Priorities in Fertility Decisions for Reproductive-Aged Cancer Patients: Fertility Attitudes and Cancer Treatment Study

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Purpose: The Fertility Attitudes and Cancer Treatment Study (FACTS) aims at better understanding the reasons and priorities of young adult cancer patients making decisions for fertility preservation (FP). Identifying the factors that center around a patient's fertility decisions will support the development of educational tools for providers and improve clinical care to meet patients' reproductive needs.

Methods: An exploratory qualitative study was conducted of 27 newly diagnosed male and female cancer patients who had presented for an oncofertility consultation. Interviews lasted ~30 minutes and were transcribed verbatim. A thematic analysis was conducted to explore the factors driving decisions for future fertility. Themes were grouped to address the following topics: reasons for/against FP, patient priorities, informational needs, support, wellness, and satisfaction with information. Strength of the theme was determined by examining the frequency of a response.

Results: Patients who chose FP versus those who did not choose FP and men versus women proved to be more similar than different in their reasoning, priorities, and informational needs for FP decisions. Patients who chose FP identified a "concern for future fertility" as a top reason to do so and "parenthood" as a top priority. For those who did not choose FP, "cancer treatment" was identified as their top priority. For patients identifying financial barriers, 50% of them were able to overcome this to pursue FP.

Conclusions: Reproductive-aged patients diagnosed with a new cancer should be referred to a reproductive specialist and provided the opportunity to come to a fertility decision on their own before initiating cancer treatment.

Keywords: oncofertility, fertility preservation, fertility preservation barriers, fertility preservation utilization, fertility decision making, fertility attitudes

Introduction

WITH ADVANCED TECHNOLOGY and treatments for cancers, nearly 85% of the 140,000 adolescents and young adults (AYAs) diagnosed with cancer each year will survive. Often, these survivors are left with facing long-term effects of their treatment.^{1,2} The desire to not only survive but also thrive after cancer treatment has resulted in the need for AYAs to make decisions as part of their treatment process that will impact their lives long after treatment.

For the majority of AYAs undergoing cancer treatment, traditional chemotherapy and radiation therapy can have irreversible effects on their fertility.^{3–6} Survivors have reported

this loss of fertility as a devastating psychosocial effect and a decrease in their quality of life, suggesting a critical need for providing effective fertility preservation (FP) services to cancer patients.^{7–9} Patients of reproductive age have to now consider their priorities surrounding future parenthood.¹⁰

In nearly 70% of young adults, the diagnosis of cancer does not change the desire for children; however, FP is often overlooked in a patient's clinical care.^{3,11} Survivor studies have identified the challenges that young adults experience with receiving adequate fertility information at the time of diagnosis: the urgency to start treatment, inadequate fertility information, and socio-demographic influences contribute to patients' access to FP services.^{12–24}

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Limited research has been conducted on patients at the time of diagnosis to explore how they make their future fertility decisions. The research on decision making thus far has been examined retrospectively and focused on the patients' experience with getting information and not on how patients prioritize factors contributing to their FP decisions.^{25–28} These studies support the need for services for AYA patients to receive fertility information or else risk these, losing their opportunity to be parents.

The Fertility Attitudes and Cancer Treatment Study (FACTS) is a two-phase study with the goal of improving our understanding of the complex factors that are involved with patients' decisions regarding future fertility. Phase 1 examined FP utilization rates and characteristics associated with FP decisions among a cohort of oncofertility patients. In phase 2, we conducted a qualitative study to better understand patients' reasons for choosing FP and to identify their priorities at the time of their diagnosis. As demonstrated in earlier studies, patients are often asked to make decisions about their fertility, with limited information about reproductive risks. Patients are left with making uninformed decisions about their future fertility.^{29,30} The following study examined how AYAs come to their fertility decisions only after receiving a fertility consultation.

The overall goal of this study was to understand the priorities and decision-making needs for newly diagnosed AYA cancer patients by exploring why some patients elect FP and others do not. To better understand the low utilization of FP, particularly among women, we compared men and women to note differences in priorities and reasons. Identifying the factors that center around patients' fertility decisions will support education for providers and improve clinical care to meet patients' reproductive needs.

