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Young Breast Cancer Survivors: Their Perspectives on Treatment Decisions and Fertility Concerns

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Abstract

Background—Younger women diagnosed with breast cancer are more likely to have survival concerns related to fertility, which may influence their treatment decisions.

Objective—This qualitative study explores how young women make cancer treatment decisions and the role of fertility concerns in that process.

Intervention/Methods—We used purposeful sampling to identify a diverse group of 20 young breast cancer survivors, half of whom had a child after breast cancer. We conducted open-ended telephone interviews and used cross-case, inductive analysis to identify themes.

Results—The main themes were: 1) I was young, I wanted to do everything possible to move forward with my life and not to have the cancer come back, 2) Fertility concerns are different for every woman 3) My oncologist was great... a huge part of my survivorship, and 4) They didn't tell me about my options and I didn't think about fertility until it was too late.

Conclusions—While fertility was important to many participants, treatment decisions were mainly motivated by survival concerns. Fertility concerns depended on life circumstances and the timing in relation to diagnosis varied. There is a need for improved information regarding the impact of treatment on fertility and fertility preservation options, even if concerns are not expressed at diagnosis.

Implications for Practice—It is critical that cancer care providers provide timely information regarding fertility. Oncology nurses are particularly well-positioned to serve this role by communicating with patients about their fertility concerns and reproductive planning prior to treatment and throughout the course of survivorship.

Keywords

breast cancer; young women; qualitative; treatment decisions; fertility

INTRODUCTION

Breast cancer treatment can increase the risk of early menopause and result in reproductive difficulties^{1–4}. This is a major concern for many young breast cancer patients and survivors

who have not finished growing their families. The risk of chemotherapy-induced amenorrhea is lower among young breast cancer patients and depends on chemotherapeutic agent and dose.⁴ However, even women who resume menstruation may face later difficulties with fertility due to ovarian damage and menopause at an earlier age^{3, 4}. Infertility alone is an emotionally challenging problem and may be even more challenging for cancer survivors⁵. Cancer diagnosis may result in delayed childbearing for many survivors who are typically advised to wait 2–3 years after treatment ends before conceiving. Those who undertake endocrine therapy, such as Tamoxifen, face additional delays. This may rule out pregnancy for many survivors, particularly those who had already postponed childbearing until later in life.

Research indicates that the informational needs of young women regarding fertility and menopause are not being met⁶. There may also be discordance between younger women's concerns about fertility issues and how this issue is addressed by their doctors^{6, 7}. Some women feel that their concerns are not taken seriously by their health care providers⁸. Younger survivors also appear to have greater psychosocial needs as compared to older survivors, particularly with respect to dealing with the physical impact of treatment and associated gynecological and reproductive consequences⁹. The need for support related to fertility and early menopause has been identified as very important to younger women^{8–11}. Infertility and concerns about reproductive issues can negatively impact on survivors' well-being^{12, 13}.

Concerns about fertility may play a role in cancer treatment decisions made by young women¹⁴. In a recent study, 12% of long-term breast cancer survivors diagnosed at age 40 or younger reported that fertility was a consideration in their treatment decisions¹⁵. Results from a Web-based survey of young survivors found that fertility concerns impacted treatment decisions about 30% of the time, although selection bias may have resulted in a greater number who were concerned about fertility¹⁴. Learning more about how young women make treatment decisions is an important step toward meeting their informational and support needs.

We conducted this exploratory study to gather information about how young women make cancer treatment decisions and to investigate the role of fertility in their decision-making process. While researchers and clinicians have begun to address the importance of fertility for young women diagnosed with cancer, there are currently no qualitative studies detailing these important issues from the perspective of young survivors. This approach provides in-depth and contextual information that cannot be obtained quantitatively¹⁶ and allowed us to identify specific areas of unmet need.

