

Fertility Issues in Adolescent and Young Adult Cancer Survivors

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Purpose: Many adolescent and young adult (AYA) cancer survivors place great importance on fertility. This study explored AYAs' discussions of fertility in the context of discussing their survivorship experiences.

Methods: Secondary analyses of a qualitative study of young adult survivors of adolescent cancers ("AYA survivors") was performed using semistructured individual interviews and focus groups. Analyses were conducted using grounded theory using thematic content analysis with an inductive data-driven approach.

Results: Participants ($n=43$) were 16–24 years old, diagnosed with cancer between ages 14 and 18 years, and were at least 6 months post-treatment. Before treatment, 5 males banked sperm and no females preserved fertility. More males (50%) than females (39%) reported uncertainty about their fertility. Three major categories emerged from the data: fertility concerns, emotions raised when discussing fertility, and strategies used to manage fertility concerns. Fertility concerns focused on dating/partner reactions, health risks, and what potential infertility would mean for their life narrative. Emotions included distress, feeling overwhelmed and hopeful/wishful thinking. Females were more likely to feel distressed and overwhelmed than males. Strategies to manage concerns included acceptance/"making do," desire to postpone concerns, and reliance on assisted reproductive technology.

Conclusions: Most AYAs in our study reported a number of reproductive concerns and fertility-related distress after treatment, which may affect other areas of psychosocial functioning. Females may be more at-risk for distress than males, particularly in situations of uncertainty and limited knowledge. Future work should explore how to best incorporate fertility-related informational and support services more fully into survivorship care. Implications for survivorship care are discussed.

Keywords: fertility, infertility, survivorship, fertility preservation, sperm banking

MANY ADOLESCENT AND YOUNG ADULT (AYA) cancer survivors express a desire to have children in the future and have concerns about their fertility, regardless of their diagnosis, prognosis, and treatment.^{1,2,3} Yet AYAs lack awareness of gonadotoxic treatment effects and have uncertainty about their reproductive potential.⁴ Additionally, developmental issues and the survivorship experience of AYAs require unique considerations.^{5,6}

When cancer occurs during AYA years, there may be uncertainty as to how much AYAs should be involved in their disease management. Despite an emerging sense of autonomy, AYAs may still be developing cognitive and emotional abilities to manage stress and cope effectively.⁶ Developmentally, AYAs are also continuing to develop executive

functioning skills involved in decision-making.^{7,8} Parental protective buffering, combined with clinicians' discomfort addressing fertility,^{9–12} may result in AYAs not receiving adequate information and support around fertility issues.

After treatment, AYA survivors report limited knowledge about their reproductive health.^{13–15} Post-treatment infertility often comes as a surprise,¹⁶ and AYAs report false beliefs regarding their reproductive potential.^{17,18} Limited knowledge of fertility preservation (FP) options and assisted reproductive technologies (ART)^{19,20} may further contribute to uncertainty or unrealistic expectations about future childbearing.

Infertility, in addition to the cancer experience, may challenge important developmental tasks involved in establishing identity and future life goals.^{8,21} Reproductive concerns in

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Preliminary findings of the data were previously presented at the 36th Annual Meeting and Scientific Sessions of the Society of Behavioral Medicine, San Antonio, Texas, April 20, 2015, and published as an abstract in the Annual Meeting Supplement issue of the *Annals of Behavioral Medicine*, April 2015.

AYA survivors have been associated with depressive and anxiety symptoms, grief, lowered self-esteem and an altered sense of identity.^{22–27} The perception of impaired fertility can negatively affect self-concept, dating and social relationships, and life planning.^{26,28–30} Fertility-related distress may increase as AYAs move beyond their cancer experience and consider building a family.^{3,23,24}

Research focused on fertility in AYA survivors has increased in recent years. In the present analyses, we explored discussions of fertility amongst AYA cancer survivors and examined potential differences by age, gender, and time since treatment. Discussions were guided by participants’ thoughts and concerns and allowed for an examination of the frequency to which AYAs raised fertility-related issues. It was hypothesized that older AYAs would have greater awareness of infertility risks and potential long-term implications and more reproductive concerns, compared to younger participants, and that females would be more concerned than males. It was also hypothesized that fertility concerns would be greater among survivors who had a longer time since cancer treatment ended.

