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## Developing a post-treatment survivorship care plan to help breast cancer survivors understand their fertility

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### Abstract

**Purpose**—Reproductive-aged breast cancer survivors (BCS) who have completed initial cancer treatment frequently want to know about their future fertility potential. The purpose of this qualitative study was to assess if the fertility-related content presented in the survivorship care plan prototype met the informational needs of post-treatment BCS, and to provide an opportunity for the target audience to review and react to the proposed content and design.

**Methods**—We conducted and analyzed transcripts from seven focus groups with BCS to evaluate their reactions to the survivorship care plan prototype. We independently coded transcripts for consistent themes and sub-themes and used a consensus-building approach to agree on interpretation of results.

**Results**—We identified five themes that describe post-treatment BCS' responses to the prototype survivorship care plan in the context of their informational needs and experiences: 1) The prototype's fertility-related information is relevant; 2) Desire for clinical parameters to help survivors understand their infertility risk; 3) Fertility-related information is important throughout survivorship; 4) Evidence-based content from a neutral source is trustworthy; and 5) The recommendation to see a fertility specialist is helpful, but cost is a barrier.

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The authors have no conflicts of interest to disclose.

#### Compliance with Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study protocol was approved by the University of California San Diego Human Research Protections Program. Informed consent was obtained from all individual participants included in the study.

**Conclusions**—BCS have concerns and needs related to their fertility potential after initial breast cancer treatment. The evidence-based information offered in our prototype survivorship care plan was acceptable to BCS and has significant potential to address these needs. Additional primary data that identify post-cancer treatment indicators of fertility would advance this effort.

### Keywords

Cancer; communication; fertility; survivorship; reproductive health; survivorship care plan

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### Background

Ten to 15% of breast cancers occur in women of reproductive age [1]. Most breast cancer patients undergo treatments that can impair ovarian function and increase risks of infertility and primary ovarian insufficiency [2]. These effects, alongside related impacts on body image and sexual health, negatively affect quality of life in survivorship [3,4]. Because many reproductive-aged breast cancer survivors (BCS) have not started or completed their families, concerns about fertility potential after completion of chemotherapy are common in this population [5–7]. For many BCS, endocrine therapy further delays pregnancy attempts, and requires consideration when making family building decisions [8–12]. However, help navigating these decisions for those who have completed their primary cancer treatment is severely lacking [7,13,14]. While the desire for information about fertility among newly diagnosed BCS is clear [15,13], the fertility information needs and communication preferences of BCS who have completed primary cancer treatment are less well studied [16,14]. Meeting this need is important for the well-being and overall quality of life for reproductive-aged women who have survived cancer [4,17–20].

To improve quality of care after cancer, survivorship care planning was recommended by the Institute of Medicine in 2006 to inform patients about effects of cancer and treatment, guide follow up care, and increase care coordination [21]. Survivorship care plans are a potentially powerful mechanism for communicating and disseminating evidence-based management of reproductive late effects to patients. However, existing survivorship care plans only minimally address reproductive health late effects (for example, [22]).

To fill this gap, we undertook development of a women’s health survivorship care plan, an educational intervention to provide evidence-based information and recommendations to address the four areas of reproductive health relevant to post-treatment BCS: fertility, contraception, sexual health and vasomotor symptoms. The current study describes results from focus groups conducted to evaluate the survivorship care plan prototype addressing fertility as part of our intervention development process. To develop the prototype, we conducted a systematic review and searched professional society guidelines for evidence on predictors of fertility potential among women who have been treated for breast cancer during their reproductive years. Our systematic review of post-treatment predictors of fertility potential among reproductive-aged breast cancer survivors yielded only one eligible study [23] and no published research indicating predictors of live birth or pregnancy. (Appendix A) We summarized current evidence and professional society recommendations related to

how a BCS can tell if she is fertile in four documents that constituted the survivorship care plan prototype. (Table 1)

Our primary objective for the current study was to assess if the fertility-related content presented in the survivorship care plan prototype met the informational needs of post-treatment BCS, and to provide an opportunity for the target audience to review and react to the proposed content and design. We analyzed feedback gathered from those focus groups, focusing on how the survivorship care plan prototype met fertility-related informational needs during the time period after primary cancer treatment (i.e., surgery, radiation, and/or chemotherapy) was completed. We then incorporated this feedback to refine the design and content of the survivorship care plan prior to testing it in an ongoing randomized controlled trial (NCT02667626). This process also resulted in identification of target areas for future research.

