

Chapter 32

The Fertility-Related Treatment Choices of Cancer Patients: Cancer-Related Infertility and Family Dynamics

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Introduction

Cancer does not just affect the person battling the disease, but the patient's family as well. Cancer can impact a broad range of family relationships from sexual relations with a partner to how someone parents their child. Family members are also often involved in the treatment decisions that someone with cancer makes, such as showing support for a particular medical decision [1] or even being the primary decision maker [2, 3]. The role that a family member plays in the decision-making process is contingent upon many factors including the age of the patient, their relationship to the cancer patient (e.g., parent vs. child), the patient's own desires [4], prior family dynamics [4, 5], and cultural and community norms [2, 3]. Family members can be involved in many decisions directly related to an individual's cancer battle including which treatment option to choose (e.g., lumpectomy or mastectomy) [6], whether or not to pursue alternative treatments [7], and end-of-life care [8].

Cancer patients also often face secondary health issues stemming from cancer and its treatment that can impact their quality of life post-cancer, such as "chronic pain, cognitive dysfunction, fatigue, peripheral neuropathies, cardiovascular and bone disease, or incontinence" as well as cancer-related infertility (p. 5) [9]. Recently, there has been greater attention paid to such related health issues that can impair an individual's life long after the cancer itself is gone, in part due to higher cancer survival rates today. Today, most people diagnosed cancer will survive and many will have to deal with the potential long-term consequences of cancer such as infertility. However, despite what we know regarding the importance of family relationships as during an individual's battle with cancer, we know much less about how the sequelae of cancer, such as infertility, impacts these family relationships. Moreover, there has been very little research conducted on the role of family members in patient's decisions regarding such secondary health consequences stemming from cancer or its treatment.

Our aim in this chapter is to broaden our understandings of how cancer impacts an individual's family life by looking directly at how the secondary health issue of cancer-related infertility affects family relationships. Our central research questions in this chapter are as follows:

- (1) Which family relationships are impacted by cancer-related infertility?
- (2) How does the potential infertility of a cancer patient influence relationships with their family?
- (3) What role do family members have in a cancer patient's treatment decisions regarding cancer-related infertility?

We explore these questions by drawing on interviews with 52 younger women who were diagnosed with breast cancer at 40 years of age or younger. Based on our respondents' experiences, we conclude that infertility fears and concerns are a prominent way that family members show social support; but also that cancer related infertility can place a strain on family relationships. Moreover, we find that a wide-range of familial relationships, including those with partners and parents, are affected by cancer-related infertility. We also conclude that in order to fully understand how women facing cancer make both fertility-conserving treatment choices at the time of diagnosis (e.g., emergency IVF) and later fertility decisions (e.g., whether or not to adopt), the role of family members in these decisions needs to be explicitly examined. Finally, our findings have implications for educational efforts aimed at cancer patients and their families regarding cancer-related infertility.

Background – Younger Women with Breast Cancer and Cancer-Related Infertility

Although breast cancer is usually thought of as a disease that afflicts older women, 7% of women with breast cancer are diagnosed before 40 years of age and breast cancer accounts for more than 40% of cancers in women 40 years of age and below [10]. Younger women also often face a different prognosis than older women diagnosed with breast cancer. Younger women often develop more aggressive forms of breast cancer, respond less well to treatment, have higher rates of recurrence than their older counterparts [11], and have lower survival rates [10]. Moreover, younger women facing breast cancer may be affected by cancer-related infertility. Cancers and cancer treatments vary in their impact on a patient's future fertility. While some cancer and cancer treatments may pose very little risk to one's fertility, younger women with breast cancer are considered in general to be at risk for impaired fertility. However, the risk varies across patients depending on many factors, including the treatment regimen followed (e.g., choice of chemotherapeutics), the presence of a BRCA mutation, the patient's age, and the patient's baseline ovarian reserve [12]. Both qualitative and quantitative studies on younger women with breast cancer (along with research on cancer survivors of child-bearing age more generally) have found that issues regarding potential infertility are among their top concerns (See [13] for a comprehensive review of research in this area).

