





RESEARCH ARTICLE

Perceptions of participating in family-centered fertility research among adolescent and young adult males newly diagnosed with cancer: A qualitative study

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Abstract

Background: Over half of male childhood cancer survivors experience infertility after treatment, which is known to cause distress and impact future quality of life. Sperm banking rates remain low, and little is known about how adolescent and young adult (AYA) males and their families make fertility preservation (FP) decisions. This study examined AYA and parent perceptions of participating in a research study focused on testing a new FP decision tool at the time of cancer diagnosis.

Methods: Forty-four participants (19 mothers, 11 fathers, 14 male AYAs 12–25 years old) from 20 families completed brief assessments at diagnosis and approximately one month later, including a qualitative interview exploring the impact of study participation. Verbatim transcripts were coded through thematic content analysis using the constant comparison method.

Results: Two major themes emerged: (1) a positive effect of participating in the study and (2) a neutral effect (no positive/negative effect of participation). Subthemes that emerged for participants who noted a positive effect included (a) participation prompted deeper thinking, (b) participation influenced family conversations, and (c) participation resulted in altruism/helping others. No participant reported a negative effect.

Conclusions: This study demonstrates that participation in family-centered research focused on FP among AYA males, before treatment begins, is perceived as beneficial or neutral at the time of a new cancer diagnosis. These findings provide support for future family-centered FP interventions for this population.

KEYWORDS

adolescents and young adult males, cancer, fertility

Childhood cancer survival rates exceed 80%,¹ but more than half of males experience infertility as a late effect of treatment.^{2–4} Survivors often want biological children, and infertility may cause psychosocial distress and have a negative effect on intimate relationships and quality of life.^{5–8} Thus, it is paramount to proactively address infertility risk and offer fertility preservation (FP) options before treatment.^{9,10} Sperm banking is a safe and effective FP method available to pubertal males.¹¹ Although the increasing number of fertility programs

has expanded FP access,^{12–14} sperm banking rates remain under 40% at many pediatric cancer centers.^{6,15} Older age, sexual experience, and provider recommendation increase the likelihood of sperm banking.^{16,17} However, many adolescents and young adults (AYAs) advised to bank by their healthcare team still ultimately decline FP.¹⁶

Fertility and sexual/reproductive health are sensitive topics, often difficult to discuss within families.^{18,19} A recent study conducted immediately after the initiation of cancer treatment highlighted the importance of parent involvement in sperm banking decisions.²⁰ However, AYAs and their parents may have discordant reproductive

Abbreviations: AYA, adolescent and young adult; FP, fertility preservation.

goals/concerns at the time of a new cancer diagnosis and in survivorship.²¹⁻²³ Some studies suggest adolescents have concerns about future fertility while their parents are more focused on treatment/survival.^{21,22} In the context of the physical and emotional trauma of a new cancer diagnosis, some parents defer FP decisions to the adolescent (despite developmental challenges involved in making future-oriented decisions), whereas others may hesitate to even involve their sons in FP discussions.^{24,25} In survivorship, many parents report difficulty initiating fertility-related conversations with their children (up to 20 years of age)²⁶ and underestimate their sons' desire to have a biological child.²³ These findings have resulted in calls for more prospective research and the development of novel, family-centered psychoeducational interventions for this population.^{17,20,22}

Conducting research on FP prior to cancer treatment is uniquely challenging given logistical issues and physical/psychosocial distress among AYAs and parents coping with a new cancer diagnosis. At the time of diagnosis, most families are focused on curative measures and may not think about steps to ensure future quality survivorship. Medical providers also must prioritize diagnostic tests, medical consults, and treatment plans.²⁷ To identify interventions beneficial to AYAs and families, it is important to first determine if participation in research at the time of cancer diagnosis is viewed as positive or burdensome. Thus, our goal was to examine perceptions of participating in a research study testing an FP decision tool among AYA males newly diagnosed with cancer and their parents. AYAs for this study are defined as 12 to 25 years, based on the adolescent and emerging adult population²⁸ seen at many pediatric cancer centers and the average age of male pubertal onset (and thus eligibility for sperm banking).