Methods

Participants were between 15 and 25 years old at consent, between 14 and 21 years old at diagnosis, and completed cancer treatment(s) at least 6 months prior at a large metropolitan cancer center. Potentially eligible participants were randomly selected and stratified by gender and current age. Recruitment letters were sent to 90 survivors and/or parents with follow-up phone calls. From recruitment, 28% were unavailable for study participation, 28% were lost to follow-up, 9 refused and 5 were ineligible. Interviews and focus groups were conducted in person. The study was approved by the institutional review board.

Data collection

Participants completed either an individual interview ($n=26$; approximately 90 minutes) or a focus group (four groups; $n=17$). Focus groups were conducted separately for males and females and for older versus younger participants. Interview and focus group questions and subsidiary probes

were developed to cover a range of topics related to AYA survivorship (e.g., health and peer relations, disclosure, meaning of survivorship). Fertility-related data collection was limited to a single question with follow-up probes (Table 1).

Data analysis

Interviews and focus groups were audio recorded, transcribed, and imported into ATLAS.ti for data analysis.^{31,32} Analyses were guided by grounded theory using thematic content analysis with an inductive, data-driven approach.³³ An iterative process of individual and consensus coding was done by four researchers (clinical psychologist, qualitative methods specialist, and two trained research assistants) to create the codebook (inter-rater reliability >80%); codes were applied to the narrative content by the team where appropriate.

The current analyses used fertility-related codes only. Relevant quotations were reviewed by two trained coders independently and collaboratively to identify patterns, develop a thematic framework, and perform consensus coding with respect to fertility topics based on frequency and salience. Consensus from multiple independent coders enhances the quality and credibility of findings³⁴ and is an established and effective method of attaining confidence in outcomes.^{35,36} Thematic findings were compared across gender and age groups and as a function of time since treatment.³⁷ No thematic differences based on method of data collection (individual interviews vs. focus group discussions) were observed and therefore results were combined.

Results

Sociodemographic and clinical data are presented in Table 2. Participants ($n=43$; 58% female) were 16–24 years old, on average 15 years old at diagnosis, and 3.3 years (SD=2.1) post-treatment. Most ($n=33$) discussed fertility and fertility-related codes were generated and analyzed. Prior to treatment, 5 males (12%) banked their sperm and no females underwent FP, per self-report. Nineteen participants (10 males; 9 females) were uncertain as to whether treatment had affected their fertility. Males were more likely to report uncertainty than females (50% vs. 39%). Ten participants (3 males; 7 females) had been told by a clinician that treatment

TABLE 1. FERTILITY-RELATED QUESTIONS AND SUBSIDIARY PROBES INCLUDED IN SEMI-STRUCTURED INDIVIDUAL INTERVIEWS AND FOCUS GROUPS (N=43)

| <i>Data collection</i> | <i>Questions and subsidiary probes</i> |
|-------------------------------------|--|
| Individual interviews ($n=26$) | 1. Do you know if the cancer has affected your fertility or ability to have children? a. How do you feel about this? b. Is it something you have thought about at all? |
| Focus groups (four groups; $n=17$) | 1. Have you thought about your desire or ability to start a family and have children? a. What attitudes or thoughts come to mind? What do you think about? i. Is this something that you are concerned about? Why or why not? ii. When do you think about this? What triggers these thoughts? iii. Have you talked with a doctor or anyone about your fertility? b. Do these concerns affect your current relationships, the relationships you would consider having in the future, or your future plans? |

Ten participants did not discuss fertility during their interviews, leaving a sample size of $n=33$ with meaningful fertility-related data (individual interviews, $n=19$; focus groups, $n=14$). Participants who did not discuss fertility were more likely to report their fertility had not been affected by treatments. No other systematic differences were observed between participants who did vs. did not discuss fertility (i.e., based on gender, age at diagnosis or consent, or time since treatment).

