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Fertility Preservation and Adolescent Cancer Patients: Lessons from Adult Survivors of Childhood Cancer and Their Parents

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Building on 40 years of progress in cancer detection and treatment, survival rates for childhood cancers have risen from 20 % to almost 80 % [1,2]. Approximately 270,000 Americans are childhood cancer survivors and, by 2010, an estimated 1 in every 250 adults will be living with a history of childhood cancer [2,3]. The early and late effects of treatment are beginning to take on greater importance for survivors, their families and providers [4]. Increasing numbers of childhood cancer survivors are beginning to face a new challenge in returning to normalcy after cancer.

Infertility is one of the most common chronic medical problems reported by childhood cancer survivors [5] and can be a primary concern particularly among female survivors [6]. Female infertility has biological and psychosocial implications that cannot be easily addressed given the ethical and legal questions surrounding fertility preservation [7–9]. Recent advances in fertility preservation may soon offer potential methods for females of all ages to protect their reproductive capacity from damaging radiation and/or chemotherapy [10]. Current literature focuses on the further development of preservation techniques and the numerous ethical and legal questions, but little knowledge is available on the attitudes and opinions of childhood cancer patients and their parents regarding fertility preservation.

Progress is being made in understanding the fertility issues that women may face after treatment. Infertility as an isolated health problem can be emotionally devastating for a woman [11] and is often viewed as a loss of one's sense of femininity [12]. The risk of infertility touches on the most intimate aspects of a woman's life after cancer, particularly her relationships, future plans for a family, and concerns about pregnancy and birth [4,12–16]. For cancer survivors who may be dealing with additional physical and emotional concerns, infertility may add yet another concern to an already lengthy list of fears and worries [17]. Some survivors describe that the loss of fertility can be as painful as facing cancer itself [15,18]. The situation is further complicated by the fact that female cancer survivors, particularly pediatric cancer patients, lack clear-cut options to address their fertility that are available to their male counterparts. Advancements in semen cryopreservation and intracytoplasmic sperm injection (ICSI) have revolutionized the reproductive outlook of male patients who have reached puberty [19]. Recent advances in reproductive science are beginning to change what is possible for female survivors as well.

Traditionally, few options existed for female cancer patients who may want to have their own biological children in the future. The only two established techniques women have for fertility preservation are protecting the ovaries from radiation and emergency in vitro fertilization (IVF) [20,21]. While protecting a patient's ovaries has become common practice, emergency IVF cannot be offered to patients diagnosed with cancer before puberty because mature oocytes cannot be collected [22]. The promise for female patients with childhood cancer lies in the strides made toward ovarian transplantation and in vitro follicle maturation. Ovarian transplantation involves the removal and cryopreservation of ovarian

tissue before treatment and the reintroduction of tissue after treatment, either orthotopically or heterotopically, such as in muscle or subcutaneously [23]. Researchers have demonstrated that transplantation of cryopreserved ovarian tissue has led to human embryonic development when accomplished heterotopically [24] and to a live birth after orthotopic transplantation [25]. Another promising method of fertility preservation is in vitro maturation of immature oocytes. Similar to ovarian transplantation, ovarian tissue is removed and cryopreserved before fertility-threatening treatment. Once a woman is prepared to have a child, follicles can be isolated from the thawed tissue, matured in vitro in a three-dimensional culture system, and the mature oocyte can be fertilized through IVF. Murine oocytes have been collected from in vitro grown follicles, matured, and fertilized in vitro, which has resulted in live births [26]. Human trials, where one ovary is laparoscopically removed before treatment, are being conducted on adult patients in order to begin the experimental process of perhaps one day delivering this option to female cancer patients.