METHODS

Study participants

Participants were early stage breast cancer survivors (Stage I or II) diagnosed at age 40 or younger. We recruited from the Women's Healthy Eating and Living (WHEL) study, a multisite randomized, controlled trial to evaluate the effectiveness of a high-vegetable, low-fat diet to reduce recurrence¹⁷ and through a local affiliate of the Young Survival Coalition (YSC). We used stratified purposeful sampling to identify a diverse group of young breast cancer survivors, including equal enrollment of participants who had a child after breast cancer and those who had not.

The first author enrolled participants and conducted the telephone interviews. Twenty-eight women from the WHEL study fit the sample parameters. Of the 17 women we contacted, 16 agreed to participate. One participant was excluded from this analysis because of her unique

situation as a woman treated for cancer during pregnancy. After making an announcement to the local YSC affiliate, 5 young survivors contacted the study and enrolled, for a final sample size of 20. The final sample size was determined by informational considerations; recruitment ended when saturation had been reached and no new information was provided by participants¹⁸. The study protocol was approved by the University of California San Diego and San Diego State University. Participants provided consent to use direct quotes in publications.

Interviewing and data collection

We conducted and recorded 20 in-depth telephone interviews between February and March, 2008. Interviews were 45 to 75 minutes in duration. We used a semi-structured interview guide so that each participant was asked a similar set of questions. Questions were open-ended to facilitate conversation on each topic and participants were encouraged to elaborate on their answers.

The selection of questions was guided by existing literature and Social Cognitive Theory (SCT) provided a framework to explore environmental- and individual-level influences on decision-making^{19, 20}. Specifically, we focused on the role of health care providers and individual outcome expectancies and expectancies. Outcome expectancies refer to the values placed on a particular outcome and individuals are expected to behave in a way that maximizes the valued outcome. Another key construct is outcome expectations, the anticipated outcomes that guide a person's behavior^{19, 20}. In this study, we explored how younger breast cancer survivors' values regarding fertility and having a child after breast cancer (expectancies) and beliefs and anticipated outcomes about future childbearing (expectations) related to their cancer treatment decisions. The interview guide included 40 main questions about individual values and expectations regarding fertility and childbearing after diagnosis, provider discussion and recommendations about treatment options and fertility, provider relationships and communication in general, and how decisions about treatment were made. For example, we asked: How did you go about making decisions about your cancer treatment? What expectations did you have about your treatment? Did concerns about fertility play a role in your treatment decisions? If so, how? What were your expectations about fertility and pregnancy after breast cancer? Where did you go for information about fertility issues? Did you talk to your doctor about fertility or pregnancy after treatment? If so, what were you told?

Analysis

We used cross-case analysis, where data from all participants were combined rather than analyzed as individual cases¹⁶. We identified themes using an inductive approach, where themes and sub-themes emerge from dominant concepts in the raw data. This approach allows for modification of ideas and themes throughout the analysis process to accurately represent participants' experiences. After examining data across each topic of the interview guide, we explored outcome expectancies and expectations as they related to treatment decision-making. Although SCT provided a structure for exploring potential influences on treatment decisions, our analysis was not restricted to SCT constructs. We began by examining themes within each sub-group to determine if there were differences based on childbearing status post-diagnosis. After finding no clear differences between groups, we combined all data for analysis. The first author developed codes and interpreted data through an iterative process involving extensive review of the transcripts and constant comparison. This process included continuous coding as new data were collected in order to resolve potential gaps in questions and biases that may appear and reviewing the final coding to ensure that the meaning and intent of the participant comments was captured accurately¹⁸.

Final themes were decided on after discussion with co-authors. Transcripts were imported into the QSR NVivo 8 software package ²¹ to code, sort and analyze the data.

