



Attitudes and practices about fertility preservation discussions among young adults with cancer treated at a comprehensive cancer center: patient and oncologist perspectives

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Abstract

Background Young adults (YAs, ages 18–39) diagnosed with cancer face multiple challenges that affect their health-related quality of life, including the potential for cancer-related infertility. Providing information about the risk of infertility and options to maintain fertility is critical for YAs who are newly diagnosed. However, barriers to effective communication exist for oncologists and their patients. The purpose of this study was to interview medical oncologists and YAs from the same cancer center to examine attitudes and practices about fertility preservation.

Methods Semi-structured interviews were conducted with medical oncologists ($N=12$) and YAs within 2 years post-treatment ($N=24$), representing the most common cancers affecting YAs. Interviews were audio-recorded, transcribed, and coded using qualitative methodologies with the analysis software NVivo 10.

Results Twelve oncologists (50% female, 67% <50 years) and 24 YAs (67% female, $M=29$ years) completed interviews. Common themes across oncologist and YA interviews were the roles of cancer type or stage and patient interest or parity in influencing the decision. The most important factor for YAs was to receive accurate, in-depth information. Unique themes for oncologists focused on clinical aspects of their patient's disease. For YAs, they shared about the emotional impact of cancer-related infertility and desire for support from trusted others.

Conclusions Results provide a better understanding of the attitudes and practices about fertility preservation discussions among YAs. Given the common factors affecting fertility preservation decisions, models of shared decision-making may be ideal for

YAs and oncologists. Future interventions should explore tailored applications of this approach for YAs newly diagnosed with cancer.

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Introduction

Approximately 90,000 young adults (YAs, ages 18–39) in the USA are diagnosed with cancer annually [1]. This can significantly affect their health-related quality of life, including infertility or other reproductive challenges [1]. Numerous national organizations [2–4] have established guidelines to enhance oncologist adherence and facilitate patient and oncologist discussions about fertility preservation options prior to proceeding with fertility compromising treatments. With few exceptions [5–7], adherence to guidelines to discuss fertility preservation options with patients is suboptimal [8–12].

Lack of communication about fertility preservation options with YAs may be due to several factors. Oncologists face many communication challenges when discussing fertility preservation with their patients. These challenges can be related to oncologist attributes (e.g., knowledge barriers), patient attributes (e.g., cultural or religious prohibitions for assisted reproduction), and healthcare or institutional factors (e.g., time demands) [13–17]. Institutional resources to support fertility preservation decision-making are highly variable [18, 19].

YAs want to be fully informed about their infertility risks and options for having children. Yet this information remains a common unmet need [20–23]. It is critical for institutions to ensure that fertility preservation communication occurs as soon as possible after diagnosis so that patients are appropriately informed and able to make decisions based on values, priorities, and goals that may or may not include fertility preservation procedures. Thus, the goal of this study is to explore attitudes and practices about fertility preservation using qualitative, semi-structured individual interviews with medical oncologists and YAs from the same cancer center. By examining these patterns, we are well-positioned to identify where oncologists' and YAs' perspectives converge and diverge and strengthen the evidence base to inform future care.

Methods

Participants and procedures

This work was conducted in compliance with the Northwestern University Institutional Review Board. Oncologists were eligible if they were attending medical oncologists at the Robert H. Lurie Comprehensive Cancer Center (RHLCCC) and treated patients with common cancer types in YAs: breast, gynecologic, neurologic, gastrointestinal, sarcoma, lymphoma, leukemia, and genitourinary/urologic. Medical oncologists at RHLCCC complete a best practice alert in the YA's medical record to confirm their discussions about potential treatment-related infertility and to provide referrals for more in-depth discussions with reproductive specialists, if needed. RHLCCC has a full-time fertility patient navigator and numerous institutional resources to address patients' reproductive health concerns, representing a "best case" scenario for addressing YAs' reproductive health needs. For this purposive sample, the study principal investigator (JS) contacted 12 eligible oncologists to describe the study and all consented to be interviewed.

YAs were eligible if they were diagnosed with one of the above cancer types between the ages of 18 and 39, treated at RHLCCC, within 2 years post-treatment, and met with a

fertility navigator or reproductive specialist (regardless of a decision to engage in assisted reproduction). We reviewed YA data from the electronic medical record to pre-screen for eligibility. After obtaining oncologists' permission to contact their patients, 49 YAs were called by the study coordinator, and 37 YAs were screened. Of those, 1 YA declined, but 36 YAs were eligible and agreed to participate with 24 YAs (67%) returning signed consents.