Methods

Study design

The two-phase FACTS study incorporated a sequential explanatory mixed-method design. The results of the quantitative phase drove the topics analyzed in the second phase. In phase two, an exploratory qualitative study was conducted by using the principles of critical theory to explore the patient factors driving decisions for future fertility. The critical theory methodology explores explanations, or theories, of a group

and examines differences between groups. Often, analysis is directed by existing theories about the population.^{31,32}

Patients participated in a 30-minute semi-structured interview within 30 days following their fertility consultation. The interview script was developed by using premises from the literature, phase 1, and an initial pilot study to gather information on factors affecting FP decisions before cancer treatment (Supplementary Figure S1; Supplementary Data are available online at www.liebertpub.com/jayao). Interviews were audio-recorded and then transcribed verbatim. The transcripts were immediately coded by using Atlas.ti 7.0 to determine whether saturation had been reached. Approximately one-half of the interviews (14/27) were independently coded by two coders for internal reliability; the primary author coded the remaining interviews. The inter-coder reliability rate was 94.5%, with all disagreements being decided by the primary author. Two patients changed their FP decision after the interview and were analyzed per their final decision.

Recruitment

Recruitment was conducted at two reproductive medicine clinics in Denver, Colorado, from April 24, 2014 through July 9, 2015. All newly diagnosed cancer patients 18–45 years of age who received a fertility consultation by a study-trained reproductive specialist were eligible for recruitment. Those with a relapse, secondary diagnosis, in remission, initiated treatment, without testes or ovaries, pregnant at the time of diagnosis, or unable to conduct the interview in English were not eligible. There were no exclusions based on cancer diagnosis or stage. The Colorado Multiple Institution Review Board (COMIRB) approved the study for conduct.

The fertility consultation provided information to patients, including: their risk profile for fertility loss, FP options, baseline fertility assessments, options for nongenetic children, and risks of FP treatment. In most cases, patients had <72 hours to make a FP decision.

Analysis

Demographic data were analyzed by using Fisher's exact statistic for categorical variables and *t*-tests for continuous variables to determine whether the decision groups (yes FP and no FP) were characteristically different. The interview

Initial read through text identifying specific segments of information	Label the segments to create codes by deductive reasoning	Categorize codes into relevant topics: Reasons, Priorities, Needs, Support, Wellness, Satisfaction	Reduce overlap and redundancy of codes	Identify themes within the categories Create a model incorporating the most important themes using summative analysis
27 interviews	Total codes: 328 (143 original; 185 new)	7 categories	Average 43.9 codes per category (20–54)	Average 7.4 themes per category (2–11)

FIG. 1. Synthesis of qualitative data: a framework for the synthesis of the qualitative data based on critical theory.

transcripts were synthesized by using a content analysis approach, specifically a summative thematic analysis (Fig. 1).^{33,34} Summative analysis allowed for the quantification of codes to explore the frequency of themes. Themes mentioned with a greater frequency were inferred to have higher priority among the study population.³⁴

The initial topic areas and 143 codes were created based on findings from a literature review and the quantitative study.^{35,36} An additional 185 new codes were derived for a total of 328 codes. Codes were grouped deductively into themes emerging from the data. Themes were grouped to address the following topics: reasons for/against FP, patients'

priorities, and informational needs. Themes were ranked based on how frequent a theme was reported.

Results

Study population

Thirty-one patients were approached for inclusion; 27 (87%) consented to participate in the study. The average age of participants was 30.3 (19–41) years old. Overall, 56% (15/27) of participants chose FP (sperm or embryo/egg cryopreservation) and 56% (15/27) were women. Among men, 67% (8/12) chose FP whereas 45% (7/15) of women chose

TABLE 1. CHARACTERISTICS OF REPRODUCTIVE-AGED NEWLY DIAGNOSED CANCER PATIENTS SEEKING FERTILITY CONSULTATION (N=27); APRIL 24, 2014–JULY 9, 2015