TABLE 2. SOCIODEMOGRAPHIC AND CLINICAL INFORMATION (N=43)

| Variable | n | % | Mean | SD | Range |
|------------------------------------|----|------|------|-----|---------|
| Age at consent (years) | | | 19.6 | 2.8 | 19–20 |
| Age at diagnosis (years) | | | 15.4 | 1.5 | 14–19 |
| 15–19 years old at diagnosis | 25 | 58.1 | | | |
| 20–24 years old at diagnosis | 18 | 41.9 | | | |
| Gender | | | | | |
| Female | 25 | 58.1 | | | |
| Male | 18 | 41.9 | | | |
| Ethnicity | | | | | |
| White | 28 | 65.1 | | | |
| Hispanic | 7 | 16.3 | | | |
| African American | 4 | 9.3 | | | |
| Asian/Pacific Islander | 3 | 7.0 | | | |
| More than one race | 1 | 2.3 | | | |
| Single (unmarried) | 43 | 100 | | | |
| Cancer diagnosis | | | | | |
| Lymphoma | 17 | 39.5 | | | |
| Sarcoma | 10 | 23.3 | | | |
| Leukemia | 4 | 9.3 | | | |
| Germ cell | 3 | 7.0 | | | |
| Neuroblastoma | 2 | 4.7 | | | |
| Thyroid | 2 | 4.7 | | | |
| Central nervous system | 1 | 2.3 | | | |
| Craniopharyngioma | 1 | 2.3 | | | |
| Melanoma | 1 | 2.3 | | | |
| Ovarian | 1 | 2.3 | | | |
| Pancreatic | 1 | 2.3 | | | |
| Type of treatment | | | | | |
| Multimodal treatment | 34 | 79.1 | | | |
| Chemotherapy only | 2 | 4.6 | | | |
| Surgery only | 7 | 16.3 | | | |
| Time since treatment ended (years) | | | 3.3 | 2.1 | 0.9–9.3 |
| <2 | 16 | 37 | | | |
| 2–5 | 18 | 42 | | | |
| >5 | 9 | 21 | | | |

had not affected their fertility; 2 females had confirmed infertility; one female was told she was at risk for premature ovarian failure; and one female was pregnant.

Analyses identified three fertility themes: fertility concerns, emotions raised when discussing fertility, and strategies used to manage fertility concerns (Tables 3–5). Major themes and subthemes were not mutually exclusive categories. Thematic differences between males and females emerged with females discussing fertility with greater frequency and with greater detail and depth of emotions. Time since treatment was associated with a greater likelihood of reporting minimal or no fertility concerns; however, among females, it was also associated with increased worry about dating and partner reactions. There were no significant thematic differences between younger and older participants.

Fertility concerns

Within fertility concerns, three subthemes were identified: dating and partner reactions, health risks, and adjusting life narratives to include potential infertility (Table 3).

Dating and partner reactions. Concerns about dating and disclosing potential fertility problems to a future partner were discussed by many participants, with females raising this concern more often. Most participants who discussed this were more than 2 years post-treatment. Interpersonal concerns and the social context of childbearing were often discussed by female survivors. Females reported feeling pressure related to dating and others' expectations. For example, one female referenced an ex-boyfriend's family wanting proof of her childbearing capacity. Males discussed the importance their female partners' (non-cancer survivors) placed on childbearing and parenthood.

Females had awareness of a shortened reproductive time-frame due to the risks of premature ovarian senescence. This was reflected in their plans to "put pressure" on a future partner to start family-building earlier than they may have otherwise (e.g., "I can't wait around").

Health risks. Concerns also included potential health issues for oneself and the health of a future child. Passing on a genetic risk for cancer to an offspring was the most common subtheme that emerged equally for males and females. Survivors reflected on their parents' experiences and imagined themselves in a similar situation. Added to this was an imagined feeling of responsibility for a future child's diagnosis. For several participants, these concerns decreased their desire to have a biological child, despite receiving information from clinicians that such concern was unfounded.

Females reported additional concerns about how their own health would be affected by a pregnancy, including whether their bodies were strong enough and the potential risk of cancer recurrence. Females were conscious of their physical limitations due to side effects of cancer treatments and worried about their health, questioning whether they would be able to carry a pregnancy and deliver a healthy baby.

