

How do you feel about fertility and parenthood? The voices of young female cancer survivors

Jessica R. Gorman · Samantha Bailey · John P. Pierce ·
H. Irene Su

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Abstract

Purpose Young adult cancer survivors are often unaware of their fertility status and uninformed regarding their fertility and fertility preservation options. This qualitative research study explores the fertility and parenthood concerns of reproductive-age female cancer survivors and how they make parenthood decisions.

Methods Population- and clinic-based recruitment methods were used to identify a diverse group of survivors between the ages of 18 and 34 years. Our final sample size included 22 participants who attended one of seven focus groups. We used cross-case, inductive analysis to identify themes.

Results The following main themes were identified: (1) A hopeful but worried approach to fertility and parenthood, (2) Frustration with a lack of choice or control over fertility, (3) Young survivors want information about their fertility, (4) Young survivors want better continuity of care in survivorship, (5) Cancer diagnosis and related fertility problems introduce relationship challenges, and (6) Decisions about parenthood are complicated.

Conclusions The diverse group of young cancer survivors in this study identified several common needs and concerns regarding fertility and parenthood. This study illustrates that young survivors could benefit from improved information regarding their fertility and parenthood options throughout

survivorship, better coordination of medical care, and support navigating many emotional and practical issues that arise when considering their reproductive and parenthood options.

Keywords Fertility · Parenthood · Reproduction · Cancer · Survivorship · Adolescent · Young adult

Introduction

Both childhood and adolescent and young adults (AYA) cancer survivors are increasingly surviving their disease [1, 2], resulting in a substantial and growing population of female cancer survivors of reproductive age. Young cancer survivors are less likely to have biological children than the general population [3–5], although the factors influencing this outcome are unclear. Some cancer treatments are associated with late effects on reproduction including premature ovarian failure and infertility [5–7]. Most young survivors are unaware of the impact of their treatment on their fertility status [8], and there are limited clinical tools to measure fertility and ovarian function [9].

Previous studies with young cancer survivors have highlighted the importance of patient–provider discussions of fertility issues and identified concerns about infertility, risk of cancer recurrence, impacts of pregnancy on personal health, and sexual function [8, 10–15]. Fertility concerns are paramount for many young cancer survivors and associated with poorer quality of life, depressive symptoms, and distress [16–18]. However, patient informational needs regarding fertility issues are not being adequately addressed among AYA survivors, a medically underserved population to which reproductive potential may be particularly important [14, 19–22]. Furthermore, there is limited research on how these concerns may vary across racial and ethnic

J. R. Gorman · S. Bailey · J. P. Pierce
Cancer Prevention and Control Program,
Moores UCSD Cancer Center, University of California,
San Diego, La Jolla, CA, USA

H. I. Su (✉)
Department of Reproductive Medicine and Cancer Prevention
and Control Program, Moores UCSD Cancer Center,
University of California,
San Diego, La Jolla, CA 92093-0901, USA
e-mail: hisu@ucsd.edu

groups, but some indication that young survivors from non-white racial and ethnic groups may have greater informational needs regarding fertility [20].

While research indicates that fertility and parenthood are important issues that concern many young survivors, biological parenthood is less likely than in the general population [3–5, 23, 24]. There is evidence that both biological and psychosocial mechanisms may impact this outcome [4, 11, 25]. In this qualitative exploratory study, we aim to further explore the fertility and parenthood concerns of a diverse group of female AYA survivors and the mechanisms that may help us understand their reproductive decisions.

Methods

Participant recruitment

We enrolled participants between February and July 2011. To increase diversity in the participant pool, we used both clinic- and population-based approaches to recruitment. Participants were recruited by providing information about the study at obstetrics and gynecology practices, student health, Moores Cancer Center at the University of California San Diego, and Rady Children's Hospital San Diego. Community-based recruitment methods included advertisements (e.g., university newspapers, Craigslist) and outreach through local cancer support and advocacy groups (e.g., I'm Too Young For This! Cancer Foundation).

We identified 33 participants who were eligible and interested in participating in a focus group. The final sample size included 22 participants who were able to attend one of the scheduled groups. The final number of focus groups was determined by informational considerations; recruitment ended when saturation had been reached and no new information was provided by participants [26]. The study protocol was approved by the University of California San Diego Institutional Review Board.

Interviewing and data collection

The principal investigator (JG) and a research assistant (SB) conducted seven focus groups, 1.5 to 2 h in duration, between February and August 2011. We used a semi-structured interview guide so that we covered the same general topic areas during each focus group. Questions were open-ended to facilitate conversation on each topic, and participants were encouraged to elaborate on their answers and talk with each other during the meeting. Data were recorded and transcribed for analysis.