As research begins to enter the clinical arena, a large number of unanswered questions remain regarding the application of the procedures, the legal and ethical considerations involved, and the receptiveness of patients and their families to fertility preservation. Thus far, very few studies have considered the viewpoints of childhood cancer patients and their parents [27]. Since decisions regarding fertility preservation must be made before treatment begins, parents, physicians, and patients are required to make a complex decision in a short amount of time during an extremely stressful situation, similar to the anxiety involved in the informed consent process of clinical cancer research trials [28]. In order for fertility preservation to become a realistic and valued addition to the treatment of childhood cancer patients, a better understanding of the decision-making process that parents and their children go through at the time of diagnosis and their interest in fertility preservation is needed. Further, a more thorough exploration of the patients' and parents' thoughts regarding the child's fertility at the time of diagnosis as well as later in the patient's life will be valuable in the continued advancement and eventual application of fertility preservation.

Methods

Study Design and Sample Recruitment

This qualitative exploratory study consisted of four focus groups: two with adult women who were diagnosed and treated for cancer as adolescents and two with their parents. The purpose of the study was to explore and compare the attitudes towards fertility and fertility preservation among and between the survivors and parents. Eligibility criteria for survivors included diagnosis and treatment for cancer between the ages of 13 and 21, English-speaking, and willing to participate in a tape-recorded focus group. Eligibility criteria for parents of survivors included English-speaking and willing to participate in a tape-recorded focus group. Survivors were recruited from the Survivors Taking Action & Responsibility (STAR Program) at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, Chicago, IL and were eligible to participate with or without a corresponding parent. All patients had received treatment that could impact their fertility. Patients were either in ovarian failure or were at risk for infertility due to treatment. This study was approved by the institutional review board of Northwestern University and all participants signed informed consent forms prior to participating.

Data Collection and Analysis

The research team (SEY, SKR, KJY, EAH) developed separate moderator's guides to facilitate the survivor and parent focus groups. The guides began with introductions, some general guidelines for conduct, and a disclaimer stating that the moderators were not involved with fertility preservation research. Topics addressed in the moderators' guides

included (1) short- and long-term concerns at the time of cancer diagnosis, (2) attitudes about fertility at the time of diagnosis and presently, and (3) reactions to a proposed clinical research study in ovarian tissue preservation. For the third topic, participants were asked to read an educational brochure on a proposed clinical research study in ovarian tissue cryopreservation that explained the purpose of the study and the procedures involved, including laparoscopic surgery to remove an ovary. A mock focus group was conducted with adult female research assistants acting as survivors to provide training for the moderators and test tape-recording equipment. The focus group moderators (SEY, SKR, KJY, and TV) took turns working through the moderator's guide and interacting with the mock survivors. Two focus group moderators (SEY and SKR) are licensed clinical psychologists and another (TV) is a licensed clinical social worker.

Following the mock focus group, minor revisions were made to the moderators' guides and the actual focus groups were scheduled. A total of four focus groups were conducted; two groups of survivors (facilitated by SEY and KJY) and two groups of parents (facilitated by SKR and TV). Focus groups were conducted on June 9 and June 11, 2005. Research assistants were present during all focus groups to administer consent forms and participant intake questionnaires and to take notes and operate tape recording equipment. All focus groups were conducted at Northwestern University, Feinberg School of Medicine, Chicago, IL. Each focus group lasted approximately 1.5–2 hours. Food and beverages were provided, but no monetary incentives were offered to participants.

Audio tapes were transcribed verbatim. A 10-page section of transcripts from the June 9 survivor focus group was reviewed to standardize how important themes were to be extracted from the transcripts. Following this exercise, SEY and KJY separately reviewed the transcripts for the survivors, summarized common themes *within* each focus group and *across* the two focus groups, and then met to reconcile discrepancies and finalize the summary of extracted information. SKR and EAH followed the same procedures for analyzing the transcripts of the parents, and CLN also contributed to the summary of the parents' transcripts.

Results

Sample Characteristics

Four survivors and three parents participated in the first set of focus groups, and six survivors and seven parents participated in the second set, held two days later. The median current age of the ten survivors was 26 years with a range of 23–36 years. Median age of survivors at the time of diagnosis was 14.5 years with a range of 13–21 years. Nine of the ten survivors were diagnosed with Hodgkin's disease and one with Ewing's sarcoma (Table 15.1). Eight of the ten survivors received chemotherapy and all received radiation.

