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ORIGINAL ARTICLE

Exploring patient and provider perspectives on the intersection between fertility, genetics, and family building

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Abstract

Objective Adolescent and young adult (AYA) cancer patients have distinct medical and psychosocial needs and fertility is a key concern. Early age of onset is a risk factor for hereditary cancer and AYAs are more likely to experience reduced fertility. This has implications for future family building decisions and fertility preservation (FP) and genetic testing/counseling (GT/GC) education.

Methods Patients diagnosed with cancer between the ages of 18 and 39 and health care providers (HCPs) who treat AYA cancer patients were recruited from a single institution. Qualitative interviews explored AYA patients' and HCPs' concerns regarding their experiences discussing genetics and FP.

Results The majority of patients ($n = 17$) were female (59%), and the majority of HCPs ($n = 18$) were male (67%). Overall, participants had differing perceptions of FP and GT/GC-related information provided during the clinical visit. Patients indicated initiating the conversation about FP and did not recall HCPs discussing GT/GC with them. HCPs indicated patients were often overwhelmed with too much information and comprehension of this discussion is limited. HCPs also felt patients' emotions/beliefs determined their information-seeking behavior specific to FP and GT/GC. Participants felt educational materials should be developed and delivered in a video format depicting a patient–provider interaction or patient testimonial.

Conclusion AYA patients are often overwhelmed by a cancer diagnosis; the complexity/volume of information regarding FP and GT/GC may hinder understanding and decision-making about family building. Educational materials that help patients understand what questions to ask HCPs about FP and GT/GC should be developed to improve knowledge, psychosocial well-being, and future family building decisions.

Keywords Adolescent and young adult · Cancer · Education · Oncofertility · Reproductive health

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Over 70,000 adolescents and young adults (AYAs) are diagnosed with cancer in the USA each year, accounting for approximately 6% of all new invasive cancer diagnoses [1]. The AYA population is typically defined as between 15 and 39 years old [1]. Cancer treatment can reduce patients' fertility or cause sterility [2]; thus, one highly relevant issue for AYAs is the impact of a cancer diagnosis and associated treatment on future fertility [3–7].

While AYA cancer patients have identified childbearing as an important priority [8], the possibility that future genetic children could be at increased risk for cancer is also a concern for AYA patients, perhaps to the extent that some may avoid childbearing in fear that their child may inherit cancer [9–15]. The National Comprehensive Cancer Network (NCCN) guidelines recommend patients of reproductive age (AYA patients) be counseled about fertility preservation (FP), genetic risk, and reproductive options including preimplantation

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genetic testing (PGT) for several hereditary cancer syndromes [16]. The intersection of these topics may impact AYA's future family building decisions.

Oncologists consult with AYA patients at a critical juncture when they are both processing their diagnosis and learning about the possible hereditary basis of their cancer and the potential impact of cancer treatment on their fertility [17]. Thus, oncologists are in an ideal position to discuss fertility, potential genetic risk(s), and implications for future offspring. However, relatively little is known about if or how oncologists discuss genetic risk for cancer in future offspring, nor the impact of this discussion on future reproductive decisions with patients. This study explored the following: (1) AYA cancer patients' and healthcare providers' (HCPs) discussions about genetic risk and genetic testing and counseling (GT/GC) and FP; (2) patients' concerns regarding fertility and genetic risk; and (3) patient and HCP's recommendations for educational materials regarding FP and genetic risk.

Methods

Recruitment

Participant recruitment commenced upon Institutional Review Board (IRB) approval. Patient eligibility included the following: (1) diagnosed with cancer between the ages of 18 and 39; (2) diagnosed after April 2012 (when NCCN issued guidelines for AYA patients regarding FP and GT/GC) [18]; and (3) received treatment at our institution. Patients with various cancer types (i.e., melanoma, colon, leukemia/lymphoma) were considered for recruitment, as these cancers have a spectrum of possible genetic risk, resulting in a need for providers to address this risk and discuss GT/GC. Patients with these cancer types may have also received treatment that could have impacted their fertility, resulting in a need for discussions with providers about FP and fertility issues. Patients were recruited through clinical records, outreach activities, and flyers and completed screening eligibility questionnaires over the phone with the study coordinator.

HCPs (i.e., physicians, advanced practice professionals, genetic counselors, or psychologists) who delivered care to AYA patients and typically have conversations with patients about FP and GT/GC were eligible for participation. A letter describing the study was sent to leaders from nine clinical programs that treat AYA patients. Clinician leaders were asked to share study information with other HCPs in their programs. Interested providers completed phone eligibility screeners. Patients and HCPs who met eligibility criteria were scheduled for either a phone or in-person interview conducted by two study team members.