Life narrative. Participants reflected on the impact their cancer experience has had on their life narrative and expectations for future childbearing. Several spoke of the first time they realized the fertility risks associated with treatments and imagined the impact infertility would have on their future selves ("that was the first time that I realized [cancer] would affect the rest of my life"). Alternatively, some participants were hopeful that fertility would not be a problem despite known impairment or indicated a reliance on ART, thereby maintaining their ideal life narrative with respect to childbearing. Some females adjusted their ideas about dating to accommodate potential fertility-related difficulties. One female decided, due to her uncertain reproductive capacity, that she would be open to dating men with children. Three males mentioned adoption as an alternative to having biologically related children and one female appeared undecided as to whether she would consider adoption.

Participants also discussed the ways in which cancer-related changes impacted their self-concept and potentially their ability to fulfill important roles in life, including being a parent. For example, a female diagnosed with osteosarcoma had undergone surgery to remove a leg and wondered whether her future children would accept her as a mother with one leg. Although not related to fertility specifically, her body image concerns overlapped with ideas of motherhood and relationships with future children.

TABLE 3. THEME 1: FERTILITY CONCERNS (N=33)

| | | Percentage of males | Percentage of females |
|---|--|---------------------|-----------------------|
| Dating and partner relationships | | 8% | 20% |
| Female; 24 years old; osteosarcoma | “I feel a lot more pressure ... I do want to get married and then have kids. I want to have more than one. I want that. ... I do want to have a child, so I mean regardless, if I’m not married, nobody special in my life-if somebody is I would kind of put the pressure on them to, like, ‘I can’t wait around, so it’s either this or it’s nothing.’” | | |
| Female; 24 years old; Hodgkin’s lymphoma | “But kids are a big deal in my community, because like I said people get married young and have kids and everything, so it’s definitely an issue when it comes to dating. Like the guys, like you can say, ‘I’m fine,’ but they might want more proof than that. And I don’t have proof right now, you know? ... One guy I was [going to date] ... his family was like, they wanted me to take some sort of test.” | | |
| Health risks | | 39% | 30% |
| <i>Personal health</i> | | | |
| Female; 21 years old; gestational trophoblastic disease | “Is my body strong enough to make a strong baby ... because I know my body and I know how weak my body is, and I’m worried about what if I don’t survive the labor.” | | |
| Female; 22 years old; melanoma | “Oh my goodness, what if I get pregnant and then my moles just advance?” | | |
| <i>Future child’s health</i> | | | |
| Female; 18 years old; non-Hodgkin lymphoma | “If I do ever have kids, one of my kids being diagnosed with it, that’s something that I fear. Not because, you know, I don’t want to deal with it. It’s just I know how it feels, and being that I experienced it now I would know how my child is feeling. So it’s like, ‘those thoughts went through my head, I don’t want that to go through your head.’” | | |
| Male; 16 years old; Burkitt’s lymphoma | “I don’t even know if I worry about being able to have kids so much as I worry about whether I want to have kids, because if it’s like a genetic cancer, if I want to take that risk. ... I’d have to think long and hard about whether I’d rather adopt and not ... if there’s the slightest chance that I might, you know, have caused one of my kids to have it then I couldn’t—I couldn’t do that to them.” | | |
| Life narrative | | 31% | 20% |
| Female; 16 years old; Sertoli Leydig tumor of the right ovary | “I have one ovary taken out, and like my dream has always—like I used to always play Barbies when I was little, and I would always have families, and that’s been my dream forever. And it was really, really scary for me.” | | |
| Male; 16 years old; Berkitt’s lymphoma | “That was a really bad day ... they were like, ‘Oh, you might not be able to have kids.’” And that was sort of like the straw that just really—I think that was the first time that I realized it [cancer] would affect the rest of my life.” | | |

Quotes are divided by subthemes. Within each subtheme, quotes are grouped by sex, with those from female participants listed first, and ordered by age.

Emotions raised when discussing fertility

Discussing fertility elicited emotional reactions for most participants ranging from expressions of distress to feeling hopeful and positive (Table 4).