Semi-structured interviews

All interviews, oncologist and YAs, were audio-recorded, transcribed, and de-identified in preparation for qualitative analysis. Oncologist and YA interview guides are available in the [Appendix](#). All interviewers (JS, BY, AA, and MS) had prior experience conducting semi-structured interviews and received additional training from a qualitative researcher and study co-investigator (DV, a counseling psychologist) prior to data collection.

Oncologist interviews were conducted in person in their private offices. Interviewees and interviewers were matched by sex. Both interviewers (JS and BY) were Ph.D. behavioral scientists and trained in clinical psychology. Oncologist interviews lasted 8 to 32 min ($M=17$ min). Interviews with YAs were completed by phone and conducted by study investigator (JS) and study team members (AA and MS) who were both master's level trained in public health. YA interviews lasted 16 to 39 min ($M=23$ min), and YAs received a \$35 VISA gift card.

Statistical analysis

Data were analyzed by two coders for thematic content related to fertility preservation using NVivo10.0. An inductive coding style was used, whereby themes were identified in an iterative fashion. Our first step was to discuss the general sense of the participants' experiences (oncologists and YAs) based on an initial review of the transcripts. Our second step was to begin coding the data. We established coding rules and definitions, which led to the development of our initial codebook. Two reviewers (JS and BY for the oncologist data; JS and MS for the YA data) independently read and exhaustively coded text passages of the same transcripts. The degree of interrater reliability between coders ranged from 80 to 98%. Our third step was to evaluate data saturation, or the extent to which no new codes emerged. Data saturation was present by the 9th oncologist interview and by the 6th YA interview, suggesting that all relevant information was sufficiently captured within the number of interviews conducted.

Results

Sample descriptions

Twelve medical oncologists participated in the interviews (67% >50 years of age; 50% female). Twenty-four YAs ($M=29$ years of age) participated in the interviews. These YAs were primarily female (62.5%) and non-Hispanic white (58.3%) and had a range of cancer diagnoses: leukemia (17%), lymphoma (17%), brain (13%), breast (13%), sarcoma (13%), colorectal (8%), endometrial (8%), testicular (8%), and uterine (4%). All YAs met with a fertility patient navigator and were medically able to undergo fertility preservation if desired. Sixty-seven percent engaged in fertility preservation (9 banked eggs/embryos, 5 banked sperm, and 2 used gonadotropin releasing hormone agonist therapy) and 33% (5 women and 3 men) decided against assisted reproduction. All YAs were post-treatment survivors at the time of the interview.

Semi-structured interviews ($N=12$ oncologists and $N=24$ YAs)

Seventeen themes were identified across both samples. Nearly half of the themes ($8/17=47\%$) were discussed by both groups, five themes ($5/17=29\%$) were unique to YAs, and four themes ($4/17=24\%$) were unique to oncologists. The most frequently used themes for oncologists were “age,” “patient interest or parity,” “cancer type/stage,” and “treatment.” In contrast, “treatment” and “patient interest or parity” were also commonly used themes for YAs, but “knowledge,” “emotional impact,” and “trusted others’ perspectives” were relatively more important (Fig. 1). Table 1 provides a complete summary of the number of YAs who endorsed each theme and the frequency with which each theme was endorsed. With the exception of the “comfort” theme, male and female YAs had similar frequency patterns across all themes ($\leq 4\%$ difference in # of references). Example quotes for all themes are provided in Table 2. Full data are available upon request.

Shared themes from oncologists and YAs

Knowledge/information The most commonly reported theme for YAs was knowledge. It was the only theme described by all YAs and included a range of disclosures about reproductive health, cancer-related infertility, or fertility preservation options. Some YAs did not recall receiving information to guide their decision-making, while others felt sufficiently informed. Notably, the need for or receipt of clear information was a theme discussed at a much higher rate among YAs than oncologists. Only one oncologist spoke about knowledge as a barrier or facilitator of decision-making, and when it was discussed, it was to describe the lack of patient knowledge.