Data collection

During semistructured interviews, patients were asked to describe their perceptions of genetic risk for cancer in future offspring, the impact of risk perceptions on FP and GT/GC, and preferences for information/education regarding genetic risk for cancer in future offspring and FP. HCPs were asked to describe their conversations with patients, perceptions of patient understanding of information presented during clinical visits, and current practices and preferences for patient information/education regarding genetic risk and FP. Audio-recorded interviews were then transcribed. Compensation for study participation included a $50 gift card for patients and $15 for providers.

Data analysis

Qualitative data analysis was based on the approach suggested by Lindlof and Taylor [19]. Two study team members (MLK and PL) reviewed each transcript independently to identify initial themes; next, they met to review each transcript, consider possible findings, discuss common themes, and resolve disagreements. Together they developed a detailed codebook; both reviewers coded and discussed all transcripts. Utilizing the codebook, themes were analyzed again by a team member who participated in the initial analysis (PL) as well as an additional study team member (MD). The codebook was further revised during this second analysis phase and these final codes were applied to the transcripts. Coding was conducted using MAXQDA v.12.

Results

Participant demographics

Seventeen patients and 18 providers completed interviews. Most patients ($n = 10$, 59%) were female, with an average age of 32 years (SD = 5.2); approximately half ($n = 8$, 47%) were married. Patients were diagnosed with a variety of cancers including melanoma ($n = 5$, 29%), colorectal ($n = 3$, 18%), and leukemia/lymphoma ($n = 4$, 24%). Most of the HCP sample were male ($n = 12$, 67%) medical or surgical oncologists ($n = 15$, 83%). HCPs represented multiple clinical programs including breast ($n = 3$, 17%), sarcoma ($n = 2$, 11%), and cutaneous ($n = 2$, 11%). See Table 1.

Themes

Qualitative analysis identified several themes, revealing the ways in which AYA cancer patients and HCPs perceive discussions about reproductive health. Tables 2, 3, and 4 provide example quotes from patients and providers for each theme.

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Table 1 Participant demographics: adolescent and young adult (AYA) cancer patients ($n = 17$) and oncologists ($n = 18$)

	n (%)
AYA patient characteristics	
Patient gender	
Male	7 (41.2)
Female	10 (58.8)
Patient age [mean (SD)]	32.4 (5.2)
Diagnosis	
Oligodendroma	2 (11.8)
Melanoma	5 (29.4)
Colorectal carcinoma	3 (17.6)
Leukemia/lymphoma	4 (23.5)
Other (breast, testicular, thyroid, soft tissue sarcoma)	4 (23.5)
Oncologist characteristics	
Provider gender	
Male	12 (66.7)
Female	6 (33.3)
Provider type	
MD	15 (83.3)
PA	1 (5.5)
Genetic counselor	1 (5.5)
Psychologist	1 (5.5)
Site/program of provider	
Sarcoma	2 (11.1)
Hematology	3 (16.7)
Cutaneous	2 (11.1)
Breast	3 (16.7)
Bone marrow transplant	2 (11.1)
Other (genetics, urology, psychology, orthopedics)	6 (33.3)

Theme 1: AYA cancer patients' understanding about fertility and hereditary nature of their cancers

AYA patients' understanding about fertility revolved around the complicated nature of the topic and how HCPs communicated the information. While HCPs emphasized the associations between cancer, genetics, and fertility are complex, patients' attitudes and knowledge toward these topics were influenced by their emotions and preexisting beliefs.

Patient understanding about hereditary nature of their cancers Some patients were unsure or uninformed of the hereditary nature of their cancers and the subsequent impact on their future children. Thus, HCPs often encouraged patients to seek GT/GC so they can better understand and learn about these complex topics from a specialist such as a genetic counselor. A female with breast cancer (age 36) indicated "I did not know anything about my father's background, so that put me at some sort of risk that I needed to know if [it] was hereditary or not," so her oncologist recommended meeting with a genetic counselor (Table 2, row 1).

Many HCPs indicated that the complexity and volume of information presented limited patients' understanding. One breast surgical oncologist explained, due to the large amount of information to cover during each patient visit, they often refer patients to a genetic counselor to educate them on the genetic risk of their cancer and facilitate retention of information (Table 2, row 2). Additionally, HCPs noted that while they are aware they need to consider patients' health literacy, they often revert to the use of medical jargon during the visit, "we have to go down to the level of the patient…..to make them understand……. I think too often we've been guilty of using medical language, which flies right over their heads" (Table 2, row 4).