Those with cancer can take steps to help ensure that their future fertility capacity is preserved. Most experts agree that patients have the most effective options for fertility conservation prior to the beginning of treatment because of the potentially damaging effects of treatment (e.g., radiation and chemotherapy). Women with breast cancer have several options available depending on their future family goals and particular prognosis (including the stage of the disease at diagnosis, whether or not their breast cancer is

hormone receptor-positive, or if the patient has a BRCA mutation) [12]. Prior to treatment, options range from egg/embryo harvesting to more investigational treatments such as ovarian tissue cryopreservation [12]. In addition to these fertility-conserving treatment options, cancer patients may also choose to become parents through alternative routes using donor eggs, surrogacy, and adoption (for a complete discussion of the options available to those diagnosed with breast cancer, see [12]).

Despite clear indications that fertility is a major concern for younger people facing a cancer diagnosis, the topic is not routinely discussed during the diagnosis or early treatment phases. A consistent finding is that many cancer patients, male, female, adult, and child patients, do not recall having any conversation with a physician prior to treatment regarding potential fertility impairment or treatment options. In their review of research on the topic, Lee et al. [14] conclude that “recent surveys of male and female cancer survivors of reproductive age concur that at least half have no memory of a discussion of fertility at the time of their treatment disposition” (p. 2926) [14]. They also conclude that, “Even when patients do recall infertility discussions, many are dissatisfied with the quality and information provided” (p. 2926) [14].

Clearly, research indicates that not all women with breast cancer will have the opportunity to decide on a fertility-conserving treatment plan before cancer treatment begins, but many will contemplate whether or not to undergo such procedures. Many cancer patients will make other fertility-related decisions after their primary treatment has been completed, such as whether or not they should try to have another child or if they will pursue other options such as foster parenting or adoption. However, a significant aspect of family planning not present in current research is how such decisions are made within distinct social settings, particularly in the context of family relationships. In this chapter, we look at the potential influence and role of family members in the fertility-related decisions of cancer patients. By doing so, we also address another issue that has been missing in research on cancer and family relationships: how does cancer-related infertility impact family relationships?

Methods

Sample Recruitment

The data for this chapter come from in-depth interviews with 52 women who were diagnosed with breast cancer at 40 years of age or younger. Respondents were solicited through recruitment advertisements distributed by healthcare, advocacy, charitable, and support group organizations aimed at those with breast cancer. Organizations that agreed to help recruit for this study typically sent a recruitment advertisement through an e-newsletter/e-mail list or one was posted to a message/discussion board. Fliers were also posted in public spaces by several organizations where clients physically come in for treatment and support services.

Sample Characteristics

Table 32.1 presents an overview of our sample. At the time of their interviews, the mean age of respondents was 34.8 years and the average age of the respondents for their first breast cancer diagnosis was 32.4 (four women in our study were diagnosed with breast cancer twice). Within the past 3 years, 82.7% of respondents were diagnosed, with many still actively receiving treatments, such as chemotherapy and radiation at the time of their interview. All of the women in the study are still within the 5-year recurrence window with most still receiving some type of follow-up care. Additionally, 61.5% of the women are currently married/partnered with an additional 9.6% engaged to be married. Further, 40.4% of the respondents have

Table 32.1 Overview of respondents

Sample characteristics (<i>n</i> = 52)	
<i>Race/Ethnicity</i>	
Caucasian, Non-Hispanic	80.8%
Caucasian, Hispanic	5.8%
African-American	9.6%
Asian	3.8%
<i>Educational attainment</i>	
With Bachelor's degree or higher	86.5%
<i>Family status</i>	
Married/Partnered ^a	61.5%
Engaged to be married	9.6%
With children ^b	40.4%
<i>Mean age at time of interview (years)</i>	34.8
<i>Mean age at time of first diagnosis (years)</i>	32.4
<i>Age range at time of first diagnosis (years)</i>	23–39
<i>Time since most recent diagnosis</i>	
Less than 3 years	82.7%
4–5 years	17.3%
With health insurance	98.0%

^aPartnered includes those women who are not legally married but consider themselves to be in permanent partnerships.

^bThis category indicates women who identify themselves as a parent. Although the overwhelming majority of women have biological children, this category also includes non-biological children including foster and stepchildren.

children. Table 32.1 also shows that our sample is highly educated (86.5% have at least a Bachelor's degree), with most respondents having professional or white-collar jobs. Most of the respondents are Caucasian, non-Hispanic (80.8%) and all but one respondent has health insurance.

Interview Procedures and Data Analysis

Semi-structured phone interviews were conducted with respondents. Prior to the interview, respondents were read an IRB-approved statement of informed consent before agreeing to participate in the study. Interview topics included initial diagnosis experiences, family background, treatment concerns and decisions, available support networks, and the impact of a diagnosis on future family plans and their personal relationships. The interview schedule remained flexible – a respondent's responses drove the interviewing process in order to accommodate their unique experiences and perspectives. Interviews averaged 60 min.