## Methods

### Focus groups

Between March and July 2015, we enrolled BCS between the ages of 18 and 50 years to participate in focus groups. All participants received and reviewed copies of the survivorship care plan prototype prior to their focus group meeting. Focus group discussions first explored women's fertility-related experiences and informational needs in order to set the stage for evaluation of the prototype content. Next, we systematically reviewed the prototype's proposed fertility-related content to determine if the evidence-based information presented met those needs. We recruited participants via both clinic-based and community-based outreach efforts, including patients seen at University of California San Diego Moores Cancer Center, members of local support groups, and women associated with the Young Survival Coalition (YSC). Participants were recruited via email announcements, clinic-based personal communication, the Internet, and word of mouth. Study coordinators provided standardized recruitment information, including the study's purpose and expected duration of the focus group, to all potential participants.

We conducted seven focus groups with 37 participants. Four focus groups centered specifically on fertility potential. Because aspects of fertility were often raised during discussions focusing on the other three reproductive health topics, i.e. contraception, sexual health and vasomotor symptoms, we included all seven focus groups in the current analysis. Focus group participants received \$30 to compensate them for their time. The final number of focus groups was determined by informational considerations, and recruitment ended when no new information was provided by participants [24]. The study protocol was approved by the University of California San Diego Human Research Protections Program.

A study investigator (JG) and trained research team member (SADR) conducted all the focus groups to maintain interview structure, reliability, and consistency. JG and SADR are academic researchers with non-clinical backgrounds and reproductive-aged women with no history of cancer, and recognize the possibility that their positions could have affected participants' willingness to talk openly. Each group was one to two hours in length and followed a semi-structured interview guide with open-ended questions. Each participant

completed a written survey about demographics, cancer characteristics, and reproductive health prior to each group. All groups were recorded and transcribed for analysis.

We developed focus group questions about experiences and informational needs based on our prior research [25]. These included questions about context, content, discussions and decisions about fertility options and fertility potential (e.g., After your cancer treatment, did you talk with anyone about how your future fertility might be impacted by treatment?) as well as information-seeking behavior (e.g., Where have you gone for information about fertility for young cancer survivors?) We then collected specific feedback on the fertility potential content and design of the survivorship care plan prototype to determine comprehension, credibility and persuasiveness (e.g., What do you think about the wording used in this section? How can we change the information in this section to make it better?). Our interview guide was flexible to encourage a conversational style and to allow participants to raise topics.

We conducted thematic analysis. We used cross-case analysis, combining all data for analysis, and a data-driven, inductive approach where codes and themes emerge from the data [24]. Two coders (JG and AJ) independently coded the transcripts and came to consensus on a list of codes. This process included reading and re-reading the data and coding (marking text segments with descriptors) to begin developing common themes. A third reviewer (SR) used these codes to independently review and code the data. After this coding process, a study investigator (JG) and research assistant (AJ) reduced the data to develop and come to consensus on themes and sub-themes and a final overall interpretation of the findings [24,26]. We imported the data into the Dedoose software package for coding and analysis [27].

## Results

The mean age of participants at enrollment was 39.4 years (SD 5.0, range 28–50 years), which represents an older group of reproductive-aged breast cancer survivors. Participants were predominantly white (68%), college graduates (94%) and married or in a committed relationship (82%). The mean age at breast cancer diagnosis was 36.5 years (SD 5.4, range 25–45 years). Most received surgery (88%), chemotherapy (85%) and/or radiation (79%) treatment (Table 2).

We identified five themes that describe post-treatment BCS' reactions to the prototype in the context of their informational needs and experiences: 1) The prototype's fertility-related information is relevant; 2) Desire for clinical parameters to help survivors understand their infertility risk; 3) Fertility-related information is important throughout survivorship; 4) Evidence-based content from a neutral source is trustworthy; and 5) The recommendation to see a fertility specialist is helpful, but cost is a barrier.