Characteristic	Total, N=27	FP yes, n=15	FP no, n=12
Age mean years ($\pm$ sd)	30.3 ($\pm$ 5.5)	30.7 ($\pm$ 5.6)	29.8 ($\pm$ 5.5)
Gender, n (%)			
Males	12 (44.4)	8 (53.3)	4 (33.3)
Sperm banking		8 (53.3)	
Females, n (%)	15 (55.6)	7 (46.7)	8 (66.7)
Embryo banking		2 (13.3)	
Egg banking		5 (33.3)	
Race, n (%)			
White, Caucasian	19 (70.4)	13 (86.7)	6 (50)
White, Hispanic	6 (22.2)	1 (6.7)	5 (41.7)
Other minority	2 (7.4)	1 (6.7)	1 (8.3)
Education level, n (%)			
High school or less	7 (25.9)	3 (20)	4 (33.3)
Some college	5 (18.5)	1 (6.7)	4 (33.3)
College graduate or more	15 (55.5)	11 (73.3)	4 (33.3)
Relationship status, n (%)			
Married/in a relationship	24 (88.8)	15 (100)	8 (75.0)
Single	3 (11.1)	0 (0)	3 (25)
Insurance status, n (%)			
Private insurance	18 (66.7)	11 (73.3)	7 (58.3)
Medicaid	8 (29.6)	3 (20)	5 (41.7)
Self-pay	1 (3.7)	1 (6.7)	0 (0)
Cancer diagnosis ^a , n (%)			
Solid tumor cancer	20 (74.1)	11 (73.3)	9 (75.0)
Blood cancer	4 (14.8)	2 (13.3)	2 (16.7)
Skin cancer	3 (11.1)	2 (13.3)	1 (8.3)
Cancer treatment, n (%)			
Surgical treatment			
Yes	14 (51.9)	8 (53.3)	6 (50)
No	13 (48.1)	7 (46.7)	6 (50)
Chemotherapy treatment			
Yes	22 (81.5)	11 (73.3)	11 (91.7)
No	11 (40.7)	4 (26.7)	1 (8.3)
Radiation therapy			
Yes	7 (25.9)	4 (26.7)	3 (25)
No	20 (74.1)	11 (73.3)	9 (75)
Sexually active, n (%)			
Yes	24 (88.9)	14 (93.3)	10 (83.3)
No	3 (11.1)	1 (6.7)	2 (16.7)
Have children, n (%)			
Yes	8 (29.6)	3 (20)	5 (41.7)
No	19 (70.4)	12 (80)	7 (58.3)
Desire children, n (%)			
Yes	25 (92.6)	15 (100)	10 (83.3)
No	2 (7.4)	0 (0)	2 (16.7)

^aBlood: AML, CML, polycythemia vera; solid tumor: breast, colon, endometrial, ewing Sarcoma, non-Hodgkin's lymphoma, lymphomas, renal cell, synovial sarcoma, testicular; skin: melanoma.

FP, fertility preservation.

FP. None of the demographic characteristics were significantly associated with FP decision (Table 1).

Reasons for FP

Respondents were asked about their reasons for considering FP, and eight themes emerged (Fig. 2). The reasons to choose FP did not differ between the decision groups (yes FP, no FP) or gender groups (men, women). All groups ranked “concern about their fertility risks” as the top reported theme. This included patients’ concern about their current reproductive health status and for conceiving after undergoing cancer treatment. Participants discussed concerns that their fertility status would be irreversible after cancer, FP assured a chance for fertility, their fertility risk was unknown, and securing their future fertility as a priority. Fertility concerns were mentioned on average 5.4 times per patient among those who chose FP and 1.3 times per patient for those who did not choose FP.

When looking at gender, men mentioned this concern 51% of the time when discussing reasons to consider FP, whereas women provided it 37% of the time. A female patient opting for FP said: “From what we heard from our doctors, there is not a great chance that there will really be any fertility left after my treatment. So I feel like [egg banking] is our only one option.”

The second most frequently mentioned theme for choosing FP was patients’ “access to FP information and services.” Participants mentioned education, feeling informed, accessibility of FP services, and provider referral when discussing FP information and services influencing their decision. This was similarly ranked second for all groups (yes/no FP, men/women).