Five of the ten survivors were unaware of their present fertility status. On the other hand, three survivors attempted and successfully conceived a child (100 % success rate) without reproductive medicine or procedures. Additional characteristics of the survivor group are presented in Table 15.1.

The median current age of the ten parents was 54 years with a range of 53–67 years. The median age at the time of their daughters' diagnosis was 44 years with a range of 40–51 years. Three were male and seven were female. Additional characteristics are presented in Table 15.2.

Content Analysis

The focus group data for survivors and parents followed three themes: (1) short- and long-term concerns at the time of cancer diagnosis, (2) attitudes about fertility at the time of diagnosis and presently, and (3) reactions to a proposed clinical research study in ovarian tissue preservation.

Cancer Diagnosis: Treatment Effects and Decision Making—Following their cancer diagnosis, survivors were focused on short-term concerns, such as appearance (e.g., hair loss), feeling sick, missing out on academic and extracurricular activities in school, and the social impact of cancer (e.g., how friends would treat them). Survivors shared little consensus regarding their longer-term concerns post-diagnosis, but did mention concerns such as dying, relapse, and infertility. Despite worries of long-term health problems, many of the survivors reported being focused on “getting through” their treatment rather than contemplating the late effects of cancer and its treatment. Fertility was mentioned as a primary concern by a few survivors, while others felt it was not a prevalent concern at the time of diagnosis and treatment.

In contrast, parents concentrated mainly on their children’s survival after diagnosis, which was clearly the most important concern for parents, with other issues being secondary. Short-term concerns included their children’s physical symptoms such as nausea, social functioning with friends and at school, appearance (e.g., hair loss), and maintaining normal routines as much as possible. Many of these concerns, particularly appearance and maintaining normal routines, were reported by parents as their daughters’ priorities. Long-term concerns included the ability of their child to maintain optimal physical functioning such as heart and lung capacity, appearance over time (e.g., scarring), the potential for increased risk of cancer later in life and infertility. Similar to survivors, some parents reported that their daughter’s fertility was a concern at the time of diagnosis, while others, particularly fathers, stated that it “wasn’t even on the radar screen”.

Questions about the experiences of survivors and parents with their medical team and treatment decision making were also explored. All survivors felt included in discussions and informational sessions by the medical team. However, they did not feel there were any true options to be considered other than not receiving treatment, which was viewed as an unacceptable option. In addition, they felt that their parents made all of the decisions that needed to be made, which they viewed as appropriate for their age. Consistent with survivors, parents reported that little decision-making about treatment took place at the time of diagnosis. Parents viewed decisions regarding treatment as the provider’s role, while their job was to select the “right provider”. Like survivors, several parents said that they felt there were no choices to make. Parents said that they trusted their providers and “would have listened to whatever [they] said”.

“I kind of felt it was either you did this or she’ll die...I mean it didn’t seem like there was a choice...”

“And he said this...you will be fine, you will. And I never doubted that she would be fine. And maybe I was like goofy but I thought, I trust this doctor, I trust this doctor...”

An additional aspect of the parents’ experience at diagnosis was the drive to educate themselves about cancer and treatments. Parents reported that they wanted to learn as much as possible at the time of diagnosis about their child’s disease and available treatment options. One parent stated, “*I just wanted to get educated immediately because I knew nothing about it.*” At the same time, parents also reported that they felt overwhelmed by the

amount of information coming at once, and that it was difficult to comprehend and cope with long-term issues at the time of diagnosis.

Based on discussions with the medical team, survivors reported that their physicians and nurses focused on short-term treatment side-effects, like hair loss and weight gain, at the time of diagnosis, rather than long-term consequences. Survivors felt that fertility was rarely discussed by the medical team prior to treatment. According to survivors and parents, if fertility was discussed, the issue was raised during treatment, when faced with decisions regarding location and/or additional courses of radiation, or after treatment, when describing the potential for late effects.