The questions were guided by our previous research [13] and existing literature exploring fertility and reproductive issues with adolescent and young adult cancer survivors.

We covered a broad range of topics during each focus group, including knowledge about the relationship between fertility and cancer treatment; access to information and care, including fertility preservation options; feelings toward fertility, pregnancy, and parenthood; and experiences navigating fertility and reproductive issues as a cancer survivor. The interview guide was flexible to allow for new topics of discussion that were brought up by participants.

Analysis

We used a cross-case analysis where data from all participants were combined for analysis [26]. Using a data-driven inductive approach [26], we identified themes and sub-themes from dominant concepts in the raw data. This iterative approach allowed for the modification of ideas and themes throughout the analysis process to accurately represent participants' experiences. Data interpretation was an iterative process that included a continual review of transcripts to identify potential gaps in questions and additional areas for discussion. The principal investigator (PI) and research assistant independently coded the data using the following steps: (1) reading and re-reading qualitative data to become familiar with the text and begin developing codes, (2) coding data (marking text segments with descriptors) to begin developing themes and sub-themes, and (3) exploring themes by looking for variations such as differences between individuals and among subgroups. After the initial coding process, the PI further reduced the data to essential points, identified final themes, and developed an overall interpretation of these findings [27]. The final themes required consensus between two coders after rechecking the original transcripts to ensure that the meaning and intent of the participant comments were accurately captured. Transcripts were imported into the QSR NVivo 9 software package [28] to code, sort, and analyze the data.

Results

Participants' characteristics

Half of the participants were recruited through clinics and half through community-based outreach efforts. Participants included childhood, adolescent, and adult cancer survivors. The average age at diagnosis was 16.8 years, with a range of 6 months to 30 years. Cancer diagnoses covered a broad range, with the most common being lymphoma, breast, and thyroid cancer. Most participants were between the ages of 21 and 25 years and either married or in a marriage-like relationship. Just under half were from non-white racial/ethnic backgrounds, with about a third reporting Hispanic or Latina ethnicity (Table 1).

Table 1 Participant characteristics (*N*=22)

Characteristic	Number (%)
Current age (years)	
≤20	2 (9)
21–25	9 (41)
26–30	6 (27)
31–35	5 (23)
Life stage at cancer diagnosis	
Childhood (≤14 years)	5 (23)
Adolescence (15–19 years)	10 (45)
Young adulthood (20–35 years)	7 (32)
Married or marriage-like relationship	13 (59)
Race	
White	12 (55)
Non-white	10 (45)
Hispanic or Latina ethnicity	7 (32)
Education	
Less than college graduate	9 (41)
College graduate or postgraduate degree	13 (59)
Cancer type	
Lymphoma	6 (27)
Breast	4 (18)
Thyroid	3 (14)
Bone	2 (9)
Other ^a	7 (32)
One or more biological children	2 (9)
Wants a(another) child	19 (86)
Current view of fertility	
As fertile as others my age	5 (23)
Less fertile than others my age	13 (59)
Unable to have children (infertile)	3 (14)
Don't know	1 (5)

^a Other cancer types include bladder, blood, brain, eye, leukemia, ovary, soft tissue

Themes

Six themes emerged from the analysis of the focus group data: (1) A hopeful but worried approach to fertility and parenthood, (2) Frustration with a lack of choice or control over fertility, (3) Young survivors want information about their fertility, (4) Young survivors want better continuity of care in survivorship, (5) Cancer diagnosis and related fertility problems introduce relationship challenges, and (6) Decisions about parenthood are complicated.

Theme 1: A hopeful but worried approach to fertility and parenthood

Participants discussed plans to wait until a time in life when they were ready to have children to investigate their fertility

and parenthood options. For example, stating “I think when I kind of arrive at the point where, okay, I’m going to go off birth control and I’m going to start, try to work towards this, I think I’d definitely talk to my doctor.”

In general, participants felt hopeful about having children someday and found reasons for optimism in others’ experiences. As one participant said, “[My] mom’s friend...she had gotten cancer when she was 21, Hodgkin’s. And they told her you’re not able to have kids, you’re not going to have kids. And she had 2 kids. So I guess you just never know.” Additionally, participants were open to the option of adoption if they were unable to have a biological child.