### Theme 1. The prototype's fertility-related information is relevant

Overall, participants had a positive response to the fertility-related information presented in the survivorship care plan. One woman said, "*I read through this packet last night, and I was like wow this is so great, I wish I had [this] before. It is a lot of good information. I like the*

*charts on it the most. They're just easy to read...*" Another woman said, *"...I like the bottom line. It's, it's like, oh I need to read more, or okay that answers my question, I can move on."* Overall, participants welcomed the depth and breadth of evidence-based information about fertility potential after cancer, and appreciated knowing when there was a lack of existing evidence about a particular topic. They agreed that the survivorship care plan provided relevant and often times new information. As one woman said, *"Even just addressing the [reproductive health] issue is on the right track. Like acknowledging that that's an issue that women are concerned about. I feel like that's a glaring hole."* Similarly, other women commented:

"Reading through [the prototype], these are great, there's actually a lot of info in here that I wasn't aware of that some stuff that jumped out was probably stuff that my oncologist should have let me know."

"I think [the prototype is] really good... I feel like there's not a lot of information given on this stuff."

Participants also felt that the having the information in the prototype would encourage them to have conversations with their healthcare providers about fertility and having children after cancer.

"I love my oncologist, and I appreciate that her focus is making sure I get through it as best I [can]... she doesn't care if I'm going to have more kids. That's not her problem...but now [with this prototype] I can talk to her about the things I want to talk to her about when I have more information. Its' good."

"And [being off treatment], it's super exciting but it's also kind of scary, it's like wait a second, I'm on my own now? Everything feels lumpy, so to have some sort of plan, to know these [topics in the survivorship care plan] are things that could happen ...I think it also gives you a way to talk to your doctor because the door is open."

## **Theme 2. Desire for clinical parameters to help survivors understand their infertility risk**

When reviewing the prototype content, participants talked about how the information could help them interpret and put into context their own symptoms and test results. For example, one woman said:

"I would love to have maybe a range [of what is expected], because I didn't get my period within six months and I was kind of freaking out because that was the number I'd seen a lot. And it was like, until when? When do I freak out? And I think it says 'two years later' in the writing [on the prototype]"

Another said

"I had my FSH tested, and [I would like to know] what's considered high. I mean, I know that comes on your test but I still had to look it up because I was still a little confused on what it meant. And it would be nice to [have a] number interpretation."

Many participants wanted the prototype to include more details that would inform them about their infertility risk based on age or cancer treatment type:

“I don’t know if you have this information, but I think a table [showing your risk] ... would also be good along those lines, of if you are trying to get pregnant, had chemo, if you’ve had chemo and radiation, if you’re a healthy person, [what are] the chances [of pregnancy].”

“...it would almost be nice to have [information like] if you’re 25, you have a really good chance of getting your period back ... versus someone who is 40.”

Participants viewed the prototype as resource that could help them put their experiences into context. Participants explained how statistics presented in the survivorship care plan made them “*feel relief*”, “*feel better*” and gave them some “*power back*”.

### Theme 3. Fertility-related information is important throughout survivorship

Participants contemplated the ideal time to provide information in the prototype to BCS. While many wanted more fertility-related information at the time of their diagnosis, they also saw the benefit of receiving this information at the end of treatment in preparation for what comes next. As one woman said, “*I think it’s a great idea what to expect after, what to expect when you think you’re done [with cancer treatment].*” Many also felt they would be more “*ready to deal with it*” after completing their primary treatment. For example, one participant said “*...when you’re in treatment you’re just trying to survive the cancer. And, whatever [else comes up] I’ll deal with that later.*”

Others said

“You could be feeling so overwhelmed you’re like okay I’ve got too much, but then later when you start healing and when you get to that better place, then yeah so things change. This is good if you have the information and you go there when you’re ready for it. You know?”

“Even if you don’t have concerns, you might have them in six months or in one year or in two years... you know it’s available for when you might have that become an issue. And you can always change your mind. When I finished treatment, I was like I’ll never get pregnant again. And now we start discussing about are we going to get pregnant? So we change, right?”