RESULTS

Participants' Characteristics

This study includes 20 young breast cancer survivors diagnosed with Stage I (30%) or Stage II (70%) breast cancer between the ages of 26 and 38 years. Women in this study were recruited from multiple geographic regions and were diagnosed between 1 and 13 years prior to the interview. Most participants were White (85%) and had at least a college degree (65%). To ensure inclusion of women interested in fertility, half of those in our sample had at least one biological child post-treatment. All but one of these pregnancies was planned. Among participants who did not have a child, all reported possibly (n=9) or definitely (n=1) wanting a child after treatment ended. By the time of the interview, two were unable to have a child, one was trying to become pregnant, 4 were still open to the possibility, and 3 decided against having children. Those who decided not to have children reported older age, life circumstances, and concerns about recurrence, the baby's health, and potentially passing on a genetic risk as reasons. Two participants reported considering adoption but none had adopted a child.

Themes

The semi-structured interview guide resulted in four main themes with several sub-themes within each. The main themes were: 1) I was young, I wanted to do everything possible to move forward with my life and not to have the cancer come back, 2) Fertility concerns are different for every woman 3) My oncologist was great... a huge part of my survivorship, and 4) They didn't tell me about my options and I didn't think about fertility until it was too late. We did not identify distinct themes for sub-groups based on childbearing post-diagnosis or duration of survivorship. However, some unique experiences for women in these sub-groups are outlined in the discussion.

Theme 1: I was young, I wanted to do everything possible to move forward with my life and not have the cancer come back

Women overwhelmingly reported that survival and preventing a future recurrence were the primary factors motivating their treatment decisions. Participants reported feeling that they had few options when making treatment decisions, but tended to select the most aggressive approach in order to "get it over with" and "have the longest survival". This was also true for those who wanted children after their diagnosis. Many participants made comments similar that of one woman; "All I remember saying is tell me what I have to do to survive." (Age 29 at diagnosis, 2 children post-treatment).

Sub-theme 1.1: I didn't have much choice in treatment—Most participants reported that they relied heavily on the advice of their oncologist when making treatment decisions. Although some reported seeking second opinions, women generally felt that they had limited choices:

You know, I think I probably had about 25% say [in my treatment]. It was, you know, choosing the dense dose and it was choosing the weekly. That was really all I was able to do. They basically said, "This is what you're getting". (Age 35 at diagnosis, may want children in the future)

You know, I guess I did [have a say in my treatment]. It's just that I was young ... and they kept saying, you know, it's more aggressive and you know, I didn't know

all the choices I guess? So it was more like this is what we highly recommend, and when I did as for a second opinion I remember a doctor saying, if somebody tells you otherwise, I would run from that person. This is what you need. (Age 35 at diagnosis, one child post-treatment)

I mean the decisions were mine, not that I always made them, but... we got three opinions from different doctors, and did some research, and talked to some survivors... Ultimately I went with my oncologist's recommendations. (Age 32 at diagnosis, one child post-treatment)

Subtheme 1.2: Let's do it right the first time and get it over with—Participants' younger ages also led many to choose a more aggressive treatment. As one participant said, "Because I was so young, whatever would give me the longest survival rate, so you know, it didn't matter to me if I was doing 3 months of chemo or 6 months of chemo if I were to get another 4% for survival rate I was gonna do 6 months." (Age 33 at diagnosis, 3 children post-treatment).

Others also talked about the importance of choosing an aggressive treatment so that they could move on with their lives with less concern about recurrence:

...so my doctors, you know, kind of agreed that it was important that I have aggressive treatment so that I could prevent a recurrence. I mean I didn't have, I was at stage 2 so I was okay at the time, but I didn't want to ever have to deal with having cancer again. That was kind of my belief throughout the whole thing. I don't ever want to go through this again. Let's do it right the first time and get it over with. (Age 26 at diagnosis, may want a child in the future)

I think going with the most aggressive chemo that was the main factor. I just wanted it done. I wanted it over with. The same thing with the mastectomy. I mean now I look back and think, oh, maybe I should have had a lumpectomy, but I honestly wanted it gone and I just, I wanted to be able to get on with my life. (Age 35 at diagnosis, may want a child in the future)

Because of the age, ...[what] would be the best treatment for me... Just treat it as aggressively as possible. You know and basically kind of do what it took to get it, to make sure I stayed healthy. (Age 31 at diagnosis, decided not to have children post-treatment)

Theme 2: Fertility concerns are different for every woman

Fertility concerns were largely viewed as secondary to the importance of survival. The level of concern about fertility varied widely, depending on personal circumstances, values and expectations. Some participants reported that their diagnosis happened at a time in life when fertility was not a priority. Those who were planning to start or grow their families in the near future, however, reported that fertility was an important consideration. The majority of women in both groups reported choosing to move forward with the recommended treatment and accepting the possibility of infertility because survival was most important for themselves and their families.