Distress. Fertility-related distress included feeling upset, nervous, overwhelmed, and angry. Females reported more distress than males (depth of emotion expressed), particularly if there was uncertainty or the absence of clear information about their current fertility and reproductive options. Participants who were unsure of the gonadotoxic effects of their treatment

imagined how they would feel if they were unable to have children, anticipating they would feel “devastated,” “hurt,” and “lonely.” For some, distress was associated with feeling different from their peers and excluded from the “normal path” to achieving parenthood. Several participants—females more so than males—indicated fertility-related distress despite explicit reassurance from physicians that treatment had not affected their fertility..

Many females discussed emotions raised when faced with daily or unexpected reminders of infertility, including those more than 5 years post-treatment. For example, one female told a story of going to see a movie that unbeknownst to her

TABLE 4. THEME 2: EMOTIONS RAISED WHEN DISCUSSING FERTILITY (N=33)

| | | Percent of males | Percentage of females |
|--|---|---------------------|--------------------------|
| Distress | | 23% | 30% |
| <i>Considering infertility</i> | | | |
| Female; 19 years old; Hodgkin lymphoma | “I don’t want to be lonely for the rest of my life I guess.” | | |
| Female; 22 years old; melanoma | “It’s just something that I think would devastate me – if I couldn’t have kids.” | | |
| Female; 23 years old; Hodgkin lymphoma | “If I can’t have a child, it just, it would hurt. Like, it would make me feel, you know, what’s the point of me being here, if we’re here to reproduce and all this stuff? Like I don’t want to be barren, you know?” | | |
| <i>Worry, despite reassurance</i> | | | |
| Female; 17 years old; Hodgkin lymphoma | “Sometimes I think about ... could it be passed down to my child if I had a child? She [oncologist] says no because it’s not a hereditary thing, but ...” | | |
| Male; 15 years old; Hodgkin lymphoma | “... my doctor always says don’t worry about it, but then like, you know, like thoughts always come into your head about different things, and then it’s like overwhelming sometimes.” | | |
| <i>Concerns about being “normal”</i> | | | |
| Male; 15 years old; Hodgkin lymphoma | “That always scared me ... not being able to have a kid the normal way, as a regular human being would, you know. ... I guess to have a kid like the normal way, and its scary being as, not being able to do, you know, like something everyone else can do. I guess that’s my-that’d be my fear.” | | |
| <i>Daily or unexpected reminders</i> | | | |
| Female; 23 years old; Hodgkin lymphoma | “Stupid things like the movie <i>Up</i> , when the wife in the movie like can’t have a baby, like I’m sitting in the theater crying, bawling.” | | |
| Female; 24 years old; acute myeloid leukemia | “Like today I was really prepared like to talk about it, so it was like fine. But if somebody like approached me like and started poking about infertility I probably would’ve been bawling.” | | |
| Hopeful or wishful thinking | | 8% | 20% |
| Female; 16 years old; abdominal rhabdomyosarcoma | “They told me that they’d probably have to take out like one of them, like one ovary ... the radiation they also said that would destroy chances [to get pregnant] too, but I mean the one ovary is still working, so I mean it just goes to show you that they’re not always right. When they say 99% sure they don’t mean 100% sure.” | | |
| Male; 19 years old; acute myeloid leukemia | “They say it has [treatment has affected fertility]. ... I think it has. But you know ... you know, miracles can happen. I’ve seen ... I’ve seen on like shows like <i>Maury</i> or whatever, ‘the miracle child.’” | | |
| Lack of concern/minimal distress | | 31% | 15% |
| Female; 24 years old; osteosarcoma | “I am thinking about it now, but I’m not making it a major part of my life.” | | |
| Male; 19 years old; mixed germ cell tumor | “Doctors told me it can come back, like in later years so I’m not that worried. [That what can come back?] If my sperm is defective that it can come back in later years.” | | |
| Male; 21 years old; Hodgkin lymphoma | “I haven’t really thought about it. I went and donated sperm beforehand and I just never got around to checking on it.” | | |

Quotes are divided by subthemes. Within each subtheme, quotes are grouped by sex, with those from female participants listed first, and ordered by age.

included a storyline of an infertile woman: “I’m sitting in the theater crying, bawling.” Although males noted that fertility occasionally entered their thoughts unexpectedly, females appeared to be more distressed by these occurrences. For example, one female stated she felt comfortable discussing fertility as a part of the study only because she had “prepared” herself beforehand, but would otherwise struggle with unexpected discussions of fertility.