1 | METHODS

Data are part of a larger IRB-approved pilot study (October 2017-March 2019), using a pre-post design, to assess the impact of a family-centered FP decision tool among AYA males newly diagnosed with cancer. The study was conducted at a large pediatric academic center in the Midwest where an automatic consultation is placed to the fertility and reproductive health team in the "new oncology diagnosis" order set (along with other services such as referral to a psychosocial provider), and represents the first step in determining if the approach and timing of research was appropriate for families. Eligible AYAs were: (1) 12 to 25 years old; (2) expected to receive adjuvant therapy (chemotherapy and/or radiation) for newly diagnosed cancer; (3) pubertal/eligible for sperm banking (as determined in the clinical fertility consult); and (4) proficient in English. AYA males were excluded if they had a developmental/cognitive deficit that would preclude completing measures independently.

1.1 | Procedures

Visit 1. Eligible AYA males and their parents were approached in the inpatient setting after their fertility consult, before starting cancer treatment. Once consent (and assent if < 18 years) were obtained,

a demographic questionnaire and decision tool were administered to each AYA and parent separately (total visit 10-15 minutes). The decision tool (23 AYA items, 32 parent items) was adapted from existing measures.^{22,23,29} Items examined reproductive goals/concerns, such as "I (my son) has an increased risk of infertility" and "Not being able to have a biological (grand)child could disrupt my future goals." A standardized abstraction form was used to collect diagnosis/treatment information from medical records. Each participant received a \$5 meal card.

Visit 2. Study staff recontacted families at the hospital or via telephone approximately one month later. Each participant was invited to complete a semistructured, one-on-one interview with trained study staff to explore the impact of study participation. Each participant received a \$20 gift card. Interview responses were audio-recorded and transcribed verbatim. To provide insight for future FP research, data reported here were derived from the following questions: (a) We would like to ask you about the survey you completed about your parenthood goals and sperm banking when you were first diagnosed. How did completing that survey affect your decision? (b) How has participating in this study affected you and your family, either positively or negatively? How has it affected your relationships, conversations with your family, and how you feel about your decision?

1.2 | Analysis

Using an iterative process, four members of the research team (LN, TLM, CAG, and KL) independently analyzed the data through thematic content analysis using the constant comparison method.³⁰⁻³² Analysis began with reading responses to questions in groups of ten transcripts at a time to gain an overview of the data followed by a second reading to extract preliminary themes and codes. Mother transcripts were coded first, then father, and finally AYA. This procedure allowed the team to examine if themes and codes initially derived from the largest sample (i.e., mothers) held true or differed from other members of the family. The researchers then collectively reviewed the initial coding scheme, extracted quotes, and discussed reasoning for emerging themes after independent analysis of each group of transcripts. Discrepancies were resolved by group discussion, and a final codebook was created. The coding scheme was applied to ten new interviews to determine fit with the existing categories. Researchers kept notes of questions, potential comparisons, and leads for follow-up,³³ then repeated this process until saturation was reached and no new themes emerged. Interrater reliability was calculated between two of the initial coders (TM and KL) by identifying the number of times each comment was rated as fitting with one of the themes/subthemes. The level of agreement was 0.96 (kappa coefficient).³⁴

2 | RESULTS

2.1 | Sample characteristics

Of 21 eligible families, 20 (95%) agreed to participate. Forty-four participants (19 mothers, 11 fathers, 14 AYAs) completed qualitative

TABLE 1 Demographic characteristics of sample (n = 44)

Variable	AYA (n = 14)		Mothers (n = 19)		Fathers (n = 11)	
	n	%	n	%	n	%
Marital status						
Engaged/married	—	—	14	73.7	7	63.6
Single	11	78.6	2	10.5	2	18.2
In a serious relationship	3	21.4	1	5.3	—	—
Separated/divorced	—	—	2	10.5	2	18.2
Widowed	—	—	—	—	—	—
Race						
White	13	92.9	18	94.7	9	81.8
Black or African American	1	7.1	1	5.3	—	—
American Indian or Alaskan Native	—	—	—	—	—	—
Asian	—	—	—	—	—	—
Native Hawaiian/Pacific Islander	—	—	—	—	—	—
Other	2	14.3	—	—	2	18.2
Ethnicity						
Non-Hispanic or Latino	13	92.9	19	100.0	10	90.9
Hispanic or Latino	1	7.1	—	—	1	9.1
Religion						
Christian	8	57.1	15	78.9	5	45.5
Catholic	2	14.3	—	—	1	9.1
None	4	28.6	1	5.3	2	18.2
Agnostic	—	—	1	5.3	2	18.2
Hindu	—	—	—	—	—	—
Muslim	—	—	1	5.3	—	—
Jewish	—	—	—	—	—	—
Buddhist	—	—	—	—	—	—
Other	—	—	1	5.3	1	9.1
Highest level of education completed						
Some high school	9	64.3	—	—	—	—
High school diploma or GED	2	14.3	3	15.8	1	9.1
Some college, no degree	1	7.1	4	21.1	7	63.6
Associate degree	1	7.1	2	10.5	—	—
Bachelor's degree	—	—	7	36.8	2	18.2
Graduate or professional degree	—	—	2	10.5	1	9.1
Other	1	7.1	1	5.3	—	—
Total household income						
Less than \$25 000	1	7.1	—	—	1	9.1
\$25 000 to \$49 999	1	7.1	5	26.3	1	9.1
\$50 000 to \$74 999	—	—	5	26.3	4	36.4
\$75 000 to \$99 999	1	7.1	4	21.1	1	9.1
\$100 000 to \$149 000	—	—	1	5.3	1	9.1
\$150 000 or more	1	7.1	2	10.5	3	27.3
Unsure	10	71.4	2	10.5	—	—