“I will just add that... I think I remember being shocked like after treatment they are like, oh well fertility is an issue, and I am like, it is? Like I was shocked.”

“The first time I remember them talking about it was when I was done with chemo and we started radiation... Before I went to radiation they sat me and my parents down and they talked to us about fertility issues and said that you know how it was necessary to have the radiation but that might be a consequence of it. That was the first time I remember hearing about it.”

Parents had differing experiences with medical teams, in that some recalled discussing fertility and some did not. Some parents reported that they wished they knew more about the possibility of their child’s infertility and what to do before the first treatment was initiated, but acknowledged that they may not have been able to think about it at the time of diagnosis.

Importance of Fertility: Then and Now—At the time of diagnosis, most survivors reported fertility was not an issue that they considered important. As discussed above, many of the survivors first became aware of the issue when infertility was presented to them as a possible consequence of their treatment either immediately before or following treatment. Most did not remember discussing fertility with their physicians, while others remembered how disconcerting it was to learn about the risk of infertility or that they were infertile.

“...it was very upsetting when I was told at the onset of treatment that...my ability to conceive may or may not be affected, so even at 15 I was still very upset about that...”

“I feel like I’ve known from a young age that I love kids...the thought of not being able to go through...that process of being pregnant was very, very scary for me.”

“...I didn’t want to continue with treatment after they told me that I had ovarian failure. You know it was...it was very traumatic.”

When survivors were told that their ability to have one’s own children was going to be threatened, fertility gained in importance for many.

“It made it more important. That it wasn’t something I thought about really ever until they said it might be compromised. And as soon as I found out that it might be compromised, it definitely changed. It was always just something I’d take for granted and then when it may have been taken away from me that’s when it became very, very important.”

Now considering fertility as adults, almost all participants endorsed the importance of fertility at the present time and three survivors already had children. Survivors discussed how fertility had become a relevant issue, particularly as their peers marry and have children and questions about career vs. family arise in their own lives.

“I didn’t think a thing about fertility until I was 20 and people started getting married and talking about babies and stuff.”

“I think [fertility] is fairly important now, extremely, now that I have graduated from college and have a career and I am getting settled down.”

“...it is always in the back of my mind, because it is something that is important to me in the future.”

Overall, parents did not feel fertility was very important before or at the time of their child’s diagnosis, although a few mothers agreed that fertility is always a concern when one has daughters, regardless of age.

“...I don’t think that comes into play—age—really if you have a daughter... You want her to be fertile. Whether she wants to have children or not, you want them to be...capable of having a choice.”

However, most parents had not given much consideration to infertility and assumed their child would be fertile.

“I think, well, for me it was, let’s get her better and we’ll worry about it later.”

Nearly all had daughters who were 14 or 15 years old when diagnosed with cancer, and some said that fertility might have been more important if their children were older at diagnosis. Reactions about the importance of their daughters’ fertility at the present time varied between “very important” to “not that important”, but the majority of parents commented that the importance of fertility is growing and has become a current issue for their daughters.

“It became more and more important as you saw them getting well...”

“...I wasn’t thinking about fertility issues. That was a horror that was held for later.”

As parents talked about their children and the possibility of infertility, secondary concerns related to their children’s future plans and relationships also surfaced. One mother shared a concern about her daughter rushing into marriage in order to have a child, while another said that her daughter questions, “...*is anybody going to love me when they find out I can never have babies?*”

Fertility Preservation: Opinions and Reactions—The topic of fertility preservation began with a discussion of the options that survivors were aware of that are available to women who want families after cancer. Survivors demonstrated a good understanding of the available options, including adoption, IVF, surrogacy, donated eggs, and fertility drugs. Survivors appeared to have an understanding of what each option entailed, and some participants had sought out information on some of the options.

Parents also demonstrated a strong understanding of the options available to women who desire families after cancer treatment. Similar to survivors, parents were aware of currently available options as well as several experimental methods like ovarian transplantation and freezing ovarian tissue. Similar to survivors, parents appeared to both understand and be very curious about each potential option, especially the experimental techniques. Several parents also mentioned an awareness of the differences in options available for men and women.