Table 1 Endorsement of themes by participant group

Common themes	Oncologists		Young adults	
	<i>N</i>	References	<i>N</i>	References
Knowledge/information	1	3	24	173*
Treatment	10	31*	23	95*
Patient interest or parity	11	48*	21	88*
Comfort	3	4	19	51
Financial/insurance	12	18	21	41
Cancer type/stage	11	59*	16	54
Age	12	47*	8	25
Cultural/religious beliefs	4	7	7	15
Unique patient themes				
Emotional impact			19	87*
Trusted others’ perspectives			22	81*
Positive reappraisal			22	53
E-support			19	33
Fertility preservation side effects			9	17
Unique oncologist themes				
Patient readiness for preservation	9	15		
Physicians’ values	5	13		
Sex	6	14		
Time	6	9		

“References” refers to the number of times a theme was coded for the group (oncologist or young adult). References with a “*” were present $\geq 10\%$ of the time

Cancer type/stage The most commonly reported theme for oncologists was a patient’s cancer type or stage of diagnosis. The type and stage of cancer may impact the timing of treatment initiation and the potential to accommodate fertility preservation procedures. This can be particularly true among some of the more common cancer types in YAs such as hematologic malignancies and breast cancer. While YAs also mentioned these clinical factors, oncologists discussed them at a much higher rate.

Age In addition to oncologists’ focus on patients’ cancer type or stage of diagnosis, all oncologists prioritized age as a key factor in their conversations about fertility. For male patients, oncologists would consider a much wider age range, whereas for female patients, oncologists typically prioritized those discussions for women until their mid-40s. Age was rarely mentioned by patients, and when it was, it was typically to reflect on information their oncologist had shared with them.

Parity/interest YAs and oncologists frequently talked about the number of children patients had and if there was a desire for more biological children. Some YAs expressed concern

Table 2 Illustrative quotes for common study themes

Theme	Quote	Participant
Shared patient and oncologist themes		
Knowledge/information	Some patients don't have any knowl– don't have any, really, understanding of their reproductive system. That's fair. Patients certainly have very unrealistic expectations about fertility possibilities. That can be a barrier.	Male oncologist (202)
	I had discussed it with several doctors and, um, you know, I pretty much knew, after the treatment, it would be a slim chance that I would be able to do this on my own, without, you know, fertility options. You know, discussing it with my fiancé, we had decided to go ahead with the storing, doing the fertility treatments. My doctors had discussed it with me prior, and, um, you know, learning that you would pretty much have no chance of conceiving after treatment, you know, it's pretty- pretty hard to understand. It's pretty hard to take in.	YA male (106)
Treatment	I never really felt like the doctor there was hearing me and did not really give me any options.	YA female (109)
	I tell them that I assume that they will have a reasonable chance of loss of fertility...and at the same time they need to assume that they can get pregnant every time that they have sex.	Female oncologist (210)
	Um, mostly said, uh, some people come out of it totally fine once the chemo's out of their system and everything, things kind of revert back to normal. Some people, um, don't – are completely, uh, infertile, uh, for the rest of their lives. They said, about a 50/50 shot, um, so it was best to, um, bank, um, sperm ahead of time before, uh, before all that.	YA male (104)
	Definitely would be that the chemotherapy lessens, um, your chances of having another child. And that was major to me, because I very much want another child later in life. And that was one thing that he was, you know, very adamant on was, you know, the chemotherapy, it, um, kills off your eggs and lowers your chances majorly.	YA female (110)
Patient interest or parity	Um, some of these younger people, it's a bit hard to get them to think, um, you know, five years, ten years down the road, um, that they will, um, they may be glad that they had done it.	Female oncologist (204)
	Um, I guess me just being young. Um, I mean as of – you know, I don't even know that I want kids and even since I was, you know, a little bit younger I don't know that I want kids anyways but you know, I could always change my mind and me being so young and not really knowing, you know, if I wanna have a family in the future at all, you know, it just – I thought it was the right thing to do, um, in case I ever do wanna, you know, have a family with, you know, kids and I at least did something to, um, I guess try.	YA female (115)
	Yeah, uh, well, uh, prior to my diagnosis, uh, we did – we do have one child, and she was born before I was diagnosed with any, uh, with, uh, cancer. So um, we, you know, we always wanted to, uh, you know, have more kids down the line. So right when we found out about, uh, my diagnosis, we talked to the doctor, um, and I got the recommendations.	YA male (123)
Comfort	Um, having somebody who's 18, 19, 20 years old and talk about fertility issues with mom sitting in the room, it's a little bit awkward, at least, um, for the patient – some of them. Um, and then um, I suppose there's some barriers in terms of, um... physician-related, in that either given the scenario or the circumstances, you may presume one way or another, um, that fertility is, I guess, a non-issue.	Male oncologist (205)
	Yeah they were women and I just felt you know they were approachable and we had really good conversation about my treatment plan and about my life style and I just felt really comfortable sharing with them. Like I'm just an open person in general...	YA female (117)
Financial/insurance	Primarily you leave that [<i>insurance and financial issues</i>] with the social worker, but I have to be sensitive to it. It doesn't make sense to go down some long, complicated road of, "Okay, well we're gonna have you do this and this and this" if it's not possible. So I'm, I'm gonna flush that out. I'm not gonna promise, "Oh, don't worry, we'll get you your whole bunch of IVF and treatments like that before we compromise your fertility" if I don't think it's possible.	Male oncologist (202)
	They were explaining to me that fertility preservation was something that I would have to pay for out-of-pocket, and that would have been the main issue, because it's not, it wasn't covered by, like, insurances or something like that.	YA female (108)
Cancer type/stage	So if they're – if they're, um... if they're wanting to have more children and they have a potentially curable cancer, I'll discuss it with them. If somebody has an incurable cancer, I will generally not discuss it with them.	Female oncologist (209)
	My diagnosis was a hormone-sensitive breast cancer and I knew that any sort of fertility preservation meant that I would need to be, I would need to have eggs harvested, which would require them putting me on something that would affect my hormone level, and I just did not feel comfortable doing that, considering my diagnosis was a hormone-sensitive diagnosis.	YA female (101)
	Well, before the treatment, once we find out the diagnosis, we – we acted pretty fast because we knew we had limited time. Uh, this is me and my wife. Um, so like there was like a week or – or two to act. Uh, so	YA male (116)

