produced was gonna be okay so... they were more than happy to, you know, support me in it and actually strongly encouraged that I do [breast-feed].” (Mother of 2 after cancer, breastfed 4 months and 2 months). Physicians generally advised a “wait and see” approach to breastfeeding because of the likelihood of a lower milk supply. Those who were encouraged to breastfeed by their physicians did initiate breastfeeding. One participant who didn’t plan on breastfeeding reported that her doctor supported her inclination not to breastfeed in order to better screen for recurrence: “And you know so I talked to my doctors, I said should I or should I not [breastfeed], and they said you know, let’s not. We can keep a better eye on your, on you that way, your healthy breast.” (Mother of 1 after cancer, breastfed 0 months)

Several women discussed the value of the practical support and information they received from lactation

consultants, including those within hospitals and breastfeeding support groups:

*I really relied more on the maternity nurses in the hospital to get us going, and then at the lactation clinic, was phenomenal. I just highly recommend using the lactation clinic....But in general I definitely, the group was really helpful in helping me figure out ways to increase my supply and you know, I don't know, I wouldn't know the right time to pump, and when not to, you know? All that crazy stuff. When you produce the most... But, you know, I think every mom, if it's not working, it's my fault, what am I doing wrong, it's only me, nobody else has this problem, and that's why the lactation clinic's a great benefit because, you know, it is a process. (Mother of 1 after cancer, breastfed 6 months)*

Many women also discussed the importance of the support they received from friends and family members, particularly their spouses/partners:

*You know everyone was supporting... my son's father was very supportive of me breast-feeding, and you know he would do whatever he could you know? So I would pump, and then he would give him the bottle from what I pumped, you know? To try to give me a break and, you know, everyone was really supportive. (Mother of 1 after cancer, breastfed 14 months)*

**Subtheme 4b: Negative impact of social expectations** Although the majority of participants reported feeling supported in their decisions about breastfeeding, a couple of women reported feeling unsupported because of others' expectations about the importance of breastfeeding. A couple of participants discussed feeling guilty for being unable to or choosing not to breastfeed because these cultural and social pressures. One participant expressed her frustration this way: "...you get some looks from some people if you don't breastfeed." (Mother of 1 after cancer, breastfed 0 months) Another participant described a negative experience with a lactation consultant who expected her to breastfeed regardless of the challenges she was facing:

*I felt more pressure to breastfeed, because she made it seem like there was no other option. And it kind of made you feel like, you know, you're a bad mother if you don't breastfeed. So I felt less supported, and more pressure to do it, and more like a failure if I couldn't. And she didn't care whether I had one breast or two. She thought it was, other women do it, you should be able to do it. (Mother of 3 after cancer, breastfed 5 months and 4 months with twins)*

**Theme 5: Encouraging to others** Among those participants who breastfed, the vast majority reported an overall positive experience and would encourage other survivors not to let breast cancer interfere with their desire to breastfeed. However, participants also advised others to be prepared for the possibility of an insufficient milk supply, resulting in the need to use a breast pump and supplement with formula. Overall, study participants felt that breastfeeding was a personal decision and a huge commitment, but that, for them, the benefits were substantial enough to justify the effort:

*It was a great experience, and I think breast feeding is a blessing to the child and the mother, and economically. So I would encourage moms to do that if they can do it. (Mother of 1 after cancer, breastfed 6 months)*  
*Just that you, you know, you probably won't produce enough milk on one side because of the radiation and milk glands and stuff that they cut out with surgery. So you're probably going to have to supplement with some type of formula. And just, it's hard because you feel like it's taking something away from you, and that, you get mad at the breast cancer, at least I did, for that. But you know, don't give up. Breast feed on one side. I fed three kids on one side, and you know, don't let it interfere with your bonding with your baby. (Mother of 3 after cancer, breastfed 7 ½ months, 5 months and 4 months)*

*I mean it is a huge commitment... I think people think it's going to be really easy. Maybe for some people it is but, you know, so if they decide to do it, you know, definitely go to a, if you're having difficulty go to a breast feeding support group, and just get through the first 3 months, after that it's easier. (Mother of 1 after cancer, breastfed 14 months)*