Hopeful or wishful thinking. When discussing fertility-related concerns, a few participants maintained hope that they would be able to have a biologically related child despite being told that this would be unlikely (females more so than males). For example, one survivor stated, “Miracles can happen.”

Lack of concern/minimal distress. Only 18% of participants reported little or no concern about their fertility, the

TABLE 5. THEME 3: MANAGING FERTILITY CONCERNS (N=33)

| | | Percentage of males | Percentage of females |
|--|--|---------------------|-----------------------|
| Acceptance and “making do” | | 23% | 15% |
| Female; 23 years old; craniopharyngioma | “I’ve been trying to get me like a dog, because you know, like, since you can’t have kids it’s like, okay, what else can I like care about.” | | |
| Male; 20 years old; Hodgkin lymphoma | “I already have like a niece from my sister and, uh, a nephew from my brother, so, you know, I’m like, okay, if I don’t then, you know, they’re like my kids. So-whatever.” | | |
| Desire to postpone concerns | | 23% | 20% |
| Female; 16 years old; abdominal rhabdomyosarcoma | “And then like I really put my head into it, and I’m like, ‘I’m 15 years old,’ and I was really thinking about it and I’m like, ‘Okay, I would want to have kids in like another 12 years. I’ll worry about it then.’ And that’s what I keep telling myself, I’m just gonna worry about it when the time comes ... there’s something they’re gonna be able to do.” | | |
| Male; 16 years old; Berkitt lymphoma | “I think I’ve been avoiding it. I’m not sure if I want to know yet.” | | |
| Reliance on assisted reproductive technology (ART) | | 31% | 20% |
| Female; 16 years old; abdominal rhabdomyosarcoma | “If I really, really wanted to have kids and I couldn’t have kids I’d figure out a way. ... There’s something they’re gonna be able to do [referring to technology].” | | |
| Female; 17 years old; mesenchymal chondrosarcoma of the left tibia | “For me they told me, ‘Oh, your ovaries are gone.’ But they didn’t say anything about my uterus, so it’s just that, um, I could have kids. ... But I just have to steal somebody else’s like ovaries and stuff. ... There’s no way ... there is no way that this cancer is gonna tell me I can’t have kids. There’s no way. Hell no ... I’m gonna have my kids.” | | |
| Male; 21 year old; Ewing sarcoma | “I guess it gets her [fiancé] a little worried, but the fact that, you know, like hopefully worst case scenario, ... there is options of like artificial insemination ... I don’t know the story exactly, but, you know, I have a few other options, you know?” | | |

Quotes are divided by subthemes. Within each subtheme, quotes are grouped by sex, with those from female participants listed first, and ordered by age.

majority of which were at least 2 years post-treatment. This lack of concern was not exclusively limited to those who knew their fertility had not been affected by treatments. Males were more likely than females to indicate minimal fertility-related distress, particularly if they had banked their sperm. Males were also reassured by the prospect of their fertility returning, which contributed to a sense of being able to postpone fertility concerns and maintaining appropriate hope for the future.

Managing fertility concerns

AYAs dealt with fertility-related concerns by using a variety of strategies including acceptance, postponing or avoiding fertility-related distress, and taking comfort in ART options (Table 5).

Acceptance and “making do.” Some participants discussed specific attempts to promote acceptance of a future life without children by focusing on other important roles and relationships. For example, one male discussed his role as an uncle (“they’re like my kids”), and another female reported that she planned to get a dog as a substitute for caring for a child; neither participant mentioned alternative family-building options. Other participants referenced the option of adoption, but this was seen as a back-up plan if efforts to conceive naturally or future use of ART failed.