Table 2 (continued)

Theme	Quote	Participant
Age	that was the first experience. And it was all pretty quick, um, you know, from the – the information they provided us, uh, as far as fertility, you know, we – we just had that much time. Somebody who is, um, under the age of 45 – I ask them if they're interested in fertility and if they say that they are, then I talk to them about it.	Female oncologist (201)
Cultural/religious beliefs	She said that my decline, as far as like how many eggs I have, would start sooner, but at this point I really shouldn't be too concerned about my overall like amount of eggs. Um at 23, that 24, 23 that is like the peak of how many eggs you have. Um, sometimes there are cultural issues. You know, families don't believe in creating embryos.	YA female (112) Female oncologist (207)
Unique patient themes	Right now, since, you know, I am done with treatment I guess, now, I am questioning since I am Catholic, like should I use those? Like what should I do? Should I try to use those eggs or just do it naturally? So that's something I am thinking about right now, knowing that my religion is – yeah.	YA female (107)
Emotional impact	You know, I was – I'm not sure. I mean, I found it a little disturbing that there was a possibility that I might not be able to have kids on my own, naturally. That was a little, you know, hard to swallow. But knowing that there's other options, such as fertility storage, and stuff like that, I mean, that is definitely a little weight off my shoulders. Just to know that, you know, I may have difficulty. I may not be able to do this on my own, in the future. That's- that's a little shocking. So that's my biggest fear is, now, I'm not going to be able to have children. Anymore children.	YA male (106) YA female (110)
Trusted others' perspectives	But you know it was just – you know trying to figure out what to do was frustrating because – that they were saying – there was just no information one way or another, saying, yeah you'll be fine or no, you won't. So it's just kind of like well do I, don't I? You know, I didn't know you know what to do. So I mean, that was like the most frustrating situation. Most important. Um, I guess just that it wasn't – hearing that you may not be able to have children is scary and just hearing that they had options available to help you with that was important for me to hear. There was ways that I could prevent infertility. Yeah, oh and also I actually was able to talk to a psychologist and that actually helped me decide if I should just do embryos or eggs because at that time I wasn't – I am married but I wasn't – we were having problems so the fact that I was able to talk to a psychologist made me, you know, rethink because I thought I was only going to do embryos but I decided to do both so that really helped.	YA male (118) YA female (120) YA female (107)
	We were married at the time when we decided to do this, and I have been married to him, and known him for quite a while. So we were very confident this is, you know, we wanted it to be our children together. I can't exactly remember everything. Um, I just remember I was really upset and I was crying, and it was, you know, I was more worried about, well I want to have more kids, I want to have more kids. My mom just kept telling me and that's fine, but you know your health is more important. Your health is more important. And just, you know, talked me out of it, convinced me not to go see this doctor, and said, oh, it's probably going to cost thousands of dollars to store your eggs, it may not even work, you have to go through this whole big process. And just pretty much completely talked me out of it, so I just went ahead and ignored it, which I do regret.	YA female (109) YA female (110)
	I talked over it with my girlfriend, just about everything. Um so she was – I don't know. She thought I should go ahead and do it. It was just an overall discussion of the possibility of just having kids and everything.	YA male (111)
Positive reappraisal	Um well back then I was comfortable, but, like, making the decision was a tough one. Once I made the decision, I was 100 percent. You know, I didn't look back at all and now, um – now I'm thrilled because, um, I'm 14 weeks pregnant with a gestational carrier.	YA female (124)
E-support	I just went on Google and typed in IVF, and we had seen a couple of YouTube videos of people discussing what they had gone through. We pretty much based our decision on what other people had gone through and what they had decided.	YA male (106)
Side effects	With the type of cancer that I was diagnosed with, they didn't want to chance me taking the fertility drugs because, by the cancer already spreading the way it was, the fertility drugs would have accelerated it.	YA female (103)
Unique oncologist themes		
Patient readiness for preservation	If they're interested in having children, they need to think about either banking sperm, eggs, umm, to... just in case there are some sterility issues down the line, um, and then, you know, usually get some discussion. Most of them at that point, when they see me, it's probably the farthest thing from their mind at that point in time. But, we do cover it, and if they're interested, we've had people go, but some people don't want to delay their therapies.	Male oncologist (203)
Physicians' values		Male oncologist (212)