“I do remember thinking it was just totally unfair that guys could freeze their sperm and there really were no options for women.”

“If the situation were ever similar to that which it is for young males, which is to say... freeze your sperm... I think it would be outstanding. But secondarily, I think

it also gives a large measure of hope and expectation to someone at the front-end of it.”

After discussing their knowledge of available options to have families, survivors read the brochure describing a proposed study on preserving fertility by removing an ovary, cryopreserving it, and culturing follicles in vitro. Several of the survivors’ immediate reactions were supportive of the study and indicated their own interest in the study if it had been offered to them.

“...my first reaction was had this been offered when you know I was 14, I would have been like yes, yes, just do it. And I know my mother, my parents probably, would have been absolutely with let’s do it.”

“Sign me up.”

Parents echoed these reactions as well.

“Great idea. Something we would have considered.”

“[Would have]...signed up in a heart beat.”

“Very interesting. Wished this project had begun 20 years ago.”

In order to determine the degree to which participants were able to understand the procedures described in the brochure, they were then asked to describe what the research entailed. In general, survivors and parents differed in their understanding of the study. Survivors acknowledged that surgery was involved in the research protocol, but lacked a clear understanding of how the ovarian tissue would be stored and later utilized. In order to address this confusion, survivors compiled a list of questions they felt were not addressed in the brochure and would be important in assessing the costs and benefits of the study. The survivors wanted additional information on an individual’s fertility status and pregnancy risk before making a decision to enter the study, as well as further details on how the study would be conducted. Even with unanswered questions, several survivors believed that the benefits outweighed the costs.

“I see the benefits.”

“I think the benefits you know outweigh [the costs].”

Survivors named benefits such as helping medical advancement, helping other women in the future, and the possibility that they might conceive a child. Overall, survivors found it difficult to state whether the benefits outweighed the risks; individual responses ranged from favorable to undecided and some unfavorable. Despite mixed reactions and the need for more information, however, survivors agreed that such a study on fertility preservation should be presented to others as an option, including younger patients.

“I just think you need to know your options. Even though it might seem kind of weird at first you know, I mean thinking about that when you are so young. It still has to be presented to the parents and the patient.”

“It should be offered to kids younger...for sure. But I mean that’s going to be... then it’s going to be more the parents’ decision.”

Parents demonstrated a good understanding of the study’s purpose and details based on the brochure. When asked about what was involved in the research protocol, parents discussed how an ovary is removed and frozen and, through continuing research, the possibility of offering an option for having a child may become available. Like survivors, parents also compiled a list of unanswered questions regarding the risk of infertility and the effect of having only one ovary. When assessing the costs and benefits of participating in the study, some parents voiced concern about exposing their young children to yet another potentially

physically and emotionally harmful surgery, whereas others stated it seemed “no big deal” and very worthwhile pursuing. Despite raising these concerns, parents largely agreed that they likely would have chosen to participate in this study if it had been available at the time of their children’s diagnosis, particularly if they were provided more information and answers to their questions.

“...still have one ovary and a chance...I’d go for it.”

“I’d like to gamble rather than be left sterile.”

“It’s about options. It just gives you another option. And the more options you have in life the better off you are, you know?”

“...as a parent I would have loved to have something like this to share with her.”

Parents were then asked whether or not they would have recommended offering the fertility preservation study to parents of younger children. Some stated that they believed that this study was relevant for parents of children of all ages and should be at least presented.

“If it is brought to your attention, you might say, oh wow I...I never thought of that for heaven’s sakes you know...That’s right they are going to grow up and you know hey thanks...for making me feel they’re going to grow up here...”

“...if [doctors] are trained properly in how to present the facts to the parents of this child, they should be told in advance rather than, oops sorry I should have told you this before.”