We used a grounded theory approach to the data [15], where we did not initiate our analysis with preconceived notions regarding how cancer-related infertility would affect our respondents' family relationships or which family relationships would be impacted. Interviews were first coded by identifying instances where cancer-related infertility was part of a relationship that a respondent had with a particular family member.¹ Sometimes cancer-related infertility was part of a specific discussion between a respondent and a family member and sometimes it was an ongoing topic between a respondent and a particular family member. After identifying incidents and relationships that involved cancer-related infertility, these incidents/relationships were categorized as being supportive or stressful (the latter indicating that the incident/relationship caused the respondent distress or feelings of guilt).

Lastly, we identified instances where family members were directly or indirectly involved in fertility-related decisions. We looked specifically at fertility-conserving treatment decisions that a respondent made prior to cancer treatment (such as whether or not to freeze embryos/oocytes) and how/which family member was involved in these decisions. Since most of our respondents are still within the 5-year reoccurrence window (with most being within 3 years of diagnosis), most have only contemplated post-cancer options of whether or not to try to conceive naturally or whether or not to adopt. In terms of these types of post-cancer decisions, we identified how/with which family members they have started to discuss such issues.

Findings – The Interplay Between Infertility and Family Relationships

Women in this study varied in what their future family plans were. Some wanted to become first-time parents of biological children (with several being pregnant at the time of their diagnosis); some were focused on their career and had not thought about starting a family yet or did not want to become a biological parent ever; and some already had children and were not interested in additional children. Despite this variation in fertility plans, family relationships were key to their diagnostic, treatment, and early survivorship experiences. Moreover, for the overwhelmingly majority of our respondents, cancer-related infertility was, to some degree, an issue that became part of their relationships with their family members.

Who Is Your family?

To understand how cancer-related infertility affects familial relationships, we first needed to understand what the category “family” meant to our respondents. Although respondents were asked during their interviews about how specific groups (namely partner, parents, and children) were involved in their cancer experiences, most questions

¹ We only focus here on interactions with adult family members. Many women (41.5%) in our study had children and their cancer diagnosis and treatment had definitely impacted their interactions with their children; for example, respondents expressed concerns about the amount of time they were able to spend with their young children. However, we focus here on adult family member relationships because none of our respondents described discussing fertility-related issues with their children.

spoke in terms of “family” very generally. This approach allowed the respondent to create a definition of who is, in fact, their family and what family members were part of their cancer experiences and treatment decisions (general treatment decisions and decisions specifically related to fertility). Among the sample, two distinct definitions of family arose as age and relationship status varied. For those who were younger and/or not in committed partner relationships, “their family” most commonly meant their family of origin, or parents, and to a somewhat less extent, siblings. For example, Katrina,² a 33-year-old marketing specialist diagnosed a year and a half ago, is single with no children. She defines her family support network in terms of parents and siblings:

Interviewer: So who would you turn to for support during your diagnosis?

Katrina: My friends and my family.

Interviewer: Which family members exactly?

Katrina: My parents and my siblings.

Alternatively, married or partnered women were more likely to respond to questions regarding “their family” by focusing more on their relationship with their partner or spouse. For example, Cora, a 31-year-old married television writer, was diagnosed 2 years ago with breast cancer. Although she mentions other family members throughout her interview as influential in her cancer experiences, it is her husband that she sees as her primary family support system:

Interviewer: So who would you turn to for support during your diagnosis?

Cora: My husband, my close friends, my family. . . my husband was the number one go-to-person.

In recent decades, the transition to adulthood has changed considerably with increasing delays in the age of first marriage and parenthood and a longer and varied path to establishing careers and completing education [16]. This means that younger adults today are far from a cohesive group, but rather include those at very different lifestyle and family stages. For our sample, this means a range in how they defined what “family” meant to them and which family members could potentially be involved in how a younger woman facing cancer approaches fertility-related decisions.

Infertility Concerns – Shows of Familial Support

Respondents in our study described their family members as being their central support systems throughout their diagnosis, treatment, and transition to survivorship. Respondents discussed how their family members provided emotional support and helped with necessary daily tasks including assisting with childcare and looking up information on the Internet. What was striking when respondents recounted instances of social support from family members was how often the issue of fertility was central to these shows of emotional support. Although survival was clearly the main issue for all of the women and their families and not all women were concerned about their ability to have children in the future, family members often helped cancer patients come to terms with

² All names are pseudonyms.

their fertility-related concerns and the topic of infertility was a primary issue that our respondents and their families discussed.