Table 2 (continued)

Theme	Quote	Participant
Sex	So if someone’s life expectancy is less than two to three years, should we be offering them sperm banking? Is that a priority? Is that where we should be using our resources? It’s easy in men. A man could sperm-bank in a heartbeat. So the question is, for women, are we offering them false expectations? I don’t know, I’m- I think the whole process is easier with men. You store sperm and I don’t know if smokers have less viable sperm or not. I do know that women who are smoking have a much more difficult time collecting ova. So, but it’s a lot easier for men.	Male oncologist (206)
Time	In my practice, when I meet a new patient, the general goal is to have a treatment plan formulated and the wheels turning by the end of that hour, as crazy as that sounds, but for some younger patients and patients where the diagnosis of cancer is not clear – it might be like a precancer or it’s a mass that we’re not sure ‘til we get in there but this is going to influence our surgery, um, I have brought people back for separate discussions if I feel like it’s too much in one day.	Female oncologist (211)

that their cancer diagnosis and potential infertility would make them less desirable partners, and so their interest in preserving their fertility was a priority to mitigate those fears. Others had actively been thinking about and planning to have children. Oncologists were intentional about discussing patients’ interest in future biological children and discussed this theme at a relatively higher frequency than YAs.

Treatment Discussions about the potential gonadotoxic effects of treatment were important, relatively common, and equally salient for YAs and oncologists. YAs expressed awareness of how the treatment would impact their

reproductive potential. Oncologists also described ambiguity in situations when a definitive determination of impact on fertility could not be made.

The remaining shared themes comprised <10% of the content for YAs or oncologists:

Financial/insurance Most YAs mentioned the various costs associated with assisted reproduction and the role it had in contributing to their decision. In this sample, YAs who proceeded with assisted reproduction and those who did not discussed this factor at the same, relatively low rate (5%). All oncologists described the role of finances or insurance but did not prioritize those discussions with patients (allowing the