Sub-theme 2.1: I wasn't thinking about it at that point—Some women reported not thinking about fertility at the time of their treatment because having children was not a priority at that time. One participant said, "I was already 36, so I really, I wasn't, I wasn't married yet, so I wasn't kind of banking on it, that maybe kids were going to be an option anyway, let alone after cancer..." (Age 36 at diagnosis, one child post-treatment) Others reported:

...my son was so little. He was only 5 months old, so you wouldn't really be thinking about, at that point, quite the next one... I just wanted to do whatever I had to do to get rid of it. (Age 27 at diagnosis, 1 child post-treatment)

I just wanted to survive. I wanted to get rid of the cancer, so wanting to have a child took second stage at that point. (Age 38 at diagnosis, wanted but unable to have children post-treatment)

Sub-theme 2.2: Fertility was important—Those participants who had been trying to conceive or planning to start a family soon were more likely to report that fertility concerns impacted their choices:

And I made it very, very clear to everybody that fertility was extremely important to me. I was two months away from my wedding, and we were talking about getting pregnant right away...my oncologist really didn't tell me that Tamoxifen was an option, but at that point I was concerned about, you know, my fertility obviously after all of that, and then I just kept thinking how, my age, and that I didn't want to do 5 years because I was 35, and I thought that puts me at 40. And I get off of it, what are my chances of getting pregnant at that point ... And so I decided not to do it. (Age 34 at diagnosis, 1 child post-treatment)

Well, I think my desire to have one more child weighed heavily on that [treatment] decision. I chose the surgery and the radiation. They chose chemo, but I knew chemo would affect the reproductive system and so I decided to throw that out and chose not to take chemo at that time. (Age 34 at diagnosis, 1 child post-treatment)

One participant also discussed her decision to terminate an existing pregnancy and delay treatment to bank embryos:

...it was very smart to have terminated the pregnancy and go forward with my treatment. I think that it also made a lot of sense to bank embryos, so that we didn't have to regret any of those decisions later. It sort of gave us time to decide. And I don't, I think the few weeks that it put off my treatment wasn't risky enough... like I think the choice far outweighed that risk... especially since because I then found out that I was BRCA positive and I will need my ovaries removed. (Age 34 at diagnosis, may want children in the future)

Theme 2.3: We opted for the treatment and took the risk—All but one participant reported that despite the potential risks to their fertility, they still opted for chemotherapy.

And I did have concern of...getting pushed into pre-menopause, but you know, I still opted for the treatment. (Age 31 at diagnosis, decided against having children post-treatment)

You know, [my doctor] brought that up... he said that there was a chance that I would be menopausal and not be able to have children and we took the risk anyway. (Age 29 at diagnosis, 2 children post-treatment)

I mean we knew it was a possibility I could go into early menopause. You know? And be infertile but that didn't stop us. You know? We were still gonna do the chemo, the radiation, the Tamoxifen, everything. (Age 29 at diagnosis, 2 children post-treatment)

A few of these participants also discussed the importance of their survival for the children they already had or hoped to have in the future, saying:

I think preserving or, you know, trying to preserve my life versus trying to preserve a breast or trying to preserve my fertility, you know, I may not be there for that child that I have later on, you know, and that to me, you know, was, I'd much rather be there and have one kid than not. (Age 35 at diagnosis, may want children in the future)

I kept going back to the fact that I wanted to have children, and they said, well what good are you going to do with having children if you're not going to be here to raise them? So that probably was the big thing that made me decide, okay, I have to do what it takes to make sure I'm going to be here, and then I can go forward with having kids. (Age 30 at diagnosis, 3 children post-treatment)

Theme 3: My oncologist was great...a huge part of my survivorship

Participants in this study reported having very good relationships with their oncologists, describing them as a trusted and valuable source of information when making critical treatment decisions. However, the relationship later became strained for some women who felt that their decisions about pregnancy were not supported.