Some women even felt that their cancer and potential infertility had enhanced their relationships with partners and spouses because of the depths of support their partners displayed. Infertility concerns became a venue to talk about their future plans together and their commitment to one another. Ennette, a 28-year-old married corporate event planner, had always wanted children growing up. Upon hearing that her cancer may prevent her from having biological children in the future, Ennette was upset:

I had really hard time with it. I think I was extremely frustrated that my original plan for my life wasn't working out the way I thought it would and it was extremely difficult to I guess mourn children that I never had and the possibility that I might never have them. I think I was really upset at the fact that cancer was kind of – it was affecting another part of my life like kind of like a casualty. That otherwise I was healthy and didn't have any fertility problems.

Despite feeling that her and her husband's life's plans had been derailed, Ennette also believes the potential of infertility has brought her and her husband closer:

Interviewer: How has your relationship with your husband been affected?

Ennette: I think we've become closer. I think that we talk about the future more. It's been affected in a positive way, I think.

Kathy, a 36-year-old married physician, discussed how the potential of not being able to have biological children was a common topic of conversation between her and her husband. Kathy characterizes their relationship and their commitment to becoming parents as being very supportive: "Well he's been really supportive so that's been good. I mean it's stressful. I think, you know, he's felt bad for me. But I think he knows we'll do whatever we need to do to have a family still. I think it's been stressful, but I mean we're very supportive of each other." Like Ennette, she also feels that her cancer and potential infertility has brought them closer together, "I mean it's stressful, but we're very close. We're closer than we would have been if we hadn't been through all of this."

Parental shows of support also commonly involved fertility issues. Susan, a 29-year-old married occupational therapist, was diagnosed with breast cancer at 25 years of age. Susan and her husband would like to have their first child, but because she does not know if her fertility has been impaired due to her chemotherapy treatments, this issue is a source of concern for her: "It makes me feel – it makes me feel a little anxious, especially given that many of my girlfriends are having children right now. But I just have to wait. You know? I'm not done with my Tamoxifen yet. But I don't think that – or wish I would have done anything differently. You know? It is what it is."

At the time of her treatment, Susan's primary confidant regarding her fertility concerns was her mother since she and her husband were not yet married. Susan described her parents as being extremely supportive during her diagnosis and treatment; also, despite the fact that she knows her parents would like to have grandchildren, she does not feel

any pressure from them to have children and appreciates their understanding: “I think regardless of what happens, if we decide we don’t want to have kids, or we do have children, they’ll be supportive no matter what. There’s no pressure, at all, from them to have children.”

When our respondents discussed how supportive their parents and partners had been throughout their diagnosis and treatment, fertility issues were central to many of their family’s shows of support and heart-to-heart talks. Other family members also indicated their support as well in regards to respondents’ concerns over their future ability to have additional biological children, including discussing the topic with siblings. Daniela, a 37-year-old married mother of one, even had both her younger sister and her sister-in-law offer to carry a child for her if she needed a surrogate down the road.

Potential Infertility and Family Relationship Stress

Although the focus in much research on cancer has looked at how family support (or lack thereof) can be related to a particular health outcome, researchers have begun to consider how intimate relationships can be a source of tension as well as (e.g., [5, 17]). Among our respondents, families could be a source of tension as well as support. In particular, issues regarding fertility were often an impetus for the strained relationships with family members. Tamara, a 36-year-old married occupational therapist, terminated her first pregnancy when she was diagnosed with breast cancer. She and her husband, Matthew, then delayed her cancer treatment to do emergency IVF. She then had her uterus removed because her cancer was BRCA positive. Tamara and Matthew are planning on using the banked embryos to have biological children later on through the use of a surrogate. Tamara describes her relationship with Matthew as being generally very supportive including him supporting her decision to undergo IVF. Tamara, however, also feels bad because of the impact that her infertility has had on Matthew: “Well, you know, it’s been horrible for him because his option of having a child of his own, may have essentially been taken away . . . So that’s been absolutely devastating for him.”