Desire to postpone concerns. In some instances, participants dealt with fertility concerns and reproductive uncertainty by trying to not think about fertility issues until they were ready to have a child. These discussions seemed to reflect feeling too young to think about reproductive or childbearing decisions and wanting to avoid such concerns. One 16-year-old female noted she was surprised by her level of worry and distress related to her potential fertility problems, as she viewed herself as too young to be concerned by such issues and considered her fears to be premature.

Reliance on assisted reproductive technologies. Multiple participants felt reassurance by the availability of ART. Statements reflected the importance many AYAs place on childbearing, but also a lack of knowledge about what ART may involve and the feasibility, accessibility, and risks associated with such procedures. Participants were confident they would be able to use such technology to successfully fulfill their reproductive goals. None of the participants who referenced ART indicated an awareness of its actual success rates, lack of data in cancer survivors, or the practical aspects of pursuing such treatments.

Other themes identified

Risky sexual behavior. A critical aspect of AYA survivors’ fertility-related experience was noted by reports of

engaging in risky sexual behaviors to verify infertility. In one instance, a female survivor was told by her doctor that she was infertile, yet despite this, she described “testing” her fertility by having unprotected sex and attempting to become pregnant “just to see.”

Experiences with providers. Interactions with clinicians when discussing fertility included feeling ignored and dismissed (e.g., “she kind of brushed me off”). Other participants stated their doctors had not addressed fertility during or after treatment, which contributed to uncertainty about their reproductive potential. In such instances, participants were uncertain as to whether such discussions had been irrelevant in their disease management or reflected a treatment gap.

Discussion

This study explored the fertility-related experiences of AYA survivors of cancers diagnosed during adolescence. Findings represent participant-driven discussions of fertility topics as part of a larger study. AYAs reported a range of emotions and strategies used to manage fertility concerns, with distinct gender differences. This study provides a unique perspective of AYAs’ most pressing thoughts and concerns related to their fertility. Observations of the ways in which AYAs manage fertility issues in survivorship, in particular, add to a small body of literature exploring fertility-related coping strategies³⁸ and have important implications for survivorship care.

Most AYAs indicated some concern about their fertility and reproductive future. With minimal prompting, females discussed fertility more frequently and showed more distress than males, particularly when there was uncertainty. Consistent with the literature,³⁹ males who banked sperm felt reassured and worried less about fertility than males who did not bank sperm, though both groups indicated less distress than females. No female participants preserved their fertility and it is unknown whether this would have ameliorated their concerns, though psychosocial benefits of FP have been reported.⁴⁰ While both males and females reported concerns about passing on a genetic risk to a child and wondered how infertility would impact their future lives, females had additional worries about pregnancy-related health risks. They were also more acutely aware of their reproductive timeline and worried about dating more than their male peers.

A subgroup of participants reported minimal or no fertility concerns, even those who knew their fertility was impaired. We were unable to determine whether these participants had no concerns, had not thought about fertility risks, or whether they did not want to discuss their concerns. On the other hand, AYAs, particularly males, may not fully realize or appreciate the implications of fertility damage at younger ages,²¹ but experience distress at older ages as they begin to pursue long-term romantic relationships, consider parenthood, and face their reproductive options.^{24,41,42}

Alternatively, AYAs may have been managing fertility concerns by minimizing negative emotions in an effort to prioritize normality and reduce anxiety or grief.^{24,29,43,44} Avoidance, denial, and “repressive adaptation” have all been used to explain AYA cancer survivors’ low distress

and positive adjustment.^{45–47} Participants indicated a desire to avoid thoughts and reminders of fertility problems, reported feeling too young to worry about their fertility, and planned to address such issues in the future. For some, this may be protective, at least in the short run. In males, a normative sperm count may return even if treatment causes a temporary reduction or cessation in sperm production.¹⁶ Disregarding fertility concerns during this waiting period may be useful and avoid unnecessary distress. In contrast, many females will maintain reproductive capacity post-treatment but be at risk for premature ovarian failure. Postponing may prevent them from understanding the implications of their shortened reproductive window. Likewise, AYAs with confirmed infertility may be unable to process this loss. Future work should explore the nature of AYAs’ strategies to manage fertility concerns and how to address time-sensitive, potentially distressing fertility topics in this population.