I’m really excited about it [having kids]. Since I haven’t been told to my face, “No, you can’t have kids”, I’m always optimistic about it. But I completely love kids and I want to have babies. So it’s like, even if you’re not my own I plan to have peace with myself, I guess, to say that anybody’s kid, like, I can completely take care of them because I just love children. And I’m willing to do whatever it takes. (Age 21, adolescent cancer survivor)

While participants expressed hope about having a family, many also felt anxious and worried that they would be unable to have their own children. As one woman said, “I keep on picturing Finding Nemo with that little egg that was cracked. That’s how I think my eggs are, a little crack, coming out with the little fin.” For many, this worry resulted in a delay in seeking medical care and information about their fertility status.

It’s just become like a recent, like I said, very recent discussion so I thought about it. And it’s partly not making time for it and it’s, even though I think I want to know, part of me’s like, leans towards maybe I don’t also. So, or maybe I don’t have time to deal with that right now or don’t have the emotional energy to deal with that right now in case it’s bad news. (Age 26, young adult cancer survivor)

But it’s almost one of those things where it’s like the more we know, the more shadows there are, the more demons under the bed there are. (Age 28, childhood cancer survivor)

Theme 2: Frustration with a lack of choice or control over fertility

Participants acknowledged that a discussion about fertility at the time of diagnosis would be overwhelming and difficult to absorb. Regardless, they expressed a strong desire to be

told (and/or for their parents to be told) about the impact of treatment on their fertility and fertility preservation options prior to the start of treatment.

Participants talked about two frustrating scenarios regarding discussions about their fertility: (1) Their healthcare providers offered no information or very limited information about fertility issues, or (2) They were provided with sufficient information but were unable to take advantage of any measures to protect their fertility.

Sub-theme 2a: Healthcare providers did not provide enough information about fertility issues

Participants discussed several perceptions about why their providers had not discussed fertility at the time of diagnosis or afterward, including that providers were uncomfortable talking about it and did not think it was important.

The only things that were really brought up with me were the immediate issues of treating the tumors. It wasn't like after effects or what was going to happen in the future. It [fertility] was really not something that was discussable...It was like the doctors kind of had this almost unspoken rule that you just didn't discuss that part...It was very uncomfortable for them...and it wasn't a pleasant experience. (Age 21, childhood cancer survivor)

I think they [oncologists] just don't care about that [fertility]. I find that now still with my bone marrow transplant doctor is just like, well, you look great, cancer's gone. That's it. Well, what about like post cancer, post treatment. There's so much more to it but he just, like he's just kind of they'll go around it like. (Age 31, young adult cancer survivor)

For some, the impact of not discussing fertility prior to treatment was a major concern. As one woman said, "And I think it was very recently that anyone brought up that it was possible that they could've done some preventative measures at the time. And that was more disheartening than anything, that no one discussed that."

Sub-theme 2b: Informed but unable to take advantage of fertility preservation options

Some participants said that they had been well informed about the potential impact that their treatment could have on their fertility. However, most were unable to take advantage of any fertility preservation options because of their cancer type or stage. For example, one participant said "He did mention freezing eggs, but that there's a long wait so...he mentioned it but they really wanted to start chemo right

away. So there was no waiting." One young breast cancer survivor described her experience this way:

I didn't even know that it would affect fertility but... pretty quickly they started talking about it...I remember they told me in the doctor's office that they said something about freezing eggs...I said okay, here, I can do that. But then when they told me that I was, my cancer was estrogen positive and they weren't going to be able to freeze eggs and I just like burst into tears. (Age 27, young adult cancer survivor)

Another young woman described her frustration with her lack of options for fertility preservation.

I didn't think it was too fair because...I was really trying to do it [fertility preservation] and they said no. They're like, you don't have time, you got to go through radiation and chemo and then finally get stem cell. But they told me after I couldn't do [fertility preservation] anymore, that I couldn't have kids. So they said like after I'd done radiation on my hip ten times, they told me you cannot have kids because your ovary is right here so it hit your ovary. So they kind of told me after the fact and didn't give me no option to do it before. I was mad, but nothing they can do [now]. (Age 19, adolescent cancer survivor)

Theme 3: Young survivors want information about fertility issues from their healthcare providers

All participants in this study reported that they would prefer to receive information about fertility issues from a healthcare provider. Several women reported regret that their doctors had not talked with them about fertility, saying for example "I just wish my doctor would have talked about it more with me because she kind of would dance around the subject so we never really got to talk about it." When asked to describe when fertility issues should be discussed, participants reported that this should be done prior to treatment beginning with patients and/or their parents.

Additionally, the timing of discussions with healthcare providers was important. Participants felt that a young woman was old enough to have this discussion anytime after puberty. For example, one woman said "I mean I was embarrassed that they talked to me about [fertility] when I was 17...but at the same time I'm glad that has always been something that like I've known and can talk about." Similarly, another said "I mean, if you're a woman and you're at an age where you have your period...you should totally know about that [fertility]."