Further, she describes feeling of guilt regarding what may happen to their family plans because of her breast cancer:

My first overriding feeling when all of this happened was guilt. Very guilty for taking away the fertility options from my husband. Very much internalized that. And anger and the feeling of sort of things not being fair, or a little bit hopelessness. That now the option has been potentially taken away from us. And anger, I think anger more because as you’ll find out, as I’m sure you’ll ask me more questions, I have the BRCA gene, but I was not aware of the family history until after I was diagnosed as much. I knew about one, but not all. So had I known, we would not have put off our family plans as long as we did. So there was anger about that.

Kristen, a married 27-year-old chemical engineer, does not have children. It is unclear if her ability to have children has been compromised from her cancer treatments. However, she often worries about what will happen if she and her husband are not able to conceive

naturally because they had always talked about having children before they turned thirty: “It kind of knocks you off the path that you were on and it has an impact on your relationship. . . . I don’t know. I just felt like I, you know, I couldn’t give him what he would want from me. He wanted to have a child too, so it kind of just made me feel like I couldn’t provide for him what he wanted.”

Although Kristen describes her husband as generally supportive, the stress of her illness and the possibility of not being able to have a child together have caused them at times to take out their frustrations on one another. According to her, “It constantly seemed like we were so angry and we kind of were taking it out on each other.” Kristen says they are now trying to work through these issues and have considered adoption if they are unable to have biological children.

What was even more notable among our respondents’ narratives was how often parental relationships were a source of stress regarding their ability and plans to have future children. In fact, parental relationships were mentioned as much, if not more, than partner relationships as being a source of tension and strain. Anna, a 40-year-old divorced teacher with no children, believes her possible inability to have children in the future is a source of disappointment for her parents:

Oh, yes. They would love to have grandchildren . . . neither one of my sisters have children either. I would love to have given my parents grandchildren. They would have been great grandparents . . . I know that my mom has mourned with me that she doesn’t have grandchildren . . . And my dad hasn’t, as much, expressed a desire for grandchildren, but I know he’s – he just doesn’t talk about it as much, but that would be something he wanted.

Though Anna expresses that this issue is one that deeply affects her parents, she does not describe the situation as being contentious between her parents and herself. Rather, it is another source of concern and sadness for Anna as she copes with her illness.

However, some women expressed that this issue has in fact caused outright tension in their relationships with their parents. LaTisha, a single 32-year-old Ph.D. student, had lymphoma as a child in addition to her breast cancer. She describes having a strict Protestant upbringing where it was assumed that, as most of her relatives had done, she desired to be a young mother and would have children. LaTisha feels her relationship with her mother is strained in part due to her mother’s desire for her to have children:

It’s been not great. Like I said, I have an older brother and he didn’t have any of his own children. His wife has a child from when she was married before and so there was already this pressure on me to be the one that’s going to carry on the family line. And then cancer, I think, just made it – heightened it, because I mean there was still the expectation that I was going to have a kid, but then there was the understanding that it may be that much difficult, but it’s worth the effort to have the kid. So, yeah, it’s been – I’ve talked to my mom some about not bringing it up as much and she says she doesn’t bring it up as much, but she does it – she actually does, just in a different way. She

talks about, my mom was a twin sister, so she'll talk about her twin sister's grandkids and, oh, wasn't it great, you know, and, oh, I wish, you know, I saw them do this and it's her own jealousy of not having her own grandkids, but she kind of projects it on to me.

This tension or concern stemming from parental relationships can also have the opposite effect where parents voice their desire for their daughter *not* to have biological children in the future because of the fear that a pregnancy may not be safe. Donalyn's (34-years-old, married, no children) parents have made their concerns known about her potentially using an egg donor so that she and her husband can conceive their first child:

They don't want me to become an egg donor recipient because they feel that – and they feel that me getting pregnant on my own would make my cancer come back just because of all the estrogen and progesterone. They're kind of nervous about me becoming pregnant, with the fear of having my cancer come back.

Ellen, a 26-year-old engaged mother of one child, also describes how the topic of her having additional children has caused tension within her family – her stepmother had made several *nasty* comments about how her becoming pregnant may not be possible or potentially risky due to her history of cancer.

Family Influence and Fertility-Related Decisions

Fertility was a not a side issue or distant concern for the women in our study as they went through treatment and made the transition to being a cancer survivor. For most in our study, it was their top concern aside from their own survival. Their fears over infertility and the uncertainty about being able to have children in the future was an opportunity for family members to show support or for otherwise close relationships to be strained. The interplay between family relationships and cancer-related infertility concerns among our respondents' experiences indicates that those who are interested in how cancer patients make fertility-related decisions (both decisions at the time of diagnosis/treatment such as whether or not to pursue IVF and those post-cancer such as whether or not to adopt) should examine how such decisions are made in the context of familial relationships. Our respondents' experiences show how both supportive and stressful family relationships can shape their decisions regarding their fertility and future parenting plans.