Participants described their relationships with their oncologists very positively:

I love him. I loved him. He was a great guy. He was just slightly younger than I was, so we were kind of in the, you know, same age range of life. He was very patient, very informative, very supportive. I really, I thought he was great. He was, I think he was a huge part of my survivorship. (Age 36 at diagnosis, 1 child post-treatment)

Oh I love him. I still do. He's wonderful. He was, you know, very understanding, very kind, very...I mean sympathetic. He just was very confident that we were gonna take care of this. He just made me feel better. (Age 29 at diagnosis, 2 children post-treatment)

When asked about their oncologist's role when making treatment decisions, most women described them as a critical source of information and someone they could count on to discuss their concerns and answer their questions:

I think he was pretty much the guiding force, but he definitely let me have some leeway. I would come in and give him suggestions of other chemotherapies to use and he would explain the pros and cons of using those and also that my insurance probably wouldn't pay for them because they were for metastasized breast cancer and I said I want the biggest bang for my buck and he's like, "Well, you know, your buck's gonna be a lot higher because your insurance won't pay for it." (Age 35 at diagnosis, may want children in the future)

Trust was another important aspect of women's relationships with their doctors:

Oh yeah I mean, you just take all that for granted, you trust them and put them on a pedestal because you have this disease that you never thought in a million years, I'm 29 years old, you know? This is, and so when you're going to see someone that in your heart you're hoping this person is going to save my life, you just put all of your trust and everything into that person... I think when you're as young as I was, and yeah, I just wanted to do whatever the doctor told me was the best thing to do (Age 29 at diagnosis, 2 children post-treatment)

Finally, participants appreciated feeling that they were not "rushed out the door":

Just being able to ask questions and have them answered thoroughly in terms that I could understand, and just you know having them taking the time to kind of

basically, you know if we had concerns, making sure the questions were answered. (Age 31 at diagnosis, decided against having a child post-treatment)

She doesn't give me the standardized chat...She'll sit down and she'll, it doesn't matter if she goes an hour over one of her appointments. She'll sit with me until every question is answered and she feels like you're comfortable. (Age 26 at diagnosis, may want a child in the future)

Sub-theme 3.1: Relationships were sometimes strained by plans for pregnancy

—While participants generally reported positive interactions with their oncologists regarding future pregnancy plans, a few expressed disappointment in their doctor's reactions:

After I was well when I kept bringing up fertility and the, I didn't want to do Tamoxifen she kind of got frustrated with me I could tell and I think it changed a little bit after I got pregnant. I think she felt like I was risking a lot. So I definitely felt a shift. (Age 34 at diagnosis, 1 child post-treatment)

You know, to be honest, I had spent a year with her [my radiation oncologist], and I would have never expected it, but basically, you know, all the hopefulness she initially gave me went out the window as soon as I told her I wanted to have children, and I was all excited, and she basically said, you know, what are you thinking? You probably won't even be around to raise your children, and you'd better let your husband know that, and also, you know, what about your children...I mean, she just basically was adamant. There are many other options, you don't need to birth your own children. She was really against it, she was, I mean, like I said, I was really taken aback by the whole attitude...I was very upset by that, because it had never occurred to me that someone would think, that I had respected, would think I shouldn't have a family, and we agreed at that time that I would not see her...I decided I wasn't comfortable going back to her because I decided after researching...I mean, it didn't say that she was wrong, but they said there wasn't enough evidence out there to conclude that pregnancy itself would cause a recurrence, which is basically one of the things that she told me. So after that, I decided not to see her. My other oncologist was much more encouraging as far as pregnancy was concerned. (Age 29 at diagnosis, 3 children post-treatment)