Several participants also discussed disappointment that their doctors were hesitant to talk with them about fertility issues and wanted to postpone the discussion until they were older and at a time in life when they were ready to have children. For example, participants reported that their doctors delayed a discussion of fertility, saying “In the future, when you want children, or if you decide you want children, they we’ll worry about it then” or “Well, when you get to that point we’ll find out.”

A common reason for wanting to have information about fertility at a younger age was related to the desire to plan and prepare for the future.

They said the same thing to me, like, we’ll think about it when we get there. So they just keep putting it off and putting it off. And I’m like I’m 23 so I’m going to have to start planning where big things are going to fall pretty soon. And so I mean, I’m up for another round of radiation, like, I think next month or the month after. And they still haven’t discussed it with me...of course I called my parents and asked them...they just said when we get there we’ll discuss it. (Age 23, adolescent cancer survivor)

I kind of stopped asking about it because I got the answer we’ll find out when we get there so often. And I’d rather just know now. I think that makes planning in the future a lot easier. So then I could work towards accepting or planning otherwise. (Age 26, young adult cancer survivor)

Participants also emphasized that because young women diagnosed with cancer are generally unaware of the potential impact of treatment on their fertility or their preservation options, their healthcare providers need to initiate the discussion.

I think the doctor should bring it up, especially if it’s after puberty for a girl. Because I think knowing about it beforehand would help and then, like, at the end of treatment probably bring it up again...they didn’t say anything until the end of treatment...and I don’t know, I just didn’t think about it...I wasn’t thinking about fertility. And when they told me that I might not be able to have kids, like, I knew it in the back of my head...I mean I felt really kind of devastated at first. (Age 19, adolescent cancer survivor)

Young breast cancer survivors in this study were more likely to report having a discussion about the impact of treatment on fertility and preservation options with their oncologists.

I feel like my doctors did a good job [talking about fertility]. I think maybe because...I had breast cancer and so there’s a lot of hormone concerns with that. And so I think maybe it’s just more on their minds. Also I think that it’s because you have to do hormone therapy afterwards. I think it’s a big...I mean it’s just something that they end up discussing more, plus the age range of people. (Age 27, young adult cancer survivor)

Theme 4: Young survivors want better continuity of care in survivorship

Women in this study expressed a strong desire for improved quality of care in survivorship that focused on the “big picture.” They told several stories about their frustration with the poor coordination of care between their multiple medical providers, including care related to fertility and pregnancy planning. A young lymphoma survivor explained one of the reasons she believed her doctors were hesitant to tell her anything about her fertility.

I think that there’s a big gap also in...the issue of care for [fertility issues]. So, I don’t see the oncologist that I went through during my treatment anymore. I have a general practitioner and...my gynecologist. I think between those three there’s like a huge gap in, I don’t know if it’s knowledge or just what you’re supposed to tell someone who’s been through what I have, or the differences [between doctors]. And I think that’s probably why I get the “we’ll get there” [when you’re ready to have children] answer. (Age 23, adolescent cancer survivor)

Several participants also perceived that poor coordination of care was a problem for young adult cancer survivors in general, describing a feeling that “you have to do it all by yourself.”

So, I mean for me to physically have to bring all of my medical records to every single appointment it just like it alerts me to the fact that overall patient care is not the goal, that each department is only I guess objectifying your respective condition. So I really feel like when, especially when you have an ailment like cancer, they really need to look at the big picture because...you never know if your illness is due to what you’ve already been treated for or if it’s just a regular getting sick like everybody else. (Age 23, adolescent cancer survivor)

I had one bone marrow transplant doctor, and then the BMT nurse would say one thing. Then that doctor

would [say] another thing...and then I'm like, well who do I [believe]? It's so frustrating because it's like well who's right...I'm like, well, don't you guys all communicate?...It's really frustrating....I need to be my own doctor here and figure things out for myself because one doctor will say one thing and then....I was on one medication for like 4 years. And they were like, oh, you weren't supposed to be on that that long. (Age 31, young adult cancer survivor)

Theme 5: Cancer diagnosis and related fertility problems introduce relationship challenges

Study participants also talked about relationship challenges that arose because of their cancer history and uncertainty about their ability to have children. The first challenge was telling a potential partner about their cancer diagnosis. Two participants explained, "...telling your story to someone that you, that's basically not a close person but you feel like you want them to be is difficult to this day, 8 years out" and "Well, the whole opening up thing and telling someone, it's really hard because I don't want a pity party. I don't want someone to feel sorry for me. I don't want them to judge me."