As discussed above, research has consistently found that patients are not always told about fertility impairment during their cancer diagnosis or treatment. Some of our respondents knew of potential fertility impairment and treatment options before undergoing treatment and others only learned about the potential after their treatment had ended. But despite this variation in when they learned about the issue (and whether or not they were even interested in having any or additional children in the first place), what is clear from our study is that a wide range of family members, most notably parents and partners, feel invested in the fertility-related choices an individual with cancer makes.

When faced with whether or not to pursue fertility preservation prior to treatment, most partnered respondents describe their spouse/partner as being the person they primarily

made the decision with. For example, Julia, a 32-year-old married researcher, had a child after her cancer treatment had ended. She had contemplated doing emergency IVF prior to her chemo, but ultimately decided against it – her husband was part of her decision-making process:

Interviewer: Did you contemplate having these procedures done?

Janet: We did, but initially, to harvest the eggs, it would have taken too long and we wanted to start treatment right away. And, ultimately, we wouldn't have needed it anyway.

Interviewer: What did you see as the risks and benefits of emergency IVF?

Janet: The risk of the cancer was greater than the benefits of having that happen.

Interviewer: How did you decide?

Janet: Discussions with my husband.

Interviewer: Can you elaborate a little bit on that?

Janet: Well we just we talked about the possibility of doing the IVF and from the feedback that we had got from the doctor that he had had patients recover completely from chemotherapy; we decided that we would just chance our ability to conceive later.

Janet describes a decision-making process where she and her husband are a team where “we” had decided how to proceed. Other women describe themselves as the primary decision-maker in terms of their fertility-conserving treatment decisions with their partner's primary role as being supportive of their decisions. Allison, a 28-year-old married mother of one child, decided to delay treatment to do emergency IVF. She describes the decision as hers, with her husband being supportive of whatever she wanted to do:

Interviewer: And how did you decide to undergo this procedure? Who was involved in the decision?

Angie: It was mainly me. I mean my husband was behind me 100%, and he told me whatever I wanted to do, he was comfortable with. But, again, it was just peace of mind, getting that finished and knowing that they would be there after all that is finished.

But even if partners were the central person in the decision to pursue fertility preservation, parents' reactions and support was often still important. Ennette, discussed above, decided along with her husband to delay treatment and undergo IVF. Her parents' approval of this decision helped her feel comfortable and supported:

Ennette: Yes. They were very supportive of my decision to move forward with IVF.

Interviewer: How do you think this affected you?

Ennette: It just made me feel more confident in my decision and I think I didn't feel as alone.

When most of the women in our study mentioned the role of parents in their decision-making regarding fertility, their influence seemed to be less direct, albeit still influential,

as in the case with Ennette, who primarily made the decision with her husband. However, there were some instances of parents being directly involved. For Idelle, a single 39-year-old with no children who works in business development, her parents played a very direct role in her decision to go ahead with oocyte harvesting. Although she describes her relationship with her parents as good, her parents have always placed pressure on her to have children: “When they hit a certain age and their parents constantly say, ‘We want a grandchild like all of our friends.’”

In order to help ensure that they had grandchildren, her father was very proactive in encouraging Idelle to undergo oocyte harvesting:

Idelle: I did. I harvested eggs. So I did IVF and harvested eggs which now are in the freezer.

Interviewer: How did you decide? Who was involved in the decision?

Idelle: Me and my father, only because he paid for the whole thing.

Interviewer: How did you decide?

Idelle: Dad said, “Here’s the credit card, go get it. I want to make sure I’ll have insurance on a grandchild.”

Family influences are also apparent as our respondents discuss whether or not they would pursue alternative routes in the future to become a parent. Since most of our respondents are only within a few months to a few years post-treatment, most see the decision of whether or not to try conceive naturally or become a parent through other means as issues they will decide in the future; however, many have already begun to discuss their future options with partners. Patricia, a 39-year-old married mother of one and a writer, is content with having only having one child, but has raised the issue of adoption with her husband:

Patricia: We’ve kind of mentioned it, or I’ve kind of mentioned it. He’s not quite so sure about that. So just the fears of the risk of losing the child, the parents wanting it back or whatever. And I know some people who have been through adoptions and they are very – they’re tricky. They’re really emotional.