Conversely, others believed that the age of the child when diagnosed was directly related to the potential relevance of the study to parents, and that it would be far less relevant for parents of elementary school-age children and even pre-teens than for teenagers. Parents did agree that especially for parents of younger children, more information would be crucial in making a decision, as well as initial information about the need for concern about fertility in general.

Discussion

Survival rates have reached unprecedented levels and some cancers are beginning to be viewed as chronic diseases. In current literature, increasing amounts of attention are being focused on the long-term health and care of survivors. However, this farsighted view of life post-cancer diagnosis is not necessarily being translated to clinical practice at the time of diagnosis. The predominant concern of survivors in this study was “getting through” the treatment for the disease and battling short-term age-appropriate issues, such as hair loss and maintaining normalcy at school and home. At diagnosis, the majority of survivors were not aware of, much less concerned with, the late effects of cancer treatment, including infertility. For parents, late effects were also viewed as secondary when compared to the overriding fear for their daughter’s survival. If fertility was a concern, most adopted a “wait and see” approach described in previous literature [4,29]. With few options available to address late effects proactively, the “wait and see” approach was appropriate. However, recent advancements in cancer care and related fields, such as reproductive technologies, make considerations about a child’s future possible and critical to decision making at diagnosis and throughout the treatment process. The optimal time to intervene either to prevent possible complications and/or plan for late effects is before treatment begins. In the case of fertility preservation, ovarian tissue must be removed and cryopreserved before the ovaries are exposed to harmful radiation or chemotherapy. Survival will remain the ultimate goal of cancer treatment, but comprehensive cancer care requires planning for a patient’s quality of life before and during treatment as well as years later.

Barriers exist for patients and parents to adopt a more long-term view of cancer care. As mentioned above, planning for a child's life after cancer may seem secondary to parents and physicians relative to the larger goal of keeping the child alive. In addition, parents may be overwhelmed by the diagnosis and the large amount of information they must acquire in a short period of time. Therefore, as several parents mentioned, they may be unable to think beyond fighting the disease. Furthermore, parents and patients may take their cues about late effects being less relevant or important at diagnosis and early in treatment from providers, who tend not to focus on such issues at that point. For example, many survivors reported that they did not remember their providers mentioning the issue of infertility until making decisions about additional treatment or after completion of treatment. Some parents also reported not knowing about the possibility of infertility. These responses differ from what providers report. One survey of health care providers in the pediatric hematology/oncology department at a single institution found that over 92% of providers reported that they routinely discuss the impact of cancer treatment on future fertility with all of their cancer patients and families [30]. However, only 63.3% of providers agreed with the statement that all cancer patients receiving fertility-threatening treatment at the institution are warned about the risk of infertility by a nurse or physician [30].

Such differences between the experience of patients and their families and the reported practice of providers are important, particularly given the importance of the provider in helping establish expectations and priorities regarding treatment and decision making. Based on participants' comments, both survivors and parents do not view themselves as the primary decision maker and do not feel as though there are choices to be made, which is a commonly reported feeling among parents faced with treatment decisions [31]. With this, physicians are often thrust into the role of primary decision makers and greatly influence what patients and parents know and consider important over the course of the disease. If the medical team does not emphasize late effects and infertility at diagnosis or does not do so in a memorable and manageable fashion, patients and parents may also neglect the importance of these possible complications. Additional research on the provider's perspective on decision making and the importance of late effects at diagnosis would complement this study's work with childhood cancer patients and their parents.

Another difficulty in addressing the risk of late effects at diagnosis, particularly infertility, is that the significance of late effects changes over time and the course of the disease. As discussed by participants, infertility can evolve from a seemingly secondary issue at the time of diagnosis into a complication that can negatively impact a survivor's conception of herself as a woman and her quality of life. Many participants, especially fathers, commented that they or their daughters were too young at the time of diagnosis to consider the possibility of infertility, which underlines the fact that age is a critical factor in assigning importance to fertility. Nine of ten survivors were in their early teens when diagnosed with cancer and most of them, as well as their parents, were not thinking of marriage or having families at that time in their lives. Beginning a family has become a salient question for many of the survivors, who are now in their 20s and 30s. Survivors and parents almost all agreed that fertility is an important and relevant concern. Three survivors (30%) already have children of their own. Understanding that the meaning and potential impact of late effects like infertility can change dramatically for pediatric cancer patients over time is essential to providing care for survivors that will benefit them throughout their lifetime.