**Subtheme 5a: It might not work out** Although women had positive experiences overall, they also talked about the importance of being aware that it might not be possible for some survivors to breastfeed. Participants also discussed the importance of being prepared for the possibility of it not working out as they had planned:

*I would say it's something that is definitely worth giving it a try, but also have a back up plan like, you know, introduce a bottle with breast milk so that they're used to a bottle if you need to. (Mother of 1 after cancer, breastfed 2 months)*

*Oh, well, I mean I, I would just say if you've had radiation...there's a good chance you won't be able to breast feed. And you just have to be open to the fact that that's okay. That's just it, that's the way it is, and not stress about it, not get freaked out about it. (Mother of 2 after cancer, breastfed 4 months and 2 months)*



## Implications for research and practice

We have identified several key themes describing breast cancer survivors' experiences with breastfeeding. Our findings can be used to identify new research questions and to assist in the development of interventions aimed at supporting successful breastfeeding among this population. The majority of breast cancer survivors interviewed chose to initiate breastfeeding and participants were generally optimistic and motivated to breastfeed. Although those who breastfed experienced many hurdles, they were generally positive about their experiences and encouraged other breast cancer survivors who might be interested in breastfeeding not to let breast cancer stop them from trying. While participants in this study experienced many of the same barriers to breastfeeding as women without breast cancer, conversations highlighted a need for greater sensitivity to the challenges and pressures they may face. Milk supply was a major issue for most participants. Additional research to measure milk supply along with women's perceptions of their milk supply, and possible methods to increase milk supply would provide valuable information to aid in the development of interventions to support initiation and maintenance of breastfeeding. Based on the themes identified in this study, potential interventions include: professional assistance with breastfeeding initiation and building milk supply; opportunities to discuss specific concerns and needs about breastfeeding during prenatal visits; and improved postpartum support, such as through professional lactation consultants or other survivors who have breastfed.

Despite their enthusiasm, participants discussed several significant breastfeeding challenges. Difficulties related to having only one lactating breast, including lower milk supply, physical pain and exhaustion, posed significant obstacles for this group of breast cancer survivors. Literature on the experiences of breastfeeding women in general outlines similar challenges. Common reasons given for ending breastfeeding include sore nipples, inadequate milk supply, infant having difficulties, and perceptions that the infant was not satisfied [29]. The perception of insufficient milk supply is a common reason for the decision to wean, even in the general population, although it is unlikely that there is a physiological cause for this for the vast majority of women [1, 30]. Although this study did not measure physical milk supply, participants did report on their perceptions of milk supply. Only two of seven participants, less than 30%, who received a lumpectomy reported having any milk available on the side that had been operated on. Even for those most committed to breastfeeding, participants reported that lower milk supply typically resulted in a need to use a breast pump and to supplement with formula. Although the problems encoun-

tered by breast cancer survivors mirror those of women without breast cancer in many ways, the availability of milk from only one breast appears to have amplified these.

Anxiety about breastfeeding was something that many women reported experiencing during pregnancy, generally stemming from concerns about having a sufficient milk supply. Connell et al [7] also reported that decisions about breastfeeding were difficult for many women. However, these authors reported that women's anxiety was largely related to fear of recurrence. Participants in this study discussed fear of recurrence in relation to pregnancy, but only one participant identified this fear as a factor in her decision about breastfeeding. Several participants in this study reported that they spoke to a healthcare provider, typically an oncologist or obstetrician, about whether it would be possible and safe for them to breastfeed. Overall, women reported that their physicians encouraged them to breastfeed, but they did not provide additional education or support for breastfeeding. Some women looked to other sources for information; a few participants mentioned looking online, one went to a breastfeeding class, and others looked at breastfeeding books. Participants reported that information specific to breast cancer survivors was unavailable. Appointments such as prenatal visits would provide a valuable opportunity for providers to discuss the specific concerns and needs of breast cancer survivors who are interested in breastfeeding. This would also be an ideal time to connect women with support services that they might need postpartum, such as lactation consultation and breastfeeding support groups.