Patient emotional state impacts motivation for genetic information Providers noted that patients' emotional state may hinder understanding of information presented during the visit. They noted patient distress about the initial cancer diagnosis may decrease motivation for genetic testing and the ability to ask questions. One sarcoma HCP described patients as being "like a deer in the headlights." They explained that patients are often "so overwhelmed as a young person to have cancer and think 'my life is ending very quickly,'" and cannot think about the hereditary nature of their cancer, genetic risk for future children, or FP (Table 2, row 6). Relatedly, one genetic counselor indicated patient motivation for learning about inherited risk of cancer, receiving genetic testing, and more aggressive treatment options may stem from witnessing a family member experience cancer and associated challenges, which can be catalysts for a patient to receive GT/GC (Table 2, row 7).

Patient beliefs impact genetic counseling and testing and fertility preservation preferences Several HCPs felt patients' beliefs impacted intentions to receive GT/GC. One breast surgical oncologist described a patient whose parents were both diagnosed with breast cancer, but did not want to receive genetic testing because she believed her cancer diagnosis was inevitable (Table 2, row 8). Similarly, some patients suggested the ability to have children was not in their control. One male with brain cancer (age 27) believed "if it's not meant for me to have kids, it's not meant [to be], but if it is, it is." (Table 2, row 9).

Theme 2: Differing reports of information provision regarding fertility preservation and genetic testing/counseling

Patient and HCP recollection of FP and GT/GC conversations differed substantially. First, half of the patients indicated their HCP never discussed FP or GT/GC. One male diagnosed with lymphoma (age 39) emphasized, "There were no

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Table 2 Theme 1: AYA cancer patients' understanding about reproductive health, fertility, and hereditary nature of their cancers

Subtheme	Definition	Exemplar quotes
Subtheme 1.1: Patient understanding about hereditary nature of their cancers	When patients express concern or providers describe patients' understanding about the potential to pass their cancer on to their future children	Row 1: "I did not know anything about my father's background, so that was a risk, that put me at some sort of risk that I needed to know if I was hereditary or not." — *36-year-old female with breast cancer* Row 2: "I think it's a step process. You have to understand that when you are having that first cancer talk with a patient that they only hear about ten percent of what you say anyway, from the cancer standpoint. So, I cannot imagine that they have glommed onto the genetic part better than that. So, I would say they probably only hear ten percent and that's the other advantage of sending them to the genetic counselor because now again they have another appointment to bring other ears with them and it's focused on only that aspect." — *Provider: breast surgical oncologist* Row 3: "I think within the first five minutes or so of our session they really know their stuff and then it seems like as time goes on – like when I see them again for results, sometimes I'm like 'that is not at all what I told you.' So, it's interesting how probably just learning in general is like that where sort of right afterwards, I really feel like I really got through to that patient. They really got what I was saying. Then I'll talk to them again later and I'm like, no, that's not, you know." — *Provider: genetic counselor* Row 4: "We have to definitely go down to the level of the patient and the common man to make them understand what we want them to understand. I think too often we have been found guilty of using medical language, which essentially flies right over their heads. After about ten minutes of the initial interview process, you have lost them completely." — *Provider: cutaneous (skin cancer) clinic* Row 5: "Since I am double stranded they did tell me the risks and what could happen if I did get pregnant and decided to keep the baby because it would ultimately be – the risk would be 100% that at some point they [the future child] would develop some type of cancer." — *26-year-old female with colon cancer*
Subtheme 1.2: Patient emotional state impacts motivation for genetic information and testing	When providers describe how patient emotions about having cancer and going through treatment often impact their motivation to seek information about genetic testing and reproduction options	Row 6: "They're just so overwhelmed as a young person to have cancer that nobody ever thinks of that and immediately, obviously, they think that they are going to die or they are going to die pretty soon. That's immediately what they think. So, I just think they get lip locked because they are just so overwhelmed just by the shock of having cancer at such a young age, and then thinking that, "My life is ending very quickly." So, initially when I see them, that's kind of how they are. They're like a deer in the headlights and stuff."