(Continues)

TABLE 1 (Continued)

Variable	AYA (n = 14)		Mothers (n = 19)		Fathers (n = 11)	
	n	%	n	%	n	%
Diagnosis type						
Brain and spinal cord tumors	2	14.3	—	—	—	—
Leukemia	1	7.1	—	—	—	—
Lymphoma	6	42.9	—	—	—	—
Solid tumors (non-CNS)	5	35.7	—	—	—	—
Total CED						
< 4 g/m ²	3	21.4	—	—	—	—
4 g/m ² or greater	5	35.7	—	—	—	—
Unknown	6	42.9	—	—	—	—

interviews (visit 2). Qualitative data were missing from 11 participants who did not participate in visit 1 or declined the interview portion of visit 2. Demographic information is presented in Table 1.

2.2 | Qualitative interview themes

Saturation was reached after the first 20 interviews. Two major themes emerged: (1) positive effect of participation and (2) neutral effect (no positive/negative effect of participation). Participants who reported a positive effect noted: (a) participation prompted deeper thinking; (b) participation influenced family conversations; and/or (c) participation resulted in altruism/helping others. Each theme was reported consistently among mothers, fathers, and AYAs, although AYAs did not report altruism. Themes are summarized below with representative quotes.

1. Positive effect

- A. *Prompted deeper thinking.* Many parents said participation had a positive impact by prompting deeper thinking and causing them to focus on other important issues besides the cancer diagnosis. Parents also indicated participation helped them consider their child's perspective and wishes.

Mothers:

The questions help you put things into perspective. There might be things that I can't think about because my mind is so focused on something else. (Mother of 20-year-old)

It's definitely given us food for thought. How much do we know our child...brought things we've already talked about into clearer focus. (Mother of 17-year-old)

The survey...kept asking me what I thought my child would think, and I was trying to consider that...at his age he doesn't know. It made me think a lot about his feelings and what he might want later. (Mother of 13-year-old)

...your whole world stops one day when you come in here and you're hit with everything ...like a million doctors are coming in...you're trying to process things so that wouldn't have been something that I would've thought of. (Mother of 14-year-old)

Fathers:

Everybody thinks about life with their kids or having this talk, but we never envisioned having to have...something like that and... then for your child to be ill...made us all think. (Father of 12-year-old)

Positively, because we wouldn't even be thinking about these issues [FP] for our 12-year-old if it hadn't been brought up. The leukemia diagnosis, obviously that was our number one focus...it's good that we're thinking about it. And you guys... caused us to think about it, so I think that's a positive. (Father of 12-year-old)

Several older AYAs noted the positive impact of participation on their thoughts about FP and parenthood.

It asked a lot of questions I hadn't really thought about before. (18-year-old)

[It made me think about] what the consequences were if I didn't do it and what do I gain from this. (20-year-old)

It made me think more about it...about the whole situation. Like if I actually...made the right decision to not donate or conserve. (17-year-old)

The survey...kind of it laid it out for you...and it kind of helps me decide what I want to do. (20-year-old)

B. Influenced conversations

Several mothers, fathers, and AYAs shared participation in the study positively influenced their conversations and allowed them to speak about FP more openly.