Participants further explained how this discussion was complicated by the fact that they may be unable to have biological children someday. Women described some of the ways this issue made dating difficult.

That's [dating is] so weird. It's like when do you tell someone, "Oh by the way, like, I had cancer and there's a chance I won't be able to have a kid. Is that a problem?" (Age 30, young adult cancer survivor)
...The last person I dated, like that was kind of what broke it. Even though you're only a month in that just was the final straw discussing children and options, just because I wanted to be open from the start. So now I guess I have a new approach where I'm going to figure it out if we get there. And it hasn't come up in conversation. (Age 23, adolescent cancer survivor)

Other women also talked about how cancer-related fertility issues could impact on a more stable relationship.

And so I guess the problem for me wouldn't be whether or not I want to adopt or have my own kids but whether or not my partner would want to have their own kids or adopt so that complicates things....It feels like it's something that only you have to deal with...it could be a deal breaker. (Age 23, adolescent cancer survivor)

Finally, some participants were worried about the potential negative impact that fertility problems would have on their partner. One concern regarded involving a partner in a difficult medical process in order to become pregnant.

...but it's, when you start going for the [fertility] treatments and when you start dealing with medical professionals, that's when it gets a little bit kind of like, where do you turn for the best options for that and how do you make the best informed decisions together when you've already been through it? You're the cancer survivor and the person that you're marrying probably has no idea what they're dealing with because they didn't go through the cancer with you. (Age 28, childhood cancer survivor)

Theme 6: Decisions about parenthood are complicated

When asked about their feelings and plans toward future parenthood, survivors in this study identified several factors impacting their decisions and future plans. These included both emotional and practical barriers to parenthood.

Subtheme 6a: Emotional barriers to parenthood

Participants identified two primary emotional obstacles to parenthood—worry about their personal health and survivorship and worry about their potential child's health.

Many women expressed concerns about their child's genetic risk and family history of cancer.

Actually I, personally, I worry about having a child just because I know a lot of my family's had cancer and I have had cancer...Its like am I, [are] my genes are just predisposed to cancer and is it responsible for me to have a child? (Age 30, young adult cancer survivor)

I think potentially the genetic thing [is a worry] as well because in our family line there's been like, going back for generations, there's been solid tumor cancers kind of like, every generation somebody has gotten something. So I think that definitely would be a little bit of a concern. (Age 25, childhood cancer survivor)

Others discussed anxiety about how pregnancy might negatively impact on their health.

...and then I've heard of women who had breast cancer and pregnancy makes it grow more and so hopefully it's all gone now. But if it wasn't, I think I'd be really nervous the whole time. So it's like I

really, really want to be able to have kids. But when I actually start trying to realistically think about it I know that I'd be really nervous and then if it was a girl I'd be really nervous. (Age 27, young adult cancer survivor)

Young women were also worried about their own long-term health and survival and how that might impact their family.

...and more for me now knowing all the long-term side effects of things, definitely like recurrent disease somewhere else or just secondary cancer. Getting sick and I don't know, like you already had a child when you were sick, and I just can't even imagine. (Age 25, childhood cancer survivor)

I do want to try to have my own kids. But if I were to get sick when they were young how are they going to deal with it? So I'm not necessarily only worried about my kids having to deal with it for themselves, I'm worried about how it's going to affect family structure, how it's going to affect morale or their emotional development, things like that....There's no manual so we're all kind of just best guessing it. And I just don't, I just don't know how it will be if I can't be there for my kids the way that I want to after I have them. (Age 23, adolescent cancer survivor)

Subtheme 6b: Practical barriers to parenthood

Participants described several practical barriers to parenthood. One young survivor described her feelings this way:

So, you know, the possibility of having kids is just this road that's full of like landmines for me. Oh, I really want kids, like the one thing I've always wanted is children. But to have them is going to be a really big obstacle course. (Age 28, childhood cancer survivor)

Participants discussed three main practical obstacles to parenthood: (1) the costs of becoming a parent, (2) the need for financial stability, and (3) having a life course that would allow them to have a child within a potentially shorter window of fertility.

Participants overwhelmingly reported cost as their "number one" concern when thinking about becoming a parent. Costs included medical treatments that might be necessary to have a biological child, such as services provided by a fertility specialist, the cost of pursuing adoption or surrogacy, and the cost of having a child that could require expensive medical care. One young survivor said, "I think if I had better health insurance I probably would [see a fertility

specialist], but I have such a high deductible I can't justify it right now....still paying it off, cancer bills." Similarly, another reported that cost was a major issue, "especially when you're young and you're trying to make it and support yourself." Anticipated costs associated with having a child, including time and effort, were viewed as significant barriers to parenthood.