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Table 2 (continued)

Subtheme	Definition	Exemplar quotes
		— *Provider: sarcoma program* Row 7: "I find that patients are usually more motivated and not just AYA but just in general or are usually more motivated for testing and learning about inherited risks if they have seen a close family member pass away from cancer. A woman who watched her mother die of breast cancer at 37 is more likely, I think – I do not know the data – but seems more likely to be more aggressive and do a bilateral mastectomy instead of screening. I think that also holds true for just wanting that information as if they had already seen someone go through cancer and die and they are like, okay, let us try to avoid that and be proactive and get that information." — *Provider: genetic counselor*
Subtheme 1.3: Patient beliefs impact genetic counseling and testing and fertility preservation preferences	How patient beliefs often determine reproduction and genetic testing/counseling decisions	Row 8: "I've had a woman where both her parents had breast cancer. I mean for a male to have breast cancer and you have both parents have breast cancer and every one of the parents' siblings have died at a young age and that person herself has breast cancer and she's in her 30s and does not want to get tested. I'm like, "Are you kidding?" She said, "Well, my fate's my fate. What's the purpose of knowing?" So, again that surprised me." — *Provider: breast surgeon* Row 9: "As much as I pray and I go to church, I really feel like if it's not meant for me to have kids, it's not meant [to be], but if it is, it is. That's kinda the mindset I set for myself." — *27-year-old male with brain cancer* Row 10: "No, it was just a matter of – this is where my faith plays into it – it's a matter of just trusting what God has in store for me and if he wants me to have babies, then it'll happen. You know? I do not want to push the issue; try to play God." — *38-year-old male with melanoma*

conversations about that at all." Similarly, when patients were asked about conversations with HCPs specific to GT/GC, one male with melanoma (age 28) indicated that "if they (providers) did discuss it, I don't remember," while one male with brain cancer (age 27) indicated he "never asked, or even heard of GT before."

In contrast, HCPs reported they spent time explaining these issues, but indicated these conversations typically occurred after treatment, reducing the relevance and utility for patients. What often stood out to HCPs was that many patients are unaware that their cancer treatments may have consequential effects on their fertility (Table 3, row 1). One HCP in the hematologic malignancies program explained that infertility is not usually discussed until after patients have received chemotherapy and a transplant, which can drastically limit FP options for patients. He shared that sometimes his patients will bring it up months after transplant: "They ask me, 'What about having children?' then I'm really in an even worse position because we're unlikely to be able to offer them a good option…because then they've gone through everything [already]" (Table 3, row 2). Many HCPs indicated they would often initiate conversations about GT/GC through conversations about genetic risk. One breast surgical oncologist indicated genetic risk is often discussed early on when a patient's surgical management plan is presented, as family history plays a role in determining this plan. They explained they often use this conversation to discuss how GT/GC can provide benefits for their family (Table 3, rows 3 and 4).

Few HCPs indicated patients would initiate discussions about genetic risk for future children. The few patients who

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Table 3 Theme 2: Differing reports of information provision regarding fertility preservation and genetic testing/counseling

Theme	Definition	Exemplar quotes
Differing reports of information provision regarding fertility preservation and genetic testing/counseling	AYA cancer patient and AYA provider descriptions of the information that is provided during the clinical visit regarding fertility preservation	Row 1: "This is just a sampling of my own experience, but I can tell you more often than not, they [referring to patients] are surprised to hear about it [fertility issues due to cancer treatment]. And they are also surprised to hear that it may be a problem for them. A lot of patients are – have not yet fully put together the idea of how the chemotherapy could affect their fertility—and how that may or may not jeopardize their ability to have children. So, it can be kind of like a very sobering conversation to tie those two things together." — *Provider: bone marrow transplant* Row 2: "So they are already at risk for having infertility. That's where I'm taking a more active role. But as I shared before, what I've observed on several cases is it's relatively common that people bring that up with me after a transplant. Let us say months later. They'll just ask for me, "What about having children?" And then I'm really in an even worse position because – meaning I unlikely – or collectively, we are unlikely to be able to offer them a good option. That is based on their own preserved fertility. So because then they have gone through everything. The therapy, the transplant, the everything." — *Provider: hematologic malignancies program* Row 3: "So, part of the job as a surgeon because we are usually what I call the gatekeeper. So, we are the first people to encounter a newly diagnosed cancer patient. So, part of our job is to set the stage for down the road. So, we not only talk about the cancer that they have and how we are gonna surgically operate on them or surgically plan for them, but in making that plan, part of it is a family history and assessing for genetic risk." — *Provider: breast surgical oncologist* Row 4: "Just recently one of my patients has P-10. So, again there was thyroid cancer in the family. She had thyroid cancer. So, it makes sense to look for the genes that would go to thyroid cancer because that's what's in her family. So, I explain all of that to them and then I say to them what's the benefit to them of knowing the information. "How is that gonna change our current plan?" So, if they do have cancer, how is it gonna change our current plan? But, depending on the genetic mutation, it could impact our surgical choice for sure. I also tell them that, at the end of the day, it may not impact my surgical choice, but it may impact the medical oncologist in how they are gonna treat your cancer and I do not go into the details, but that kind of philosophy. Then I tell them that it could inform us about other cancers that they are at risk for that we would need to watch them for and not just only be focused on their breast cancer because they may be at risk for ovarian, melanoma, whatever so that we can make sure that they get screened. But then I also then tell them how it helps their family because the implications are that any blood relative can get tested if they are over 18 if they wanted to and they can choose to disclose their results or not disclose their results to their family." — *Provider: breast surgical oncologist*