As fertility becomes an increasingly salient issue for survivors, uncertainty about fertility status remains for many. Half of the survivors in this study were unaware of their present fertility status, a rate comparable to those reported elsewhere [14]. Such uncertainty complicates a survivor's ability to make decisions about having a family and assessing her need to pursue alternative reproductive options. Furthermore, survivors' uncertainty

regarding their fertility status can lead to unsafe sexual behaviors, such as unprotected sex, or feelings of rejection and tension in intimate relationships [14]. As described in this study, the question of infertility can be detrimental to survivors and their relationships, as noted in one mother's hope that her daughter will find someone who will love her although she may be infertile. Such concerns about infertility highlight the psychosocial effects of the risk or reality of infertility among childhood cancer survivors. As survivors receive long-term follow-up care, sexual practices and psychosocial health must be addressed.

Fertility preservation for cancer survivors is being developed with the goal of alleviating uncertainties and restoring the reproductive choices many survivors believed they would always have. As survivors and parents discussed, fertility was something they took for granted until learning about the possible late effects of their treatment. With this mindset, survivors and parents were overall very receptive to learning more about the proposed fertility preservation research study. Although survivors and parents agreed that infertility was not a primary concern and that diagnosis and treatment can be overwhelming, both agreed that fertility preservation was something they would have considered and would at least have liked to be presented with as an option. Parents' reported eagerness to learn about fertility preservation at diagnosis follows many parents' desire to educate themselves as much as possible during their child's illness, which is a common and useful coping strategy that helps lessen the feeling of uncertainty [32–34]. Parents also mentioned the large amount of hope that the fertility preservation study would have offered their family because it focuses on their child's life beyond cancer, not simply the next round of treatment. In addition to the interest of patients and families in fertility preservation, a survey of pediatric oncology providers found that over 96% of respondents believed that all cancer patients at risk for infertility should discuss fertility preservation options [29]. Furthermore, 86.7% of providers agreed that children of any age, if developmentally appropriate, should be included in such discussions [29].

Participants viewed the fertility preservation study as an encouraging project, but several hesitations were also discussed. Such reservations must be taken into account when presenting fertility preservation to young patients and their parents. As mentioned above, parents are presented with a large amount of information at diagnosis and during treatment, in addition to the emotional burden of knowing their child's survival is uncertain. The diagnosis and the treatment process are often an overwhelmingly stressful and emotionally draining time period, during which parents often exhibit elevated levels of anxiety, depression, and posttraumatic stress symptoms [35–38]. Decisions regarding fertility preservation should occur before treatment begins, yet parents are typically naïve, unfamiliar with, and inexperienced with treatment options for their child's disease. This difficult situation underlines the importance of a well-trained and prepared medical team that can deliver the necessary facts and options that parents must consider in a comprehensive yet manageable fashion.

After reviewing the brochure participants received about the proposed fertility preservation project, several suggestions for presenting fertility options to parents of childhood cancer patients were compiled. One inference drawn from participants' comments was that how the information about the study is presented and by whom are critical elements of the decision as to whether or not to participate. Unlike merely providing families with a brochure, which was done in the focus groups, participants agreed that they would have appreciated a presentation on the project that contained personal, specific, tailored information, delivered in a sensitive and compassionate manner by a professional. Participants believed that such a presentation would have significantly enhanced their level of comfort, confidence, and ability to assess the risks and benefits of participating in such a study. Another recommendation that arose out of the focus group discussions was that parents believed that

the possibility of infertility and proposal for fertility preservation should be discussed with parents by a woman due to the sensitive nature of the topic. Additionally, parents believed that for maximum acceptance, fertility preservation should be presented to parents as part of their child's treatment "package" when discussing cancer treatment options, similar to clinical trial research options. Parents also added that learning about other childhood cancer survivors' experiences with fertility would aid them in making a decision regarding fertility preservation. Parents commented that although fertility may seem of secondary importance at the time of diagnosis, hearing others' experiences would help remind them that their daughter may also grow up and one day want children. For the majority of childhood cancer survivors, fertility will only grow in importance, which is an important consideration for parents of future patients to keep in mind who may face a decision about their young daughter's fertility.