Megan is 38-years-old, has been married for a year, and she and her husband hope to have children someday. She was not aware that there were options, such as emergency IVF, prior to undergoing chemotherapy and is unsure of her current fertility status. She and her husband are also unsure if she should actually try to conceive in the future, but they have extensively discussed other options:

Megan: Well, for me personally, I don’t think I have to give birth for it to be part of my family and I think both adoption and foster parenting would be great. I still think that it creates a family and I’m fine with that.

Interviewer: Would you consider surrogacy?

Megan: We have discussed surrogacy. So, yes, I guess we have – we are considering it.

Interviewer: And why are you considering it?

Megan: It would be an opportunity for the child to be part of my husband.

Respondents were most likely to discuss issues such as adoption or surrogacy in the context of their partner/spousal relationships, but parents' opinions could still be influential. And some parents have even suggested that respondents adopt. In fact, Jasmine, a 31-year-old with no children and a long-term partner, would prefer to try to have her own child, but is waiting to be past her 5-year reoccurrence window. However, her mother has already pushed the topic of adoption even though Jasmine had let her know her parenting plans: "She wants grandchildren and I think she was, earlier on, talking about adopting while I was in my 5 year waiting time when I'm on ovarian suppression."

Although parents and partners were often discussed as primary confidants in regards to fertility concerns and plans, other family members could also be involved in discussions regarding options such as adoption. LaTisha, discussed above, whose mother has put much pressure on her to become a mother, has considered becoming a foster/adoptive parent and has turned to family members, such as her aunt who is also a breast cancer survivor, to discuss the topic:

Interviewer: Would you consider adoption or foster parenting?

LaTisha: Yes. I have foster parents in my extended family. My aunt is a foster parent and I've talked to her, and she's also a breast cancer survivor. But she was a foster parent first. And so I've talked to her some about that and also sort of looked into adoption organizations that are friendly to cancer survivors.

Conclusion

A limit of our study is that our sample is homogenous in terms of race/ethnicity and socioeconomic status. A more diverse sample is needed to more fully understand how younger women with breast cancer experience cancer-related infertility in the context of their family relationships since cultural norms regarding who is involved in medical decisions, the importance of having children, and how individuals interact with healthcare workers can vary by cultural group. Nonetheless, our study shows that cancer-related infertility impacts more than just the cancer patient – relationships with her partner and with her parents are also affected – and any fertility-related decisions are made within the context of these supportive and stressful family relationships. Future research on medical decision-making in terms of cancer more generally should expand on the growing body of research that examines how disagreements and strain among family members and relationships can ultimately shape treatment choices [5, 18].

Our research also has implications for the increasing number of resources for cancer patients on the topic of fertility. Many websites that are aimed toward adult cancer patients have resources regarding infertility for partners. Additional materials regarding infertility that are directed toward parents of adult cancer patients may also be beneficial. The goal of these resources is not for parents to encourage or discourage certain options for their sons and daughters, but to provide parents with the means to understand the

issues. Since many of the women in our study, particularly those who did not have a long-term partner or spouse, said they most leaned on their parents for support, information geared toward the parents of adult cancer patients may be valuable. Recognizing that parents may be the primary support team of adult cancer patients can help to ensure that valuable treatment and fertility information is not overlooked by being placed under headings and labels that indicate “for partners/spouses” only.

There are also support and educational resources aimed at family members who have a loved one going through cancer. Based on the reported involvement of respondents’ partners and parents regarding fertility concerns and decisions, such support and educational resources should recognize very directly that part of coping with a family member’s cancer may involve mourning one’s own life’s plans and goals, which may involve having additional or first-time children and grandchildren. Moreover, research that directly examines family members of cancer patients is needed in order to have a greater understanding of how family members experience and cope with a cancer patient’s potential infertility.

The suggestions above are meant not only to help family members navigate and come to terms with a cancer patient’s diagnosis and potential fertility impairment but also to design pathways to help a patient make the best decisions for themselves. The experiences of Ennette and others in our study clearly show that how confidently fertility-related decisions are made can hinge on how family members, such as parents and partners, react to and support such decisions. Moreover, research has shown that patients who are comfortable with their treatment decisions and their role in the decision-making process can have better health and emotional outcomes [19, 20]. For example, Lantz et al. found that when breast cancer patients’ preferences for their involvement in treatment decisions matched their experiences (e.g., not being under or over-involved), they were more satisfied with the treatment process and outcomes and experienced less regret/ambivalence [20]. Therefore, patients who are happy with the fertility-related treatment choices they make, how they arrived at those decisions, and feel supported by their families may experience positive consequences (e.g., greater satisfaction) beyond whether or not they are able to have children in the future. Our suggestions above are not meant to push adult patients into making decisions that are best for their parent or their spouse; rather, our aim is to provide information to those who are already part of and influential in these decisions in order to help patients best communicate their needs, wants, options, and ultimate decisions.