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Table 3 (continued)

Theme	Definition	Exemplar quotes
		Row 5: "When they start feeling more comfortable, [it's] because they have [built] a rapport with you a little better. It's hard on them at that first initial visit – The first one or two visits they are shocked about the cancer; they do not know you; they do not know to trust you. And, that's difficult to win over in a very short period of time when you interact with those patients. The problem with waiting until rapport and trust have been established it is too far along in their treatment to offer them good options." — *Provider: orthopedic oncology* Row 6: "[Fertility] was a concern when I started to get onto a trial drug. At the time, we had expressed that concern to the doctors at the time. That, will there be any effect on future ability to have children? And we were told that there would not. We did not pursue it any further at the time. We did find out, when we were attempting to have children recently, we did have some problems with that and ended up having to see a fertility doctor to help with that. And looking back on it, I wish we would have asked for some testing just to determine if there were any problems at the time or if anything had happened with that. Because now, I'm just left wondering, was this a result of the cancer treatments, or was it always there, and it just wasn't a problem with the first child? So, that was something that I wish – looking back on – I wish we had addressed." — *34-year-old male with melanoma* Row 7: "There are a couple of small exceptions, but almost always, they [have] received a good amount of chemotherapy as their initial therapy to get them into a remission, and then that is the point that they actually refer them for a transplant consult. So, and usually, I try to discuss this very issue about fertility, and do they want to see someone about understanding their opportunities. I'm talking to them about that at that first consult, and so they have already received therapy. So, they are already at risk for having infertility. That's where I'm taking a more active role." — *Provider: bone marrow transplant* Row 8: "I was speaking with my doctors about it because I was worried about whether I was going to be getting radiation or chemo because where my lymph nodes are actually inguinal, so it's right there where my ovaries and everything was, right there, so I was worried about that in the beginning of how they were going to treat it and how it was going to affect me one day. I was told that [what] I was getting was not going to harm me genetically to have kids, and I was also told that melanoma is not hereditary." — *27-year-old female with melanoma*

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noted their providers did discuss fertility indicated that, if the discussion took place, the patients initiated it. One female diagnosed with melanoma (age 31) stated, "I think I was the one who brought up fertility….. I don't remember hearing it from them first."

Theme 3: Preferences for future educational content

When asked about preferences for educational materials about fertility and genetic risk, patients and HCPs suggested varying content, tools, and mediums of communication.

Preferred content: information about IVF, sperm banking, and genetic risk Patients expressed interest in receiving more information about FP, including oocyte and sperm cryopreservation. They suggested this would have been helpful in order to gain a better understanding of how these options work, and how it might impact the initiation of care at diagnosis and into the future. For example, one male diagnosed with lymphoma (age 41) indicated that specific information about IVF would have been helpful at the onset of diagnosis to fully understand concepts like fertility and cancer treatment (Table 4, row 1). HCPs were more likely to mention that information should be provided to patients about the genetic risk for future children. One HCP in the sarcoma program suggested that a frequently asked questions sheet for patients should be developed that should include information regarding genetic risk for future children, in conjunction with diagrams and risk percentages based on family history. They indicated this would be important in helping patients understand personal risk and would help them ask their oncologist important follow-up questions (Table 4, row 2).

Preferred medium of information Several patients mentioned the importance of tailored information and in-person discussions with HCPs when learning about inherited cancer risk. One male diagnosed with melanoma (age 27) explained that face-to-face interaction is "just more personal" and can be more beneficial, particularly when utilized in conjunction with educational materials (Table 4, row 3). Patients also expressed a desire for videos which depict patients with similar cancers discussing their feelings and experiences in testimonials. One male diagnosed with lymphoma (age 39) explained that incorporating video testimonials featuring patients discussing their fears, experiences, and successful outcomes could help other patients cope with feelings of loneliness and isolation (Table 4, row 4).

HCP suggestions primarily focused on communication during the visit and potential methods to assist patients in communicating more effectively with HCPs. One provider in survivorship care recommended that viewing a patient–provider interaction may be helpful for patients to better understand what questions to ask and how to facilitate discussions with HCPs (Table 4, row 5). Both patients and providers noted tailored informational brochures with an overview of relevant information would be beneficial at the initial diagnosis (Table 4, row 6).