Theme 4: They didn't tell me about my options and I didn't think about fertility until it was too late

Those participants who were concerned about fertility reported talking to their doctors, researching the issue online, and talking to other breast cancer survivors about these issues. Most participants, however, felt that they received fertility-related information too late and often did not have time to make informed choices on treatment and fertility preservation. Specifically, participants mentioned interest in banking embryos, alternative chemotherapy regimens that would be less likely to negatively impact on their fertility, and ovarian suppression. Furthermore, participants also discussed the uniquely negative impact that infertility can have on the life of a young breast cancer survivor, reinforcing fertility issues as a priority issue in patient care. Participant comments reflect the importance of addressing this shortfall in timely fertility-related information:

I think it's really important that the people who make the diagnosis of, you now have cancer, should be the ones to introduce fertility options to people...Like, other women I spoke to... had very slow-growing tumors, and said to their physicians, I really want to have children when I'm older, I'm nervous about how this is going to affect me. And no one told them that they could bank embryos. No one told them.

And so they got rushed into chemo with a slow-growing tumor, and she's in the middle of menopause when I finally meet her. And she didn't know about Lupron, and she didn't know about banking embryos, and she didn't know about any of it. So, yeah, it's a huge issue. (Age 34 at diagnosis, may want a child in the future)

Well, it wasn't until after we were about ready to start chemo, he said, you know if you want to have kids you might want to freeze your eggs. So that was what, like a week before I was supposed to go in, I was supposed to think about freezing my eggs! (Age 30 at diagnosis, decided not to have a child post-treatment)

I didn't even think about fertility until like a day or two before I was supposed to start [chemotherapy], and I wasn't going to change my course. (Age 29 at diagnosis, 3 children post-treatment)

The only thing I would do would probably...freeze my eggs, because at the time I didn't even think about doing that. (Age 31 at diagnosis, decided not to have a child post-treatment)

But they didn't give me an option like types of chemo either. When I talked to other breast cancer survivors they had choices of like types of chemo and also another pill that they could take that would kinda shut off their ovaries during chemo so the blood flow wouldn't go to it, to help them preserve them and they didn't even discuss that with me at all. I didn't even know those were options until after I finished my treatment...If I would have known there was different types of chemo that I could do...I would have chosen maybe a less, even though I, I still had the best outcome..I would have chosen to do that just to do whatever I can to try to preserve my fertility. (Age 34 at diagnosis, 1 child post-treatment)

Those more recently diagnosed were more likely to report finding information online (e.g. Fertile Hope and Young Survival Coalition) and talking to other young survivors about their experiences. These participants were also more likely to be uncertain about their future reproductive plans at the time of the interview, but wanted to have the option open for the future. Those with longer survivorship were more likely to have already made their reproductive choices and were also more likely to report a scarcity of information about fertility after their diagnosis. As one woman said, "When I was diagnosed, I know it was 10 years ago, all the research and everything all was towards women who were older... I went to support groups and stuff and that [fertility] was my concern. Everybody else had already had their kids and everything, so it wasn't ever really discussed and the information wasn't really out there" (Age 27 at diagnosis, 1 child post-treatment).

Sub-theme 4.1: It's a huge issue...fertility problems stay with you for life—

Several participants also discussed the tremendous and negative impact that fertility problems have on young breast cancer survivors. As one survivor said, "It's a huge issue, huge issue... and no one tells you anything about this." (Age 34 at diagnosis, may want a child in the future). Another participant who was told that she would not be able to have children after her cancer treatment said:

And the [fertility issue] is huge, it's just, it's more, that was the bigger blow than the cancer diagnosis was. The, oh my God, I can't have kids now. That was way bigger a blow than "you have breast cancer" because the breast cancer you treat and it's over with. And, but the fertility issue stays with you for life...it changes the whole course of your life. And you know the breast cancer is just a chapter in your life and then it's over, and you keep going. But, to not have kids, changes everything. So, you know, it's huge." (Age 34 at diagnosis, 1 child post-treatment)