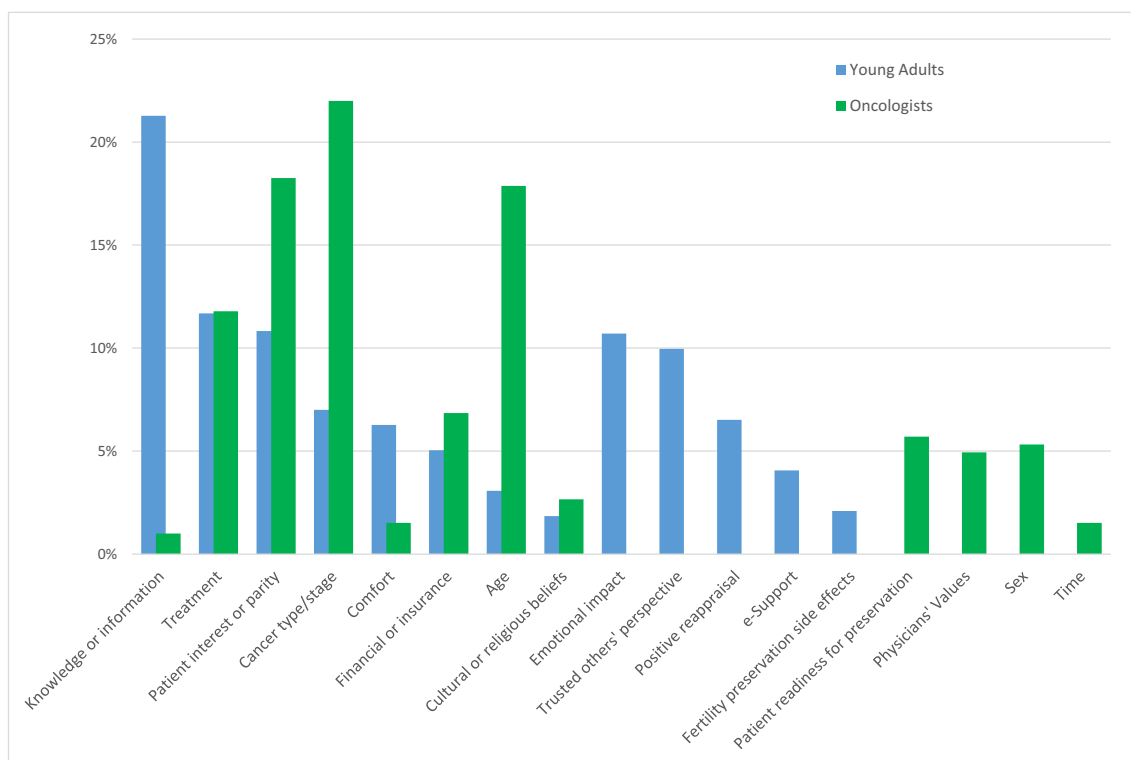


Fig. 1 Frequency of themes by participant group

social worker to address those concerns). They acknowledged the need to “be sensitive” to that component of the decision-making process.

Comfort YAs described how emotionally comfortable (or not) they felt when discussing fertility options with their oncologists. Though rarely mentioned by oncologists, they would describe how the conversation might be awkward or uncomfortable for younger patients with their parents in the room.

Cultural/religious beliefs Both oncologists and YAs discussed the role that their cultural or religious values or beliefs had in influencing their fertility preservation decision-making. This was the least mentioned shared theme and discussed by the fewest number of YAs. When cultural or religious beliefs were disclosed, they were typically shared as a reason for not pursuing assisted reproduction.

Unique themes from patients

Emotional impact The emotional challenge of navigating potential cancer-related infertility and uncertainty was the most frequently reported unique theme among YAs. They reported anxiety/worry/fear, depression/sadness, and even regret.

Trusted others’ perspectives For many YAs, deciding if and how to move forward with fertility preservation was a process that involved multiple conversations, typically with a partner but also included professionals, family members, and close friends. This reflected a continuation of prior conversations about family building and also reflected more complicated conversations about surrogacy.

Positive reappraisal The emotional impact of navigating a decision about fertility preservation was often negative. It was not exclusively so, however, as some YAs spoke of reframing their experience in more positive terms. This was typically an adaptive coping strategy used to re-affirm the fertility preservation decision that was made.

E-support Still other YAs described their use of and reliance on Google, YouTube, websites, blogs, or a variety of e-tools. These resources were typically used to address knowledge gaps or seek confirmation for decisions made. Still others used these tools as a means of support to learn from others who had navigated similar situations.

Fertility preservation side effects Perhaps surprisingly, potential side effects from the fertility preservation options were infrequently discussed by YAs. When they were disclosed, it was typically focused on the invasive nature of certain procedures and was only shared by the female participants.

Oncologists likely did not reference this theme because these discussions were often the purview of the reproductive endocrinologist.

Unique themes from oncologists

Patient readiness for preservation Oncologists would occasionally reference the stage that a patient was in with respect to fertility preservation. They might describe them as being unaware and not having considered it at all vs. thinking through the options and undecided vs. knowing that they want to move forward with specific fertility preservation options. These conversations would obviously impact potential referrals to reproductive specialists.

Physicians’ values Some oncologists would acknowledge the degree to which their beliefs and attitudes influence discussions about fertility preservation. This often emerged for oncologists when treating a patient that had a poor prognosis or limited resources. They might voice an internal tension between the ability to do something (i.e., assisted reproduction) and whether that option is the “best” decision given the patient’s circumstances.

Sex For oncologists that treated patients of both sexes, they would discuss the role that biologic sex plays in fertility preservation decision-making. This would often overlap with the treatment plan and cancer type/stage discussions since the importance of timing and ease of a fertility preservation procedure (e.g., sperm banking) vs. more invasive approaches (e.g., egg freezing) were typically emphasized.

Time One of the least frequently discussed themes was the amount of time oncologists spent discussing fertility preservation concerns with patients. For those that referenced it, they described how that aspect of the treatment planning visit would be prioritized relative to other considerations and how it aligned (or not) with the patients’ needs and priorities.