Resources for family members Patients and HCPs indicated educational information for family members and caregivers would also be beneficial. Patients expressed a desire to control who received the information and when, particularly as it related to their children. Some patients indicated family resources would be helpful because their spouse or parent was interested in learning about their cancer and would search for information online or would ask providers questions during the clinic visit. One male with melanoma (age 34) indicated his spouse "was the person that often asked those questions or held on to and referred to that material" and she "was the one looking into that for me, more than I was myself." (Table 4, row 8).

HCPs also felt educational resources should be developed for family members. Specifically, they suggested materials to increase awareness in relation to the genetic risk of cancer among family members. HCPs felt some family members may mistakenly believe that because they are currently unaffected by cancer, they are not at higher risk. One breast surgical oncologist suggested this could help unaffected family members understand their own risk and cope with potential guilt of not being affected by cancer (Table 4, row 9).

Discussion

The current study explored patient and HCP discussions and concerns about fertility and genetic risk. Cancer treatment can have consequential effects on a patient's fertility. This is often a concern among the AYA cancer population, in addition to concerns about genetic risks for future children, and these are either explored when patients are too far along in their cancer treatment to preserve fertility [20] or addressed by HCPs and misunderstood by patients [4].

AYA cancer patients in this study often reported that important concepts such as FP and GT/GC were not discussed or they did not recall a discussion. Among patients that reported having these discussions with their HCP, most indicated that they had initiated the conversation. This information-seeking behavior is common among AYA cancer patients; they often desire to be fully informed about cancer treatment effects on fertility and FP options [21]. However, HCPs often underestimate the importance AYA patients place on discussing FP options [21]. HCPs may believe broaching the subject of potential infertility due to cancer treatment is often "like adding insult to injury" [22]. This may explain why patients in our study indicated they initiated the fertility conversations. Additionally, while PGT is a method of assessing genetic risk

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Table 4 Theme 3: AYA cancer patient and AYA oncologists' preferences for future educational content

Theme	Definition	Exemplar quotes
Subtheme 3.1. Preferred content: information about IVF, sperm banking, and genetic risk	When patients express interest for educational information specific to in vitro fertilization (IVF), sperm banking, and the genetic risk of their cancer	Row 1: "It certainly would have been a little bit more helpful to fully understand things regarding IVF at that time. And I know that does not have anything to do with genetic inheritance, but nonetheless I think that's the appropriate time is at the very beginning to fully understand what the future might hold." — *41-year-old male with lymphoma* Row 2: "I do not know if it would be allowable to have them enter in either their cancer diagnosis or their family history in very general terms just kind of discuss their risk themselves or having it list certain risk factors and what those risk factors would mean for a certain patient with one or more risk factors in terms of the risks for inheritable cancer diagnosis. I think just overall just general information geared towards the patients themselves so that way to ask questions you know like if they say – I mean I think one of the big questions, the general questions, we'll get usually is like, "So, I got cancer. Will my kids have cancer?" kind of thing. So, having those spelled out in a question-answer kind of format like unlikely for most patients where there are certain ones and then kind of delving in deeper so that way patients can get readily good answers that explains it pretty well. …I know we can get too, too specific and that might make it a little bit too technical for them or even like sometimes even like diagrams and things like that so that way they can – or charts or things – that they can look at specific ones like if they know like they have had a number of breasts or brain or cancers in the family and they themselves have a certain type. Then it might say the percentages or the increased risk but say could be increased risk. Consider referring to genetic cancer counseling kind of thing. So, something it gives them a little bit of information, but that way for those patients that might have a higher risk, they can get more information kind of in person." — *Provider: sarcoma program*
Subtheme 3.2. Preferred medium of information	When patients and providers express preferences for specific modes of information transmission such as educational materials or face to face interactions. Also when patients and providers express a preference for tailored educational packets that should be developed and tailored specifically to their type of cancer and the treatment they are going through.	Row 3: "It's always good to talk to someone face-to-face, maybe to have someone specifically for that purpose to talk to the – because it's just more personal… And obviously, the pamphlets and everything, they are good as well, but just to get a face-to-face confirmation. I know that doctors only have so much time in the day, and they have a lot of patients, so to have someone for that would be – I think would be beneficial." — *27-year-old male with melanoma* Row 4: "The doctor speaking to the patient, I think there should also be a testimonial from the patient who's went through it – their experience, their outcome, their fears before doing it. How they felt after the process, whatever that was, it should be shared across the board so that you are able to give anyone who's looking into it insight from both sides. I mean, it does not have to be long. I think having an online forum where you can review the areas, videos and testimonials just to get insight about other people because unfortunately, as much as we know cancer is a major issue, when you are going through it, you still feel alone." — *39-year-old male with lymphoma*