I mean that's [cost is], like, our number one concern. I always say that people that get pregnant when they don't try, I'm like, you got pregnant for free! I think that's like the hardest thing. I'll have to pay for my kid. Just knowing that, so I'm frustrated with how much it actually costs to go through all of that. (Age 25, childhood cancer survivor)

Yeah I mean it's a whole thing. In vitro, it's shots and it's like hormone shots and you see the doctor a lot. It's like a whole thing and I don't know if I'm willing to commit to that. (Age 19, adolescent cancer survivor)

Women in this study identified a need for greater financial stability as a precondition for parenthood. This need for financial stability was associated with concerns about personal medical care as a cancer survivor, potentially having a complicated pregnancy, and worries about having a child with medical problems.

I'm, first of all, I know that I'm going to have to wait longer than I would have liked to, to have kids, whether adopted or my own because I need to be financially ready for whatever, whatever that situation brings because adopting is very expensive...and making sure that I have a [health] plan that covers everything that my child could possibly need, it's going to be, I mean, I've just settled that. I'm going to have to wait maybe 4 or 5 years longer than I would have wanted to....And so now I'm thinking to myself if I don't hustle with my education then I'm not going to be able to afford to have cancer. And if my kids have cancer I'm not going to afford for them to get proper treatment. (Age 23, adolescent cancer survivor)

Finally, participants discussed their concerns about when and how they would find time to have a child. Several women reported anxiety about having a "shorter window" of time in which to have a biological child felt pressure to get their "ducks in a row" in time.

And I'm also worried about that window, like between like 28 and 37. Is that the only time I'm going to have? So I mean I just don't know like I have more, more treatments and more scans coming up. And it's kind of

like this looming like you never know what they're going to find. And they always think they just found something. And then you don't find out till like 3 months later that it was nothing....So I just kind of also worry about like when I have them like will my window of opportunity be smaller, will I be able to pinpoint that window of opportunity, if I want to have another one after I've already had one and I find out I can't, how will that affect my family or how will they emotionally deal with, yes. So I mean the further you think into the future the more complicated it gets. (Age 23, adolescent cancer survivor)

So everyone's kind of told me you may have a shorter window. So when I finish my hormone therapy in three years like I feel like I need to kind of like get on it and then like try to, if I'm going to have kids, have them then. (Age 27, young adult cancer survivor)

Implications for research and practice

It is critical for researchers and clinicians to understand young female survivors' concerns about fertility and parenthood in order to address them adequately. Having children is an important aspect of life for many women that may carry an even more significant meaning for cancer survivors [8, 29]. The results from this qualitative study provide insight into how adolescent and young adult survivors navigate decisions about fertility and parenthood and some of the barriers they face. The common themes and concerns we identified across a diverse group of young women in this study may help direct both future research and clinical efforts to address the fertility and parenthood concerns of these young women.

This qualitative study was an important step toward developing an appropriate and valid measure of concerns about fertility and parenthood among young female cancer survivors. Much of the discussion during focus groups revolved around both the emotional and practical concerns facing young survivors who were uncertain about their fertility status. While there is evidence that young female cancer survivors have reduced rates of fertility and biological parenthood [3–5, 23, 24], it is unclear to what degree this is due to biological rather than to social or psychological mechanisms [4, 29]. It is possible that emotional and practical concerns about fertility and parenthood, such as those identified in this study, also have an impact on these outcomes. Reproductive outcomes research exploring both biological and psychosocial mechanisms would provide a more complete understanding of the observed differences between cancer survivors and the general population.

Young survivors in this study discussed several psychosocial and practical concerns about fertility and parenthood. Consistent with other studies [8, 11], these included concerns about the health of their potential child, worries about their own health and survival, and concerns about discussing fertility issues with a partner. Women also felt pressure to be in a sufficiently stable relationship and financial situation before considering parenthood. Financial concerns could result in delayed pregnancy and influence parenthood decisions [4]. While worried and unsure about fertility, participants were generally hopeful about becoming a biological parent and also expressed positive feelings toward adoption and surrogacy.

Also consistent with previous research [8, 14, 21], participants identified a need for more information about fertility and parenthood options throughout survivorship. When asked when and how they would like to learn about fertility issues, participants reported that they wanted their doctors or another healthcare provider to initiate a discussion about their options around the time of puberty and continue to raise the topic as part of ongoing care. This may be even more important for AYA survivors who may be particularly concerned about fertility and unaware that their options for parenthood could have been impacted by their treatment [8, 14, 19, 20, 22].