A man who elected FP noted: “It was something that once I read there was a chance for infertility, [sperm banking] was something that I wanted to do. The doctors were good at giving me the information very quickly and very easy for me to understand.” Participants also mentioned a fear of future regret, social pressures, financial support, knowledge of assisted reproductive technologies, survivorship quality of life, and cultural beliefs as reasons to consider FP. These themes occurred less than one time per patient.

Reasons against FP

Respondents were asked about their reasons for not considering FP, and eight themes emerged (Fig. 2). The groups did differ in their reasons for not considering FP. For those who underwent FP treatment, “financial concerns” was reported most frequently (43% of the time) as a reason to not consider FP. Financial concerns included: financial support, the cost of FP, cancer treatment costs, cost of raising a child, insurance coverage, and borrowing money. A woman who ultimately elected FP stated: “None of the parts [FP procedure] that we have done right now have been covered by insurance. So that is definitely a con and I think that is the biggest negative aspect.” Despite being the top reason to not consider FP, these patients ultimately overcame the financial obstacle to undergo FP. Interestingly, “financial concerns” was the fourth ranked reason given by those who did not elect FP.

For AYAs who did not elect FP, “concerns about fertility risks” was the top reason given. Participants reported being concerned about the FP procedures and medications, birth defects for future children, their reproductive health being hindered by their diagnosis, poor fertility assessments, their age, passing along a cancer gene, having a low or unknown risk for fertility loss, and conceiving on their own after cancer among their concerns for not electing FP.

Men and women did not differ in their reasons against FP. “Concerns about fertility risks” was reported as the top ranked reason for not choosing FP for both genders, followed by “financial concerns.” For 50% of the patients with financial concerns, this barrier was overcome. This was similar in both men and women.

Patients’ priorities and concerns

Participants were asked to discuss their current priorities and concerns in regards to considering FP, and 11 themes emerged. Patients’ priorities and concerns were different for those who chose FP and those who did not. For those who chose FP, “prioritizing parenthood” was the top priority or concern. This theme included AYAs mentioning: Parenthood was important, banking gametes was important, the fear of losing their fertility made them consider children, and the risk to their fertility affected them more than their cancer diagnosis. One man mentioned: “The biggest concern was can we still have kids. And once that was over it was like how we go about it wasn’t a huge deal.” Patients infrequently discussed adoption and nongenetic children as desirable options.

For those who did not choose FP, the top priority was “focus on cancer treatment.” This theme included a focus on their health, cancer treatment, and survival as priorities. As one woman described: “[Fertility] was kind of an afterthought. My first thought was I have cancer, let’s get rid of that first and we will deal with [fertility] later.”

A “fear of future regret” ranked second among priorities for both decision groups. A fear of future regret included patients reporting: keeping their options open, needing fertility risk information, FP providing a security for future children, the risk of being infertile being scary, and that the fertility decision be their own choice. Other priorities and concerns for AYA patients included survivorship quality of life, concerns for having future children, finances, and cultural and social pressures but were reported less frequently (Table 2).

FIG. 2. Ranking of patients’ reasons for and against considering FP; a side-by-side comparison. (N=27). FP, fertility preservation.

TABLE 2. PATIENT'S PRIORITIES AND CONCERNS WHEN CONSIDERING DECISIONS ABOUT FUTURE FERTILITY;
AS REPORTED BY 27 REPRODUCTIVE-AGED NEWLY DIAGNOSED CANCER PATIENTS