As an initial step, screening for unmet needs around reproductive health is likely to be beneficial. Periodic assessment of reproductive concerns will help identify issues that emerge as AYAs age and consider parenthood. For those who want to consider FP, systematic inquiry during routine healthcare visits will facilitate timely referrals. Support services may also facilitate adjustment to confirmed infertility and inspire hope that parenthood may still be achieved through ART using surrogacy (with donor gametes or a gestational carrier), adoption, or step-parenting.

For many survivors, ART and future advances in reproductive technologies will facilitate successful childbearing. However, the efficacy of ART is not guaranteed⁴⁸ and there are considerable barriers to its use (e.g., high cost; low insurance coverage). Many AYAs in our study assumed they would be able to rely on technology, and few discussed adoption as an alternative. Survivorship care should assess AYAs’ expectations for achieving parenthood and provide developmentally appropriate information about family-building options.

Addressing fertility in post-treatment survivorship care

Fertility information is one of the most cited unmet needs among AYA survivors^{49–51} and lack of information is linked to reduced mental health and quality of life.⁵² These findings highlight the importance of this topic, particularly among females, and suggest the need for increased and ongoing discussion about fertility throughout the cancer continuum. Males and females, across age groups, want providers to address fertility and provide the opportunity to discuss their concerns.^{23,53} Counseling may need to include a balanced approach of allowing for hope and optimism, while fostering realistic expectations. Some AYAs may still worry about their reproductive health even without receiving gonadotoxic treatment, despite clinicians’ reassurance,^{14,24,54} suggesting that fertility should be addressed regardless of medical factors and include repeated assessment of patients’ understanding and concerns.

The importance of fertility-related education and counseling was also reflected in reports of unsafe sexual behaviors, highlighting the broader implications of reproductive health issues (e.g., contraceptive use, unintended pregnancy, and sexually transmitted infections).⁵⁵ Cancer occurring

during adolescence, a period of increased independence and experimentation, may cause survivors to feel simultaneously more mature and socially/ developmentally delayed.⁶ There is a critical need to incorporate sexual and reproductive health counseling in AYA survivorship care.⁵⁶

Lastly, fertility topics need to be addressed with sensitivity and respect. Accounts of disappointing clinician interactions are consistent with prior studies^{53,57} and may indicate a need for improved training around these issues. While clinicians are often aware of infertility risks,^{12,58} many self-report that they lack the necessary skills to discuss the topic with patients and clinician discomfort relates to a decreased likelihood of fertility discussions.^{10,59,60} A nationwide study of oncologists found that the majority expressed interest in attending future seminars to learn more about FP.⁶¹

There are some limitations of this study to consider, including the relatively restricted age range of participants, which limited potential age-related differences from emerging. Developmental differences between late adolescence and emerging adulthood regarding the themes presented here may warrant further investigation. The sample was also somewhat homogeneous, including AYAs who were unmarried and mostly Caucasian. Future work should explore whether findings generalize to a broader sample of AYA survivors.

Conclusions

Education and counseling need to include individual fertility risks, options of FP and alternative family-building and safe sexual practices. Published guidelines highlight the need to address the unique aspects of AYA development in the management of cancer care.^{6,62} Increased attention to fertility may help to alleviate AYAs' distress, facilitate engagement in decision-making about their reproductive future, and improve long-term well-being in survivorship. Clinicians may also need better training on how to have fertility-related discussions and increase referrals to support resources, as appropriate.

Acknowledgments

We would like to acknowledge Rika Tanaka and Sarah Shenkman for their assistance with data collection and coding.

Support for this research was provided by grants from the National Institutes of Health (NIH) National Cancer Institute and the American Cancer Society (ACS MRS-07-165-01-CPPB: Jennifer Ford, PI; and NIH T32 CA009461: Jamie Ostroff, PI). This study is in full compliance with institutional review board guidelines for protection of human subjects.

Author Disclosure Statement

No competing financial interests exist.

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