Discussion

This qualitative study of stakeholder attitudes and practices about fertility preservation decision-making reveals key considerations for factors that may represent an important disconnect between YAs and their oncologists as well as those that are relatively unique to YAs and those that are more salient to oncologists. Collectively, these themes validate and strengthen the substantive literature on fertility preservation decision-making among YAs, the priorities for oncologists, and opportunities for improvement. Moreover, they also point to the potential value of a multilevel approach to better address this important, patient-centered priority among YAs.

First, among the shared themes, the largest discrepancy between YA and oncologist perspectives was the role of knowledge in the decision-making process. YAs highlighted both the benefits of adequate and in-depth knowledge in order to foster informed decision-making. Regrettably, some YAs also expressed frustration over the lack of information about the extent to which cancer and treatment would affect their fertility. This was understandably linked to expressions of decisional regret, distress, and grief—common reactions among YAs who have experienced reproductive concerns post-treatment [24, 25]. Oncologists described the role of knowledge of risks and options infrequently. What is often said in the visit is not always what is remembered or understood by YAs, and it is critical to check for comprehension [26, 27]. Accordingly, models of shared decision-making may be well received by patients and oncologists [23]. This places the onus on YAs to be informed “consumers” of information and to advocate for themselves as well as on the oncologist to allow time and “space” for these conversations to occur.

Additional YA priorities include managing their affective response to the situation and the role of significant others in their lives who provide support. For YAs, the experience is often significantly distressing and represents a non-normative event [28, 29]. Moreover, the potential for cancer to impair fertility sometimes “adds insult to injury,” and so there is a clear need for YAs to not only receive informational support but emotional support as well. This can be in the form of psychosocial support or even skilled fertility patient navigators, who can address these affective needs or provide referrals for patients who are in greater distress [30]. Involving trusted others in the decision-making can provide support and clarify YAs’ priorities and goals [31].

For oncologists, the most salient themes were clinical factors associated with type of cancer, stage of disease, and patient sex. This is not unusual given the need for oncologists to make evidence-based recommendations [2–4]. An ongoing challenge, however, is that models of gonadotoxic risk are constantly in need of updating. With newer targeted therapies, the potential risk is unknown, and the impact on fertility may take years to be identified [32]. In addition, YAs may misunderstand quantitative risk estimates. As such, communication experts advocate messaging that conveys the potential risk for *any* treatment to impact fertility, and if preserving fertility is a priority to a patient, s/he should have a conversation with a reproductive specialist [33].

This study has a few limitations. All YAs and oncologists were from a comprehensive cancer center that has multiple resources to support oncologists and patients who have reproductive health concerns, so these findings may not be representative of the larger YA

community. That said, the communication disconnects and priorities identified here are not a priori inconsistent with what we might find if the study were replicated in community settings. Moreover, the discrepancy for knowledge may even be *greater*, pointing to the need for scalable and multilevel interventions to support information needs of patients. Secondly, the interviews represent retrospective accounts of YAs’ experiences with their decision-making about fertility. Although we intentionally included YAs who were within 2 years post-treatment, the salience of some events may have passed, and the degree to which YAs may be more settled in their decisions may obscure the real-time factors that impacted their decisions. Thirdly, we cannot rule out some self-selection bias in our YA sample. We intentionally recruited YAs who considered fertility preservation but decided against it in order to capture a range of experiences, but it is possible that YAs who may have had more negative experiences were not likely to participate. Lastly, we did not specifically focus on dyadic, oncologist, and YA relationships. Examining the attitudes and practices about fertility preservation within dyads would prove even more illuminating and would be an important future direction.

In summary, these findings point to the critical role that knowledge serves in fertility preservation decision-making and the complementary ways that YAs and oncologists can leverage their respective affective and cognitive experiences to foster shared decision-making. It is important to identify factors that can support and empower patients to advocate for themselves. To address knowledge deficits among YAs and support those who may have limited access to reproductive specialists, future work should focus on the development and testing of fertility preservation decision aids to examine feasibility, acceptability, and efficacy [34–36]. Further, multilevel interventions that address the individual patient needs as well as contextual influences (e.g., providers, organizations) [37] may be particularly well suited to support fertility-preservation decision-making. YAs would benefit from more information about how the treatment will impact fertility, how preservation works, how preservation can influence their disease progression and prognosis, and the need for contraception [32, 38–40]. Oncologists can benefit from additional guidance on how to introduce the topic and knowledge of referral resources [41–45]. This can be strengthened through awareness of YA’s interest in preservation and knowing when to initiate a discussion about preservation. Ultimately, the design and testing of tools to support shared decision-making about fertility preservation is a growing area and may enhance patient-centered care for YAs with cancer.