As is true for breastfeeding women in general [1], our interviews revealed that support was integral to breastfeeding success. A few women discussed the importance of the extensive support they received from their spouses/partners. Several also reported seeking outside help from lactation consultants from within hospitals, breastfeeding support groups, and private consultations. Spouses generally provided emotional support whereas lactation consultants provided education and practical assistance with breastfeeding techniques. However, participants reported that breastfeeding support for breast cancer survivors was lacking. In addition, the majority of participants did not seek outside help and about half did not report that their spouses/partners were a source of support. These results reveal an important area for improvement in providing postpartum support to breast cancer survivors. Potential interventions include professional support through lactation consultants trained to meet the unique challenges of breast cancer survivors, encouragement of spousal/partner support, and peer support from other breast cancer survivors who have breastfed.

Participants in this study were overwhelmingly motivated to try to breastfeed. Participants' outcome expectancies (value placed on breastfeeding) and expectations (antici-

pated outcomes of breastfeeding) were supportive of initiating breastfeeding. All participants who breast fed reflected on the value of bonding with their child through breastfeeding. Participants were also encouraged by the nutrition that breast milk would provide for their infants. Women also generally reported that they expected to be able to breastfeed successfully, with several women comparing their situation to a mother with twins who could breastfeed two infants. While participants did not expect breastfeeding to be easy, the experience, including physical and emotional challenges, was even more difficult than expected for most. Those that successfully initiated breastfeeding overwhelmingly reported that the experience was exhausting. Three participants appeared better able to cope with the challenges because of their previous breastfeeding experience. Participants identified low milk supply as the primary cause of their exhaustion, which resulted in the need to use a breast pump, supplement with formula and, in many cases, to end breastfeeding earlier than planned. Not only was it physically exhausting to breastfeed, but women also commented on the emotional challenges, particularly the guilt associated with having to supplement with formula or end breastfeeding. Others have also discussed the sense of guilt that arises from social pressure to breastfeed and the added stress that women experience as a result [7]. Breastfeeding is a struggle for many women and even more so for breast cancer survivors who typically have only one lactating breast. Conversations with women in this study highlighted a need for increased support across a range of experiences, including breastfeeding in combination with formula supplementation and the decision to end breastfeeding. These findings also illustrate the importance healthcare providers' sensitivity to the heightened challenges faced by breast cancer survivors wishing to breastfeed.

This study resulted in detailed information about women's experiences with breastfeeding after breast cancer, but it also has some limitations. As with other qualitative research, findings are specific to this sample and cannot be generalized to the larger population. In addition, although we sought to interview women with a broad range of experiences and our sample included women from multiple geographic regions, participants in this study are not representative of all women with breast cancer. All but one had participated in the WHEL study, a long-term research study evaluating the relationship between dietary factors and breast cancer recurrence, and might have been more interested in health issues than the general population. All participants were White and the majority were college graduates or higher. In addition, participants were diagnosed with early stage breast cancer, which might have influenced their decisions about pregnancy and experiences with breastfeeding. Finally, our findings are largely representative of women without previous breastfeeding experi-

ence. Those participants who did have prior breastfeeding experience conveyed more confidence and persistence in their efforts.

Literature on the experiences and needs of breast cancer survivors who are interested in breastfeeding is extremely limited. Women who participated in this qualitative, exploratory study provided in-depth information about their experiences with breastfeeding after breast cancer, including their motivation, expectations, support they received, and challenges they faced. Ten of eleven breast cancer survivors in this study initiated breastfeeding. Participants were overwhelmingly motivated to breastfeed and expected to be able to breastfeed but faced considerable physical and emotional challenges. Participants described problems that are not unique to women with breast cancer, but they appear to have experienced these to an even greater degree. This study revealed a need for improved prenatal education and postpartum support to better prepare women for the challenges of breastfeeding and to provide them with resources to support their efforts. Results of this qualitative analysis indicate that interventions to support the efforts of breast cancer survivors who are interested in breastfeeding are warranted. Larger scale studies to learn more about perceived and actual milk supply and factors influencing the initiation and duration of breastfeeding among breast cancer survivors would aid in the development of such interventions.

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