Many also reported that their doctors seemed uncomfortable or uncertain about how to talk with younger patients. Some participants also felt that their doctors were dismissive, not wanting to talk about fertility until a time when they were older and ready to have children. Unfortunately, this reinforces the barrier that young women already face by waiting to consider their future parenting options until their fertility options may be limited or non-existent. To improve communication, physicians might benefit from guidance on when and how better to talk with their young patients about these issues [30]. A team approach to caring for the reproductive health of young cancer patients with oncology and reproductive specialists may also be helpful. Our results suggest that healthcare providers need to initiate discussions about fertility across the cancer continuum and refer for further counseling and testing as needed. We also identified a need for sensitivity to the fact that uncertainty about future fertility can lead to relationship challenges for young women who are dating or in an existing relationship.

Despite their desire for information about fertility, many participants were hesitant to seek medical information or testing regarding their fertility because of a fear of discovering that they were unable to have children. Unfortunately, cancer diagnosis and treatment often result in a shorter window of fertility due to earlier ovarian decline [31]. If young women delay seeking care regarding their fertility, this could result in fewer options for biological

parenthood. This suggests that young survivors would benefit from seeking earlier medical advice regarding their fertility, even if their doctor does not bring it up. While limited information is available from clinical evaluation [9] and treatment costs may be prohibitive for some, survivors could also benefit from referral to web-based resources such as My Oncofertility, Fertile Hope, and financial assistance opportunities. Our results also identified unmet informational needs regarding health insurance, financial support for fertility preservation, and non-biological options for parenthood after cancer.

While not asked about this topic specifically, study participants described feeling disappointed with the medical care they had received as young adult cancer survivors. They emphasized problems with poor coordination of care between providers and, in some cases, felt that the burden of managing their care fell to them. This issue may be particularly concerning for cancer survivors who can have long-term health issues related to their cancer diagnosis and treatment [32, 33]. The Institute of Medicine recommendations from the Committee on Cancer Survivorship address this topic as well, citing the importance of coordination among clinicians, preparation of a survivorship care plan at the time of discharge from cancer treatment, and guidelines to assist healthcare providers with identifying and managing the late effects of cancer and its treatment [33]. Identifying and addressing concerns such as these is an important step toward improving quality of care for those transitioning from a cancer patient to a cancer survivor.

This study presents in-depth information on young survivors' experiences navigating decisions about fertility and parenthood, an issue that has not been well explored in the existing literature. Listening to the voices of young cancer survivors provides important complementary data to existing research indicating that young female cancer survivors have fewer children and have children later in life than their non-cancer survivor counterparts [3–5, 23, 24]. A significant strength of this study is the enrollment of a diverse population of participants across racial/ethnic backgrounds, cancer diagnosis, age at diagnosis, duration of survivorship, and life circumstances. Themes were consistent across this diverse group of participants, suggesting that we captured a valid assessment of the experiences and concerns of young female cancer survivors. However, conducting separate focus groups by characteristics such as racial/ethnic group or cancer type may have identified some differences that we did not discover. This may also not be a representative population, and we cannot generalize our findings to all young female cancer survivors. Enrollment in this study was biased toward those who were concerned about fertility and those who were healthy enough and cognitively able to participate in a focus group. Also, while Spanish speakers were eligible to participate, only

English-speaking women enrolled. Participation of Spanish-speaking women may have identified some cultural differences and variations in themes that are not reflected in our results.

Young female cancer survivors are concerned about their future fertility and parenthood options. This study's results have implications for future research and provide insight for the clinicians who are treating this population across the continuum of survivorship. The results point toward some possible psychosocial mechanisms, such as concerns about parenthood, financial barriers, and life circumstances, which could be associated with differences in rates and timing of biological parenthood. Our findings suggest that these young women could benefit from improved information regarding their fertility and parenthood options through discussions initiated by their healthcare providers, better coordination of care in survivorship, and guidance and support in navigating both emotional and practical issues that arise when considering fertility and future parenthood. Some of the most important concerns include personal health and survival, child health, and pressure to attain certain life circumstances and financial stability before considering parenthood. The results of this study are being used to develop a valid assessment of the fertility and parenthood concerns of adolescent and young adult cancer survivors. Understanding these concerns is a first step toward developing effective targeted interventions that will meet the needs of young cancer survivors who want to become parents.