Appendix. Oncologist and young adult interview guides

ONCOLOGIST INTERVIEW GUIDE

Thank you for taking the time to speak with me today about fertility preservation for young adults with cancer. The purpose of this project is to examine patient and provider perspectives about fertility preservation options among young adults with cancer and their medical oncologists. We are interested in learning more about your experiences concerning fertility preservation for your young adult patients aged 18–39.

1. Please tell me how you decide when to discuss any fertility-related concerns with your patients.
2. Do you discuss fertility-related concerns with all of your patients? *If unclear, probe: Why/why not?*
3. On average, how much time do you spend discussing fertility-related concerns with your patients?
4. Approximately what percentage of your patients are candidates for fertility preservation? *If unclear, probe: Why/why not?*
5. Can you tell me how often you answer the EPIC questions for fertility? *Probe to find out if the questions are completed by the attending or by someone else on his/her team.*
6. At what point during your visit with a new patient do you discuss fertility-related concerns and complete the EPIC fertility questions? *(Note: May already be clear from response to #1)*
7. In which situations do you use ‘N/A’ for informing a patient about the impact of treatment on fertility?
8. When applicable, do you use the EPIC questionnaire as a direct referral to the patient navigator or do you make a separate referral? *If unclear, probe: Why/why not?*
9. Do you make direct referrals to a reproductive specialist? *If unclear, probe: Why/why not?*
10. Can you tell me what you think are the barriers to discussing fertility-related concerns with your patients? *If unclear, probe typical barriers such as: patient’s cancer stage, timing of the start of treatment, parity, insurance, or financial issues*
11. Is there anything else you think is important for me to know about your practices concerning managing patient’s fertility-related concerns that I did not ask you?

Thank you for your time.

YOUNG ADULT INTERVIEW GUIDE

Thank you for taking the time to speak with me today about the impact of cancer upon your fertility. The purpose of the study is to examine patient and provider

perspectives about fertility preservation options, and we are interested in hearing about your experiences and exploring any challenges you have faced in making decisions about your fertility. *Note: If participant is confused by or unfamiliar with the term “fertility preservation”, re-phrase as “maintaining the ability to have children.”*

1. Please tell me about your experience managing any fertility-related concerns before you began your treatment.
2. Did you understand how treatment would affect your fertility? *If unclear, probe: Why/why not?*
3. Can you tell me if you discussed fertility preservation options with your oncologist? *If unclear, probe: Why/why not? Also probe to determine who patients may have discussed fertility preservation options with in lieu of their oncologist.*
4. What do you think is the most important piece of information that your oncologist [or provider identified in #3] told you regarding fertility preservation?
5. Is there any information you wish your oncologist had told you about fertility preservation that he or she did not? Why?
6. Did you meet with the fertility preservation patient navigator? *If unclear, probe: Why/why not?*
7. Did you take any steps to preserve your fertility? *If unclear, probe: Why/why not?*
8. Can you tell me about what influenced your decision regarding fertility preservation options?
9. Please tell me how you felt about your decision after you made it back then? How do you feel about your decision now? *If unclear, probe: Are you able to have children today?*
10. Please tell me what your experience has been like with fertility follow-up care. *Note: May be N/A for some.*
11. Please tell me what resources you used, if any, from organizations that provide reproductive information and support for patients and their families. *If not mentioned, probe: Have you heard about websites like fertilehope.org, myoncofertility.org, savemyfertility.org, fertilitypreservation.northwestern.edu, liveonkit.com, or The American Cancer Society and The National Cancer Institute?*
12. Please tell me about any specific barriers or things that got in the way of you getting fertility preservation care. *If unclear, probe typical barriers such as: cancer stage, timing of the start of treatment, parity, insurance, or financial issues.*
13. Is there anything else you think is important for me to know about your experiences managing your fertility-related concerns that I did not ask you?

Thank you for your time.

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Data Availability All data are available upon request.

Code availability Not applicable.

Declarations

Ethics approval This work was conducted in compliance with the Northwestern University Institutional Review Board.

Consent to participate All participants, oncologists and young adults, provided informed consent to participate in this study.

Consent for publication No separate consent for publication was obtained. The informed consent document addressed the potential for publication of de-identified data and additional efforts to maintain participant confidentiality.

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