Another described the emotional challenges of infertility treatment as a cancer survivor:

I think that going through infertility treatments is extremely difficult for a woman who has been through breast cancer... it brings back a lot of feelings that I haven't felt in a couple years, because I, I do feel like the situation that I'm in is because of the treatments I had because of breast cancer. And I am extremely happy to be alive, don't get me wrong. I am very thankful for the situation that I'm in. But it also is just a reminder of the fact that I don't have a normal life because of an experience I had four years ago with cancer. So it's, it does bring up a lot of emotions that I kind of worked through a couple years ago. (Age 30 at diagnosis, hopes to have a child)

DISCUSSION

Researchers have identified the importance of addressing the fertility concerns of young women diagnosed with breast cancer and investigating the potential role of these concerns in their treatment decision-making^{6, 14, 22–24}. We conducted an in-depth study with young, early-stage breast cancer survivors to further explore these issues. Our results provide details about this process from young survivors' perspectives and identify specific areas of unmet needs regarding timely pre-treatment fertility information and post-treatment reproductive planning.

Interviews revealed that participants' primary motivations for making treatment decisions were improved survival and reduced risk of recurrence. The role of fertility concerns varied, depending on current life circumstances and plans for future children. Participants that valued fertility and expected to have children in the future (outcome expectancies/expectations) were more likely to have considered fertility when making their treatment decisions. At diagnosis, fertility was particularly important to those who had been trying to conceive or were planning to have a child soon. Six participants reported that their treatment decisions were based at least "a little" on their desire to preserve their fertility. For those not planning to have a(nother) child, fertility was not a concern at the time of their diagnosis. Some also reported that fertility concerns were initially overshadowed by their cancer diagnosis but became more important as time went on. Some of these women lamented the fact that their healthcare providers did not raise the issue sooner and reported that they may have made different treatment choices or looked into fertility preservation options if they had known about their options. Fertility concerns were identified as a "major issue" for several participants in this study and, similarly to other studies^{14, 15}, we found that these concerns did play a role in the treatment decisions for some. One participant chose to forgo chemotherapy and two chose not to use endocrine therapy because of their concerns. Another delayed treatment until after preserving embryos. Although the possibility of having children was an important issue for many participants, most reported "taking the risk" with chemotherapy, hoping that it would not impact on their fertility. Interviews reveal that fertility is an important issue to address both at the time of diagnosis and later in survivorship.

Participants also talked about the vital role that their oncologists and other members of their cancer care team played in their treatment decisions. They were viewed as trusted sources of information, support and guidance throughout the treatment process. Seventeen participants reported at least a brief discussion about fertility, either initiated by themselves or their doctor. However, this study sample may have been more likely to initiate this conversation because most were interested in the possibility of having a child post-treatment. In other studies, the majority of young breast cancer survivors (51–71%) reported discussing fertility issues with their doctors^{6, 14}. However, as others have indicated⁶, and as our results suggest, fertility concerns among young women with breast cancer are not being fully addressed. Although the subject of fertility was broached in the majority of cases, most

participants reported receiving insufficient and ill-timed information. The American Society of Clinical Oncology recommends addressing potential treatment-related infertility and fertility preservation options at the earliest opportunity²⁵. Consistent with this recommendation, the experiences of women in this study highlight the important role of oncologists, oncology nurses, and other cancer care providers in initiating an early discussion of fertility, including preservation options and referral to a fertility specialist. Given the often narrow window of time prior to treatment, oncology nurses can play a vital role in discussing fertility issues and addressing potential concerns. The development of patient education materials could help facilitate discussions of this potentially sensitive subject. Others have also suggested the BETTER²⁶ model as an approach to discussing fertility²³. Additional resources include the websites fertilehope.org, myoncofertility.org, and youngsurvival.org.