Theme	Code	Sample quotes
Prioritizing parenthood/fertility risks	<ul style="list-style-type: none"> • Parenthood and future children is important • Banking gametes is important • The thought of losing my fertility was a wakeup call about my feelings for children • The fertility risk affected me more than my diagnosis 	<ul style="list-style-type: none"> • "I didn't realize how much I wanted kids until I was told I might not be able to have them. Now I really want them." (No FP, woman) • "Being able to freeze my eggs was huge for me because that is a huge part of what I want to do with my life, is have a big family." (Yes FP, woman) • "There I was, blissfully content you know, not even thinking about children. And then in a flash, I then don't even have that option. Yeah it was scary." (Yes FP, woman) • "I think the biggest concern was can we still have kids. Once that was over how we go about it wasn't a huge deal." (Yes FP, man)
Fear of future regret	<ul style="list-style-type: none"> • Keep my options open • Need fertility risk information to make a decision • FP decision provided security for future • The risk of being infertile is scary • Fertility decision would be my choice • My fertility decision is not on my own terms • Considering future relationships and how my fertility will affect them • My desire for future children could change • Egg banking is my personal insurance in case my relationship changes 	<ul style="list-style-type: none"> • "I figured it was better to just do it and then if we don't want the eggs, we don't have to ever use them but at least I won't have to regret why didn't I just do that." (Yes FP, woman) • "It kind of freaked me out. Maybe later in the future I want to have more than two kids." (No FP, man) • "It could potentially be a decision made for me without me making it and so I'm making sure that I'm making the choice and doing what I want to do." (No FP, woman) • "What if in 2 years we think we are ready for kids but whoops we never took my eggs. I don't want to be in the situation where I had the chance to do something and I didn't." (Yes FP, woman)
Focus on cancer treatment	<ul style="list-style-type: none"> • I want to focus on my health right now • My cancer treatment is my priority • Survival is my priority • It is important to have comprehensive cancer care (treatment plan that considers all aspects of care) 	<ul style="list-style-type: none"> • "I am focused now on chemo treatment and getting past cancer and putting that in a rear view mirror." (No FP, woman) • "[Having kids] was kind of an afterthought. My first thought was I have cancer, let's get rid of that first and we will deal with that later." (No FP, woman) • "I have always wanted kids badly. I assumed I would have kids. But when I found out I had cancer it was so scary, and they told me I would have to wait 2 weeks to freeze my eggs! My priority is getting healthy and not kids. I just wanted to get chemo right away." (No FP, woman)
Survivorship quality of life	<ul style="list-style-type: none"> • Priority is to get back to school/work after cancer • My future fertility plans are now back on track after FP • Returning to normal is important to me • Concerned with other reproductive health late-effects (menopause, sexual function) • I would like to establish my career more before having kids • Personal life on track before having children • Will shift priorities to settling down after cancer • Want to get healthy and enjoy life again before having kids • Maintaining my femininity/masculinity is important 	<ul style="list-style-type: none"> • "My priority is to get over [cancer] then get my career back on track. I don't need to be successful before I have kids but I would like to be working and to establish myself first." (Yes FP, man) • "I was more concerned about hair loss and some of the other things. My mom had breast cancer when she was 35 and she went through early menopause and so that was a question I wanted to ask." (No FP, woman) • "[My priority is] getting healthy and getting this over and done with. Being able to be back to work and have my normal life like I did before." (No FP, woman)
Concerns for having children in the future	<ul style="list-style-type: none"> • My cancer treatment could cause birth defects in my future children • Future conception/pregnancy may be difficult • Adoption may be difficult as a cancer survivor 	<ul style="list-style-type: none"> • "I don't want to run the risks of there being birth defects and that is a huge one for me. I would never want to risk a baby not having a fair shot at life." (No FP, man) • "My doctor wants to see me in remission for minimum 1 year, but ideally 2-3 years and I am already 35! I am high risk already! So that is a little concerning." (No FP, woman) • "I was actually kind of shocked that some of the adoption agencies are not open to cancer patients. I didn't realize that." (No FP, woman)