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References

1. Bleyer A, et al., editors. *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975–2000*. NIH Publication No. 06-5767. Bethesda: National Cancer Institute; 2006.
2. Howlander N et al., editors. *SEER Cancer Statistics Review, 1975–2008*. Bethesda, MD: National Cancer Institute. http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER web site, 2011.
3. Pivetta E, et al. Marriage and parenthood among childhood cancer survivors: a report from the Italian AIEOP Off-Therapy Registry. *Haematologica*. 2011;96(5):744–51.
4. Syse A, Kravdal O, Tretli S. Parenthood after cancer—a population-based study. *Psychooncology*. 2007;16(10):920–7.
5. Green DM, et al. Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2009;27(16):2677–85.
6. Bines J, Oleske DM, Cobleigh MA. Ovarian function in premenopausal women treated with adjuvant chemotherapy for breast cancer. *J Clin Oncol*. 1996;14(5):1718–29.

7. Goodwin PJ, et al. Risk of menopause during the first year after breast cancer diagnosis. *J Clin Oncol*. 1999;17(8):2365–70.
8. Zebrack BJ, et al. Fertility issues for young adult survivors of childhood cancer. *Psychooncology*. 2004;13(10):689–99.
9. Su HI. Measuring ovarian function in young cancer survivors. *Minerva Endocrinol*. 2010;35(4):259–70.
10. Dunn J, Steginga SK. Young women's experience of breast cancer: defining young and identifying concerns. *Psychooncology*. 2000;9(2):137–46.
11. Schover LR. Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. *Med Pediatr Oncol*. 1999;33(1):53–9.
12. Thewes B, et al. Fertility- and menopause-related information needs of younger women with a diagnosis of early breast cancer. *J Clin Oncol*. 2005;23(22):5155–65.
13. Gorman JR, et al. Young breast cancer survivors: their perspectives on treatment decisions and fertility concerns. *Cancer Nurs*. 2011;34(1):32–40.
14. Zebrack B. Information and service needs for young adult cancer patients. *Support Care Cancer*. 2008;16(12):1353–60.
15. Partridge A, et al. Web-based survey of fertility issues in young women with breast cancer. *J Clin Oncol*. 2004;22(20):4174–83.
16. Canada AL, Schover LR. The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psychooncology*. 2011. doi:10.1002/pon.1875.
17. Gorman JR, et al. Depressive symptoms among young breast cancer survivors: the importance of reproductive concerns. *Breast Cancer Res Treat*. 2010;123(2):477–85.
18. Wenzel L, et al. Defining and measuring reproductive concerns of female cancer survivors. *J Natl Cancer Inst Monogr*. 2005;34:94–8.
19. Crawshaw MA, et al. Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *Eur J Cancer Care (Engl)*. 2009;18(4):381–90.
20. Hammond CT, et al. Non-Hodgkin's lymphoma survivors' fertility and sexual function-related information needs. *Fertil Steril*. 2008;90(4):1256–8.
21. Mitchell W, Clarke S, Sloper P. Care and support needs of children and young people with cancer and their parents. *Psychooncology*. 2006;15(9):805–16.
22. Closing the gap: research and care imperatives for adolescents and young adults with cancer. A Report of the Adolescent and Young Adult Oncology Progress Review Group. NIH Publication No. 06-6067; 2006. Bethesda, MD: National Cancer Institute.
23. Magelssen H, et al. Parenthood probability and pregnancy outcome in patients with a cancer diagnosis during adolescence and young adulthood. *Hum Reprod*. 2008;23(1):178–86.
24. Cvancarova M, et al. Reproduction rates after cancer treatment: experience from the Norwegian Radium Hospital. *J Clin Oncol*. 2009;27(3):334–43.
25. Schover LR. Rates of postcancer parenthood. *J Clin Oncol*. 2009;27(3):321–2.
26. Patton MQ, Patton MQ. Qualitative evaluation and research methods. 2nd ed. Newbury Park: Sage; 1990. 532 pp.
27. Ulin PR, Robinson ET, Tolley EE. Qualitative methods in public health: a field guide for applied research. 1st ed. San Francisco: Jossey-Bass; 2005. p. xxii, 318.
28. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 9; 2008.
29. Schover LR. Motivation for parenthood after cancer: a review. *J Natl Cancer Inst Monogr*. 2005;34:2–5.
30. Quinn GP, Vadaparampil ST. Fertility preservation and adolescent/young adult cancer patients: physician communication challenges. *J Adolesc Health*. 2009;44(4):394–400.
31. Byrne J, et al. Early menopause in long-term survivors of cancer during adolescence. *Am J Obstet Gynecol*. 1992;166(3):788–93.
32. Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. *J Clin Oncol*. 2010;28(32):4810–8.
33. Hewitt M, Greenfield S, Stovall E, editors. From cancer patient to cancer survivor: lost in transition. Committee on Cancer Survivorship: Improving Care and Quality of Life, Institute of Medicine and National Research Council; 2006.