This study focused on the opinions and attitudes of adult childhood cancer survivors who were diagnosed between the ages of 13 and 21 years, and their parents. There are some limitations. Responses may have varied if the survivors had been diagnosed earlier than 13 years, when questions about future fertility may have seemed even more distant; but, as several parents commented, a daughter's fertility will always be important to her parents if brought to their attention. Another limitation is that the study did not include any survivors who had tried to conceive and were unsuccessful; therefore, fertility concerns may have been less relevant to the study sample. Additional limitations include the small sample size, which was drawn from a single institution, and the lack of cultural diversity among participants. This study also raises questions about the unique dynamic between providers, parents, and pediatric cancer patients. Research into delivering fertility preservation that draws on the experience of patients and providers themselves must continue in order to ensure that advances in reproductive science benefit patients in substantial and meaningful ways.

Conclusion

At the time of diagnosis, survivors and their parents were focused on survival. Few parents remember talking with physicians about fertility at the time of diagnosis. For the majority, fertility became an issue after treatment. As adults, fertility took on greater importance among survivors and their parents, as peers married and began families. Survivors and especially parents said that they would have seriously considered a fertility preservation research study if it had been an option. Parents and survivors said that the research study would have given them hope that there is life beyond cancer. Participants also recognized how meaningful it is to have reproductive choices, something that male patients have with sperm banking. Many parents commented that they wished they had had something like this for their daughters. This level of interest among survivors and parents in a research study on fertility preservation, which does not necessarily guarantee a reproductive option, underlines the importance of reproductive choices for cancer survivors and the great relevance of fertility – an issue that "wasn't even on the radar screen" at diagnosis. When asked about extending the program to younger children, survivors and parents felt that fertility preservation is an option that should be presented to everyone, regardless of age. In order for a possible late effect like infertility to be effectively addressed through fertility preservation, options must be incorporated into cancer care beginning at diagnosis. Advancements must continue to be developed in the area of reproductive technologies, but providers also need to be prepared to discuss fertility with patients and their families and take a proactive and farsighted approach to comprehensive cancer care.

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Table 15.1

Survivor characteristics

	No. of participants (Total <i>n</i> = 10)
Non-Hispanic white	9
Married	3
Education	
Some college/technical degree (AA)	2
College degree (BS, BA)	7
Advanced degree (MA, PhD, MD)	1
Occupation	
Homemaker	1
Full-time employed	8
Full-time student	1
Primary diagnosis	
Hodgkin's	9
Ewing's sarcoma	1
Treated with chemotherapy	8
Treated with radiation	10
Location of radiation	
Chest	2
Chest & neck	2
Mantle	3
Head & mantle	1
Total body	1
Aware of fertility status now?	5
Ever attempted to conceive a child?	3
Successful conceiving?	3
Used reproductive medication or procedures?	0
Currently taking contraceptives	4
Why taking contraceptives?	
Birth control only	3
Both birth control & hormone replacement	1

Table 15.2

Parent characteristics

	No. of participants (Total <i>n</i> = 10)
Non-Hispanic white	10
Married	10
Education	
Some college/technical degree (AA)	4
College degree (BS, BA)	2
Advanced degree (MA, PhD, MD)	4
Occupation	
Homemaker	2
Full-time employed	8
Number of living children	
2	4
3	4
4	2
Has your daughter ever attempted to conceive a child?	
Missing	1
Yes	2
No	6
Not sure	1
Daughter successfully conceived?	2
Daughter used reproductive medication or procedures?	0