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Table 4 (continued)

Theme	Definition	Exemplar quotes
		Row 5: "Yeah, I mean a glossary would be – that would be good because that way if they had questions about specific words that they are seeing or even like a patient – not testimonials but – something where almost like they could like sit in on a patient asking these questions, getting real-time feedback, or a patient that does have an inheritable risk and having them ask those questions. So, almost like a video or kind of a little snippet of something so that way they can kind of see the kind of questions that they would want to ask their provider or something to kind of further the dialogue." — *Provider: survivorship care*
		Row 6: "If there was just a certain package that you got with certain diagnoses, you know? Depending on what you have and what treatment you are going through? Maybe that's where that overview brochure or information can come in and then, if they wanted to drill down deeper into it, then they can get, you know, a little more detailed. You know – like, you have had thyroid cancer; these are some things to consider. Or, you know – you have had melanoma; these are some things to consider." — *38-year-old male with melanoma*
		Row 7: "I think, maybe, some statistical information that I think when you make it personal; it's much more powerful to patients. So, probably data on what are the common mutations that we look for and certain they need that the patients can look it up or have a link through that legitimate probably interactive, if it can be interactive. Like you said, if there are some questions that they can fill out, I think that probably would be pretty good and – let us see – resources. So, like links for resources, if they are a sarcoma patient then who are the people that can provide additional services." — *Provider: hematology fellow*
Subtheme 3.3. Resources for family members	When patients and providers suggest that educational materials should be created specifically for caregivers/spouses of individuals with cancer	Row 8: "I was lucky enough to be married and have a support person there for me when I was going through. And she was the person that often asked those questions or held on to that and referred to that material. And in my case, she was the one looking into that stuff for me, more than I was myself. So, having that available to her would certainly have been helpful, as well." — *34-year-old male with melanoma*
		Row 9: "Maybe there should be something for the unaffected family member because I am sure there's a lot of emotional thing that goes there. There's a 'whew' to them, right? But at the same time, they are thinking, 'Oh, how did I get so lucky' or guilty that they were unaffected because I see that a lot where there's multiple siblings and only two of them have it and two do not. Yeah, that would be a great idea. I do not think there's anything about that anywhere. And how to follow them." — *Provider: breast surgical oncologist*

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for future children [16] and could serve as the bridge to talk about the intersection between FP and genetic risk, HCPs did not appear to integrate these concepts when they described their conversations with patients and instead discussed them separately. Similarly, patients did not connect concepts of fertility and genetic risk when they described their understanding of these concepts and conversations with providers. This suggests education focused on PGT is needed for patients, and HCPs should consider incorporating PGT into their discussions with patients [23, 24].

HCPs described how they present and discuss these concepts in detail with their patients; however, they acknowledged the volume of information covered during the initial visit may diminish patients' ability to retain the information due to the overwhelming initial distress of a cancer diagnosis. This sentiment is consistent with prior studies suggesting patients and providers feel the inclusion of fertility information at diagnosis can be too overwhelming [17, 25]. Some HCPs in our study acknowledged that while they discuss FP with patients, the discussion often occurs after treatment has started. Considering this, education and decision-making about FP may be most effective if a multidisciplinary approach is implemented into clinical practice. Key elements would include early discussion with HCPs, tailored information for patients, and facilitation of referrals to fertility and genetic specialists. A similar approach could also translate to community-based practices without in-house multidisciplinary teams that may not have the resources or capabilities to address FP or GT/GC at a single institution. Our results provide important implications for AYA patient information needs regarding FP and GT/GC that may be addressed through an education- and referral-based paradigm often used in community clinical practice. For example, providers in community-based settings could introduce and discuss these topics with patients and make these referrals to external providers to those outside of the practice/institution such as genetic specialists or psychologists; however, interinstitutional provider communication and patient compliance with referrals may be barriers that future research could explore further. Additionally, in order to help providers find referral resources in their practice area, there are resources available such as the National Society of Genetic Counselors "Find a Genetic Counselor" [26] and the Alliance for Fertility Preservation's Fertility Scout that they could utilize [27]. An oncology nurse training program that emphasized communication strategies to discuss these topics with patients and guide them in the decision-making process has significantly increased knowledge and confidence in communication skills [28, 29]. Thus, to maximize the effectiveness of patient educational materials and FP uptake among AYA patients, HCPs may benefit from participation in evidence-based training programs to facilitate communication with patients.