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References

1. Reust CE, Mattingly S. Family involvement in medical decision making. *Fam Med*. 1996; 28:39–45.
2. Maly R, Umezawa Y, Ratliff C, Leake B. Racial/ethnic group difference in treatment decisionmaking and treatment received among older breast carcinoma patients. *CA Cancer J Clin*. 2006; 106:957–65.
3. Back M, Huak CY. Family centered decision making and non-disclosure of diagnosis. *Psycho Oncology*. 2005; 14:1052–9.

4. Weber K, Solomon DH. The role of family in medical treatment decisions: a qualitative study of breast cancer survivors. Paper presented at the annual meeting of the NCA 94th Annual Convention. 2009; San Diego, CA.
5. Kramer BJ, Kavanaugh M, Trentham A, Walsh M, Yonker JA. Predictors of family conflict at the end of life: the experience of spouses and adult children of persons with lung cancer. *Gerontologist*. 2010; 50(2):215–25. (Advanced online version, August 11, 2009, doi:10.1093/geront/gnp121).
6. Whelan T, Levin M, Gafni A, Sander K, Wilan A, Mirsky D, Schnider D, McCreedy D, Reid S, Kobylecky A, Reed K. Mastectomy or lumpectomy? Helping women make informed choices. *J Clin Oncol*. 2009; 17:1727–35.
7. Ohlen J, Balneaves L, Bottorff J, Brzaier A. The influence of significant others in complementary and alternative medicine decisions by cancer patients. *Soc Sci Med*. 2006; 63:1625–36.
8. Haley W, Allen R, Reynolds S, Chen H, Burton A, Gallagher-Thompson D. Family issues in end-of-life decision making and end-of-life care. *Am Behav Sci*. 2002; 46:284–98. 428 K.A. Snyder et al.
9. Woodruff TK. The emergence of a new interdisciplinary: oncofertility. In: Woodruff TK, Snyder KA, Eds. *Oncofertility: fertility preservation for cancer survivors*. New York: Springer; 2007:3–11.
10. Anders C, Johnson R, Litton J, Phillips M, Bleyer A. Breast cancer before age 40 years. *Semin Oncol*. 2009; 36:237–49.
11. Anders C, Hsu D. Young age at diagnosis correlates with worse prognosis and defines a subset of breast cancers with shared patterns of gene expression. *J Clin Oncol*. 2008; 26:3324–30.
12. Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. *NEJM*. 2009; 360:902–11.
13. Peate M, Meiser B, Hickey M, Friedlander M. The fertility-related concerns, needs and preferences of younger women with breast cancer: a systematic review. *Breast Canc Res Treat*. 2009; 116:215–23.
14. Lee SJ, Schover LR, Patridge AH, Patrizio P, Wallace WH, Hagerty K, Beck LN, Brennan LV, Oktay K. American Society of Clinical Oncology recommendations on fertility preservation in cancer patients. *J Clin Oncol*. 2006; 24:2917–31.
15. Strauss A, Corbin J. Grounded theory methodology: an overview. In: Denzin NK, Lincoln YS, Eds. *Strategies of qualitative inquiry*. Thousand Oaks: Sage; 1998:158–83.
16. Arnett J. *Emerging adulthood: the winding road from the late teens through the twenties*. New York: Oxford; 2006.
17. Manne S, Ostroff J, Sherman M, Glassman M, Ross S, Goldstein L, Fox K. Buffering effects of family and friend support on associations between partner unsupportive behaviors and coping among women with breast cancer. *J Soc Pers Relat*. 2003; 20:771–92.
18. Zhang A, Siminoff L. The role of the family in treatment decision making by patients with cancer. *Oncol Nurs Forum*. 2003; 30:1022–8.
19. Dead JM, Leinster SJ, Ownes RG, Dewey ME, Slade PD. Taking responsibility for cancer treatment. *Soc Sci Med*. 2001; 53:669–77.
20. Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, Lakhani I, et al. Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Serv Res*. 2005; 40:745–68.