### Theme 4. Evidence-based content from a neutral source is perceived as trustworthy

When reviewing the prototype content, most women found it trustworthy because it provided a summary of evidence based on current research and was developed at an academic medical center. When asked where they would typically go for such information, most reported that they looked to the Internet for answers to their questions about fertility and menopause after breast cancer. One woman said, “*I spent a lot of time on Google looking up, you know, exactly when is my period going to come back? What do I expect?*” Despite this inclination, several women also talked about how the experience of gathering and looking for medically accurate, trusted information online was challenging. One participant said, “*Every question I would think of, I would go on the computer and... I was researching them because you can’t stop yourself. You can’t ... That’s like the worst place for people to go. It’s the worst.*” Women discussed how the survivorship care plan’s web-



based content and references to primary research and professional society guidelines would make it easier to find trustworthy information online. Some women contrasted this with materials they had seen in in doctors' offices but did not find trustworthy because of the source. For example, they talked about questioning, *"Who put this together? What was this based off of?"* and *"...sometimes I'm thinking oh, it's just being pushed because someone, pharma pushed it or whatever."* These conversations emphasized the importance of a neutral, trusted source of information.

#### **Theme 5. The recommendation to see a fertility specialist is helpful, but cost is a barrier**

When discussing the recommendation to talk to a fertility specialist in the prototype, several participants said that they had received similar information during consultations with a fertility specialist. While saw the potential benefit of talking to a fertility specialist after their cancer treatment, they felt that the cost of specialized care would be out of reach for many. Participants said, *"But I mean, it's expensive you know, to see all of these wonderful people. It's not cheap."* and *"It's just such a burden depending on your insurance, and you get all these different options but how feasible are, how feasible are they?"* Others comments about the expense were, *"It's out of pocket!?"* and *"I know I can't do that."* Some felt that, because cost was such a barrier, the expense of fertility care should be included in the survivorship care plan:

"I would say my only concern would be insurance and whether or not this type of stuff is covered. You know, I mean just my personal experience you know, after I was kind of done with treatment I wanted to see what kind of test I needed to do to even see if I was able to have you know, a baby and just like, it was very difficult for me to find resources, find just anyone that would even deal with what insurance I had. And then just to get more information and [find out] what I needed to do. So that was really hard. So maybe just touching on this like a lot of these things would not be covered. You know?"

"I would put links to whatever [financial help] there is out there, but also you're right, about putting the cost because if it's a 23 year old, they're going to be like really? That was my down payment on my house."

## **Discussion**

Participants in this study were enthusiastic about the fertility-related information included in the survivorship care plan prototype, and offered valuable feedback to refine the plan's content to ensure relevance and acceptability for intended users. While professional societies have identified strategies for informing women about the potential impact of cancer treatment on fertility potential at the time of diagnosis [28,29], the results of our study highlight the perceived benefit of receiving trusted, evidence-based information on fertility after completing primary treatment. The resulting survivorship care plan is a feasible strategy to deliver such information.

Participants indicated that the prototype was trustworthy, provided relevant information, and could help them raise questions with healthcare professionals. This is particularly important because some women feel that their fertility concerns are not adequately addressed or are



undervalued by healthcare professionals [25]. Participants expressed a strong desire for inclusion of clinical parameters to help them understand their infertility risk, but were also surprised by the limited evidence that was available to answer their questions. For a BCS who has completed primary cancer treatment, the body of evidence on predicting her fertility based on post-treatment measures remains scant or non-existent in a number of areas, which limits informed decision-making. Women also wanted to access the prototype at varying times in survivorship, when they were “ready to deal with it.” Some may feel less overwhelmed and be more prepared to think about parenthood after primary cancer treatment is over [14].

BCS in this study also pointed out that fertility consultations and services were not accessible for most women, and wanted the prototype to include information about expected cost. Indeed, only a very small proportion of cancer survivors report consulting with a fertility specialist after treatment is over [14], and some may be hesitant to seek care later in survivorship for fear of infertility [25,30]. Our results suggest that a survivorship care plan could serve as a key source of information for those who are unable or choose not to seek fertility care after their cancer treatment.

This study was unique in that we focused on developing a strategy to meet the fertility-related needs of BCS who had completed their initial cancer treatment, but there are limitations. First, our focus group sample was relatively homogenous. Participants were predominantly college educated, two-thirds were white, and they resided in an urban area with several large health systems offering cancer care. Because of this, our participants likely had better access to resources and information than many other BCS, making their challenges and unmet needs even more striking. However, the homogenous sample limited our ability to detect variation in communication and information preferences that exist across racial, ethnic, socioeconomic, and other characteristics [31]. Our sample is also limited to BCS who chose to participate in a research study about their reproductive health needs and received an incentive to do so. As such, they may have different views and experiences related to fertility-related information and communication than other BCS. We did not ask questions about participants’ sexual orientation, so were unable to explore potential differences across groups. Finally, while the sample included women between the ages of 28 and 50 years, the mean sample age of 39 is representative of women in their later reproductive years who may have different perspectives from women in their earlier reproductive years.