Patients and HCPs indicated some patients refrained from discussing FP with HCPs, stating that whether or not they would be able to have children and whether those children would be at an increased risk of developing cancer was out of their control. Research shows people who exhibit fatalistic beliefs are unlikely to engage in certain preventive health behaviors (e.g., mammograms) [30]. This may explain why some patients in our study with these beliefs did not intend to pursue GT or FP. Alternatively, previous research focused on African American women and intentions to receive GT for breast cancer found higher fatalism actually resulted in higher likelihood of GT intentions [31]. This suggests the relationship between fatalism and GT uptake among AYA patients may be multifaceted and other factors may also affect the decision to undergo GT.

HCPs in our study also felt patients' emotional states may impede their ability to ask relevant questions during a visit and understand FP and genetic concepts, particularly at a time when they are experiencing distress over a cancer diagnosis. Within the cancer context, previous research showed both patients and providers indicated GT information presented concurrently with treatment options would be information and "emotion overload" too early in their diagnosis for patients to comprehend [32]. While HCPs in our study suggest patients may be too overwhelmed to discuss and understand FP, previous research suggests provider discussions with AYA patients may act as a source of hope and comfort to patients and their families [22]. Therefore, having discussions about FP and GT/GC may mitigate negative patient emotions and could be implemented at an earlier stage in a more simplified way to ensure patient understanding.

Patients and HCPs felt educational information for AYA patients should be tailored to a patient's family history and diagnosis. Given their involvement in decision-making, participants also felt that this information should be made available for family members. Despite previous research suggesting cancer patients wish to have caregivers and family members involved in cancer treatment decisions [33], we were unable to identify existing research focused on the effectiveness of FP educational materials for family members/caregivers. Patients and HCPs in our study felt that information should be delivered in the form of educational videos; however, content preferences differed. Patients preferred patient testimonials to assist them in coping with the psychosocial aspects of their cancer, while HCPs thought patient–provider interactions would be helpful and could help improve patient communication skills. Resources are available for cancer patients that focus on FP and fertility issues due to treatment, and to help providers discuss these topics with patients [34]. However, to our knowledge, there are no existing resources for AYA cancer patients that incorporate such information in conjunction with information about genetic risk for future offspring; thus, our findings specific to educational content address a current gap and serve to directly enhance patient–

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provider communication and improve patients' genetic risk knowledge and decision-making about FP.

While patient understanding of FP has been examined in previous studies, this study is among the first to explore the intersection of several critical issues among AYA cancer patients including FP, GT/GC, perceptions of genetic risk among future offspring, how HCPs address FP with their patients, and patient and HCP perceptions of key information to be included in an educational tool. These findings will inform the development of a web-based learning tool.

While this study has many strengths, limitations should be considered. First, although all recruitment took place at a single institution, patients and HCPs were not recruited as dyads. Therefore, when patients discuss their conversations with HCPs, it is unknown whether they are directly referring to one of the HCPs who participated in our study, which could explain differences in patient and HCP perceptions of their conversations. AYA patients in our study were also diagnosed with cancer between 2012 and 2014; therefore, it is possible patients may not clearly remember all elements of provider discussions, introducing potential recall bias. Additionally, our participants were from a single institution, thereby limiting generalizability. Further, our results are based on AYA cancer care that occurs at a major comprehensive cancer center which includes multiple provider types (i.e., genetic specialists, psychologists) in one setting; therefore, it is difficult to determine how the multidisciplinary approach we propose would work in a community-based practice with fewer resources and the lack of a multidisciplinary team in one setting. Future research that focuses on AYA cancer care in community-based settings and understanding interinstitutional provider communication and patient compliance with referrals is needed. Finally, our sample consisted of only AYA patients over the age of 18 and it is possible patients under 18 may have different experiences and different preferences for information.

Conclusions

FP is often a concern among AYA cancer patients, and these concerns coincide with fears about genetic risk to future offspring. Patients in our study reported interest in and need for FP and GT/GC information. HCPs reported discussion of FP and genetics, yet acknowledged that emotional distress and amount and complexity of information covered during the initial appointment make comprehension difficult. Our findings also showed little connection or integration of genetic risk and fertility when discussing future family building options. Suggestions for educational content/tools revolved around videos depicting patient–provider interactions or patients describing their experiences with cancer, the treatment process, and what to expect in terms of GT/GC and/or FP.

Education for patients in clinical practice should be presented in different formats (e.g., tailored information packets, videos) by various HCPs (e.g., genetic counselors, oncologists). Future interventions developed based on these results can be a valuable addition to clinical care and should focus on facilitating conversations between patients and HCPs, reducing the psychosocial distress of processing a cancer diagnosis, cancer treatment, and family building.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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