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Code</i>	<i>Sample quotes</i>
Cultural and social pressures	<ul style="list-style-type: none"> • Because of my age, there is no pressure for having children • Priority is making time for my family • My partner desires children for us • There is an overwhelming amount of decisions/appointments right now • My family has expectations for me to have children • Religious reservations about FP • There needs to be greater advocacy for FP services • I don't want to have the stigma of being infertile 	<ul style="list-style-type: none"> • "I would be terrified if I was to be responsible for a kid right now. I have fun with my friend's kids and being "cool aunt," but at this point in my life I don't think I am ready for that. It would still be years down the road." (No FP, woman) • "[My family] was against adoption completely because of our religious beliefs." (Yes FP, man) • "[My boyfriend] has always wanted kids badly, his own kids and lots of them. And so it has made me scared we are going to break up if I can't have kids." (No FP, woman)
Financial concerns	<ul style="list-style-type: none"> • Finances is a priority • There will be additional costs in the future to use my frozen sperm/eggs/embryos • The cost of FP is concerning • The cost of my cancer treatment is concerning 	<ul style="list-style-type: none"> • "The fertility stuff is not included with any of the cancer treatment or the insurance. It is something that I paid for on my own. That was the biggest kind of concern that I had." (Yes FP, man) • "I do think about the money it will cost on the other side of this when I need to use [the eggs], I think about that all of the time, and how we will ever come up with that amount of money." (Yes FP, woman) • "I don't even think we talked about money for the procedures. It is the actual cost of living. Money is always a big priority. Having a baby is not cheap right"? (No FP, man)
Concerns with FP procedures	<ul style="list-style-type: none"> • Concerned about FP being unsuccessful • Concerned about the amount of hormones needed to do FP • Concerned about FP being a painful process • Concerned about my partner's fertility status • Concerned about the procedures necessary in the future to use frozen gametes 	<ul style="list-style-type: none"> • "I am a little bit nervous about how it is going to feel and whether we are going to end up with embryos, and if our pregnancy will even work." (Yes FP, woman) • "I was only able to give a limited amount of sample, and the probability of fertilization through these medical processes is really low, so that is one of the biggest worries. If I end up sterile there is still a big possibility that fertilization won't work." (Yes FP, man) • "We don't know exactly what [my boyfriend's] fertility level is either. So we didn't want to have my eggs frozen, which is not even a guarantee anyways, and then him not be fertile or him not have a sperm count that is going to be able to work." (No FP, woman)
Not concerned with FP procedures	The FP procedures did not concern me	<ul style="list-style-type: none"> • "The shots, the egg retrieval, it didn't even bother me. I know that at the end of that would mean I get to freeze my eggs so for me I was just willing to do whatever." (Yes FP, woman)
Children not a priority	<ul style="list-style-type: none"> • Already have children • Do not currently desire children 	<ul style="list-style-type: none"> • "[FP] was something that wasn't even a thought because I wasn't planning on having kids anytime soon." (No FP, woman)
Fear of disease progression	<ul style="list-style-type: none"> • Concerns about delaying my cancer treatment • Concerned about stopping medications to try to conceive in the future • Fear of my cancer spreading • Uncertainty about my future 	<ul style="list-style-type: none"> • "If anything I will have that one fear that will always be there that the hormones of being pregnant could make the cancer come back." (Yes FP, woman)

The table is a complete list of the themes and codes identified among a sample of AYA newly diagnosed cancer patients considering fertility decisions. The themes are in reference to patients' priorities at the time of decision making and are ranked in order of frequency from top to bottom. The codes are represented by a sample of direct quotes obtained during in-person interviews after a fertility consultation and are ranked within each theme.

AYA, adolescents and young adults.

Among men and women, the same three themes (*parenthood, fear of future regret, and cancer treatment*) were ranked among top priorities and concerns when considering FP. Men mentioned “*prioritizing parenthood*” as the top priority when considering FP, whereas women ranked “*fear of future regret*” as their top priority. Participants did not bring up considering pressure from their oncologist or their relationship status when discussing their priorities when considering FP.

Informational needs for FP decision making

In discussing patients’ informational needs for FP decision making, 10 themes emerged. Between both decision groups, participants similarly agreed that the top informational need was the consideration of their “*desire for children*,” which was reported 30% of the time. This theme included mention of wanting children, adoption, actively trying to conceive, and conception after cancer.

Patients ranked “*desire for FP services*” second among informational needs. This included patients discussing: desiring a fertility assessment, oncofertility care after cancer, and options for FP treatments.

Among men and women, the same top informational needs were reported. “*Desire for children*” was the top reported informational need in considering their FP decision, and the “*desire for FP services*” was second. One female patient who did not elect FP stressed the importance of having fertility information to make her decision: “*For someone that doesn’t want to have kids, to be able to talk to doctors and not have them judge you for that decision is great, and to still be given all the information... there is a lot of information that I didn’t know.*”

Discussion

The FACTS study explored differences in decision making for FP among AYA cancer patients, particularly looking at differences between men and women. Overall, we found that the groups were more similar than different in their reasons, priorities, and informational needs, highlighting the importance of providing information to reproductive-aged newly diagnosed cancer patients. These AYAs expressed a high importance of parenthood after cancer and a fear of future regret without the opportunity to consider FP options. For those who did not choose to undergo FP, their main priority was to focus on their cancer treatment; however, these patients also expressed a fear of future regret and a desire for children.