Many BCS want reliable information about their fertility potential more effectively and efficiently than the commonly implemented “wait and see” approach [15,13,16,14]. Our results suggest that the survivorship care plan was an acceptable approach to sharing such information. However, our discussions also underscored the need for more research to provide sound evidence about fertility potential to BCS who have completed their primary cancer treatment. Based on our systematic review of the literature that informed the fertility-related content for the prototype, longitudinal research evaluating how post-treatment predictors, such as biomarkers, are associated with clinically important reproductive outcomes, such as live birth, is sorely lacking. Incorporating existing and emerging evidence

into survivorship care plans may be a salient strategy to help BCS and their healthcare professionals make informed decisions about fertility and family planning.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

Overview of fertility content for the survivorship care plan prototype

| Section                                 | Description   | Content Areas   |
|---|---|---|
| 1. Question & Answer                    | Brief summary of evidence   | Is it safe to become pregnant?<br>What are family building options after finishing breast cancer treatment?<br>How can a breast cancer survivor tell if she is fertile (able to have children)?<br>Will fertility be affected by using tamoxifen?<br>Will fertility be affected in women who have BRCA1 or BRCA2 gene mutation?<br>Will fertility be affected using GnRH agonist (for example, Lupron) during chemotherapy? |
| 2. What Does the Evidence Show?         | Detailed summary of evidence with planned hyperlinks to primary research articles                                       | Safety of pregnancy after breast cancer<br>Assessing fertility after breast cancer<br>Birth outcomes after breast cancer<br>Impact of cancer and cancer treatments on fertility<br>Fertility considerations for BRCA1 and BRCA2 carriers  |
| 3. Resources                            | Recommended web-based resources for survivors and healthcare providers within each content area with planned hyperlinks | Safety of pregnancy after breast cancer<br>Assessing fertility after breast cancer<br>Birth outcomes after breast cancer<br>Impact of cancer and cancer treatments on fertility<br>Fertility considerations for BRCA1 and BRCA2 carriers  |
| 4. What do the Clinical Guidelines Say? | Summary of relevant guidelines with planned hyperlinks to each  | Clinical Guidelines from:<br>National Comprehensive Cancer Network<br>American Society of Reproductive Medicine<br>American Congress of Obstetrics and Gynecology<br>Children's Oncology Group<br>American Society of Clinical Oncology   |

**Table 2.**

Characteristics of focus group participants (N=37)

|  | Overall N=37 <sup>a</sup> |
|--|---------------------------|
| Mean age (SD) at enrollment              | 39.4 (5.0)                |
| Race                                     |                           |
| White                                    | 23 (67.7)                 |
| Non-White                                | 11 (32.3)                 |
| Hispanic/Latina                          | 7 (20.6)                  |
| Marital Status                           |                           |
| Marriage or committed relationship       | 28 (82.4)                 |
| Single                                   | 6 (17.6)                  |
| Education                                |                           |
| Less than college graduate               | 2 (5.9)                   |
| College graduate or post graduate degree | 32 (94.1)                 |
| Income                                   |                           |
| 50,000                                   | 3 (8.8)                   |
| > 50,000                                 | 26 (76.5)                 |
| Prefer not to answer                     | 5 (14.7)                  |
| Mean age (SD) at breast cancer diagnosis | 36.5 (5.4)                |
| Cancer stage                             |                           |
| 1  | 7 (20.6)                  |
| 2  | 13 (38.2)                 |
| 3  | 12 (35.3)                 |
| 4  | 1 (2.9)                   |
| Cancer therapy                           |                           |
| Surgery                                  | 30 (88.2)                 |
| Chemotherapy                             | 29 (85.3)                 |
| Radiation                                | 27 (79.4)                 |
| Hormonal                                 | 20 (58.8)                 |

<sup>a</sup>Due to missing responses, not all numbers add to 37