We also explored women's post-treatment fertility and reproductive experiences. Most participants in this study were interested in the possibility of having children post-treatment and half of them did have a child. Every participant who was thinking about pregnancy reported discussing the option with their oncologist. Several participants reported that their doctors supported their plans. However, some were disheartened by the lack of information and support received from their oncologists or others in their cancer care team. A few participants reported that their doctors "were not on the same page" and did not seem to respect their desire to have a child. Some doctors were worried about the potential impact on survival, although research does not indicate poorer outcomes after pregnancy^{27–33}. Additionally, although many participants did have a child post-treatment, some were given distressing news that they may not be able to conceive. Those participants discussed the "life-changing" and "devastating" impact of potential infertility and one described this as an even "bigger blow" than her cancer diagnosis. Another talked about the frustrating challenge of going through fertility treatment as a cancer survivor because it brought back similar emotions to those felt during cancer treatment. While treatment-related infertility may be less likely among younger women⁴, the impact of treatment on reproductive health can have a long-term consequences^{12, 34}. Young survivors interested in pregnancy, particularly those who are experiencing problems with fertility⁵, are in need of improved information and support^{6–8}. Potential sources of support include oncology nurses, psychologists, and social workers.

This preliminary study provides unique, in-depth information about the treatment decisions and fertility concerns of young women diagnosed with early stage breast cancer, but it does have several limitations. Although diverse in many ways, our purposeful sampling strategy biased toward those interested in fertility (i.e. half of participants had children as cancer survivors). As in other qualitative research, this study's findings are specific to this sample and cannot be generalized to the larger population. To broaden our study population, we included more recently diagnosed women from the Young Survival Coalition in addition to participants enrolled in a long-term dietary intervention (WHEL study). However, participants are not representative of all young women with breast cancer and most were White and had a college degree. Finally, this study does not include physicians' perspectives and relies on women's recall of their experiences, which may have been more limited among longer-term survivors.

Not surprisingly, survival was the primary motivator in participants' treatment decisions. However, fertility was also very important to many and led a few women to make different decisions over the course of their treatment. Those with outcome expectancies/expectations favoring fertility and future childbearing were more likely to report that fertility was a consideration in their treatment decisions. Interviews also revealed an important opportunity for improved quality of care by providing more timely information regarding both the

potential impact of cancer treatment on fertility and fertility preservation options. Interviews suggest that this is crucial, even for those who do not identify fertility as a concern when diagnosed. Participants also discussed the important role that their oncologists and other cancer care providers played through the course of their treatment. These providers are in an ideal position to encourage young patients to explore their fertility preservation options prior to treatment and to develop an acceptable treatment approach that incorporates their long-term reproductive plans. Oncology nurses have an important role to play in facilitating these discussions^{23, 24}. Our results indicate a need and opportunity to develop patient education materials that incorporate ongoing advances in treatment and fertility preservation and help women and their providers make informed decisions.

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Table 1

Participant characteristics.

Characteristic	No. Participants
Age at diagnosis	
< 30	7
30–34	10
≥ 35	3
Race/ethnicity	
White	17
Hispanic	3
Education	
No college	1
Some college	6
College degree or higher	13
Cancer stage	
I	6
II	14
ER/PR Status [†]	
ER+/PR+ and ER+/PR–	10
ER–/PR–	10
Surgery	
Lumpectomy	12
Mastectomy	8
Treatment	
Adjuvant chemotherapy	19
Radiation	14
Endocrine therapy	7
1+ child born pre-diagnosis	4
Wanted children pre-diagnosis	
No	1
Maybe	6
Yes	13
Wanted children post-diagnosis	
No	1
Maybe	9
Yes	10
Tried/Did not prevent pregnancy after treatment	11
Tried medical/alternative therapy to become pregnant	4
Irregular periods during or after treatment	11
Doctor reported treatment-	3

	No. Participants
Characteristic	
related ovarian damage	
Treatment decision based in-part on fertility preservation	6

¹ Presence of estrogen and progesterone receptors