Parenthood was the most frequently occurring theme when discussing reasons to choose FP and patients’ priorities, suggesting that the threat to one’s fertility is a critical factor to consider when managing AYA cancer patients. It is the factor that is the most relevant to AYAs choosing FP, even overcoming financial concerns. For our patients, the fertility consultation provided information and a forum to discuss the patient’s feelings about parenthood and FP options. The AYAs represented in our study demonstrated coming to terms with their feelings toward future parenthood to come to a harmonious decision. A majority of patients mentioned a fear of regret if they did not pursue FP, whereas patients did not express regret in their final FP decision.

We expected to see AYAs indicate that their oncologist and/or their relationship status were influencers in their FP

decisions, as indicated in previous studies.^{18,25,37–41} However, the interviewed participants did not mention either of these as influencers or priorities in their decision making, leading us to believe that decisions for FP were made independently and that patients came to a decision after weighing their desires and concerns for future fertility.

The major barriers to FP treatment among AYA patients were their concerns about their fertility potential followed by their financial concerns. One-half of patients with financial concerns overcame financial barriers to pursue FP treatment. Only one patient noted having insurance coverage for a portion of the FP procedure. For patients who did not undergo FP, they also identified a lack of access to FP information/services and not prioritizing future children as top reasons against choosing FP. Reproductive-aged patients were the most likely to overcome the barriers for FP when prioritizing future children and by having appropriate access to information and services for FP treatment.

Earlier survivor studies similarly identified that patients’ urgency to start treatment, cost, inadequate fertility information, and socio-demographic influences contributed to patients’ access to FP services, particularly among women.^{12–24} In our study, time, age, gender, cultural beliefs, and social pressures had little influence on patients’ fertility decisions. When consulting AYAs with a new cancer diagnosis, providers need to be aware of the patient’s desire for parenthood and concerns about their future fertility and avoid making referrals based on socio-demographic characteristics or cost concerns.

Strengths and limitations

To our knowledge, this is the first study to look at patients’ decision making for future fertility at the time of diagnosis. Often, patients are studied after they lose the opportunity to consider FP or without all the information for considering FP treatment. We have demonstrated in both phases of the FACTS study that FP utilization is increased when patients are provided a fertility consultation. Another strength was our inclusion of both men and women. We know that men are more apt to utilize FP^{42,43}; however, in our study, we have demonstrated that there are few differences in reasoning, priorities, and informational needs between men and women who choose FP and those who do not choose FP.

It is possible that patients in the FACTS study were biased because they received a fertility consultation. Our study sample, however, included patients who were both interested and not interested in future parenthood. Another potential bias is that patients may have received information or opinions about FP before their consultation and were not open to hearing information otherwise.⁴⁴ For example, patients still expressed a concern for birth defects or success rates with using assisted reproductive technologies, despite information otherwise. This internal bias, or congeniality bias,⁴⁴ suggests that preconceived notions may contribute as to why more patients are not choosing FP.

Conclusion

Young cancer patients who chose FP and those who did not choose FP were so similar in their reasoning and priorities that providers need to consider oncofertility services for all AYA cancer patients. Our study demonstrates the importance of a FP consultation for all patients so that they may

contemplate their reasons and priorities for future parenthood. Patients have expressed a desire to participate in their fertility decisions and to receive information regardless of their desire for children or financial concerns. Patients have also demonstrated making independent decisions about their future fertility.

All reproductive-aged patients diagnosed with a new cancer should be referred to a reproductive specialist and provided the opportunity to make their own future fertility decisions before initiating cancer treatment. Informed decision making will lead to AYAs feeling content with their fertility decision and alleviate feelings of regret and frustrations later in life.

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Author Disclosure Statement

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