Mothers:

It pretty much opened the doors...it helped us explain things and talk as a family. (Mother of 16-year-old)

It made it easier to talk to him...He filled it out too, and I think that by both of us doing that, it got him thinking about it a little bit, and I wasn't just having to explain everything on my own. (Mother of 13-year-old)

I think it was good, positive for us to do these surveys to help make our decisions because if not... if we didn't have the surveys and talk out what we can do then...I would've been like oh I don't know...I don't know much about it, I don't know what to do...now I know what to do. (Mother of 16-year-old)

Fathers:

Positively because I didn't know until we had these conversations, [patient name]'s feelings about kids. (Father of 17-year-old)

If your child is 18, 19 years old it's very easy for them to say I'm never having kids... It's like [patient name], you're saying that now...and that might be 100% true down the road, but if you decide to have kids, and there's a way that you can have a biological child, wouldn't you rather have that option? (Father of 20-year-old)

AYAs:

These questions kind of helped knowing like I had to ask my parents what I had to gain from it and what hope for the future. So I guess that helped, because I didn't think about it. We don't have conversations about it until you guys ask us about it. (13-year-old)

C. Altruism/helping others

Mothers and fathers, but not AYA, frequently noted participation resulted in altruistic feelings, by helping other families facing a new cancer diagnosis.

We just wanted to do it, so that if it would help someone else that needed...if it helps somebody else make the decision. (Mother of 15-year-old)

It's good...to help other families and make them aware, and you know, know what their options are... (Mother of 20-year-old)

It affects me positively if I can give you something positive to pass along...that makes me feel good...being able to be a part of it where I can make it better for others... (Mother of 13-year-old)

If somebody else can help somebody else out that's great in this situation. (Father of 21-year-old)

Maybe people in the future will be affected by the study...it's going to ultimately benefit somebody in the future... (Father of 16-year-old)

2. Neutral

A minority of participants noted no direct benefits and shared that participation did not affect them one way or the other.

I don't know that it's affected us one way or the other. It hasn't made any difference. (Mother of 18-year-old)

I don't think it's affected us. (Father of 15-year-old)

It didn't really affect us at all. (AYA, 17-year-old)

3 | DISCUSSION

This study highlights largely positive reactions to participating in research piloting a new FP decision tool among AYA males newly diagnosed with cancer and their parents. Decision tools and/or interventions based on behavioral frameworks have been found to be helpful in other scenarios, such as decisions about mammography,³⁵ and have recently been used in the context of FP.³⁶ However, a major challenge in FP research in the setting of a new childhood cancer diagnosis is the short period of time within which assessments must be administered. Inadequate time/urgency to start treatment is commonly cited as a barrier to discussing and completing FP in pediatric/AYA cancer populations.³⁷ Specifically, both parents and oncology providers may believe FP is a secondary issue at the time of a new cancer diagnosis and prioritize treatment.^{27,38} Recruiting for research during this time is thus often thought to be impractical and/or burdensome. To date, studies in this area have primarily been retrospective, often several years after treatment completion.^{5,7,39} Although findings of those studies have helped inform guidelines and improve care,⁹ they have been limited by recall bias. Given these gaps, a qualitative study to explore the impact of participation in FP research at diagnosis was an important next step.

The most common benefit reported in this study was that participation prompted deeper thinking about fertility/FP and provided more clarity. Many parents (particularly mothers) said participation helped them consider FP and future fertility more clearly, while they were preoccupied with other aspects of their sons' new cancer diagnosis (e.g., treatment, prognosis). This is particularly significant as parents have a major influence on FP decisions.²⁰ Parents also commonly stated that survey items and participation prompted them to consider their sons' future parenthood goals, often for the first time. Previous studies have demonstrated discordance between parents and AYAs with regard to reproductive goals and concerns, with parents often underestimating the AYAs' desires and preferences for biological children.^{21–23} Deeper thinking about future parenthood and implications of FP decisions was also noted by some AYAs, which is salient as future-oriented thinking is limited in early-mid adolescence.⁴⁰

Beyond the effect on thought processes, parents and AYAs shared that participating influenced their conversations with one another (created opportunities for fertility-related conversations, facilitated information-sharing), highlighting the "family-centered" aspect of this study. This is an equally valuable outcome given the challenges AYAs and families have reported in approaching conversations about fertility and reproductive health.^{5,19,24} Parents also reported a sense of altruism as a benefit of participating in the study. This is similar to prior research among parents where "helping others" has been reported as a benefit/incentive, but different in that the AYAs in this study did not report that benefit.^{41,42} Perhaps differences in AYA reactions may be explained by the emotional implications of a new cancer diagnosis, in comparison with studies where youth participating in research were less ill or otherwise healthy.^{41,42}

There are important ethical considerations in conducting research at sensitive time points such as acute trauma, end-of-life, and at initial

diagnosis of a life-threatening or life-altering condition.^{41,43–45} Potential concerns are heightened when conducting research on minors, where special efforts must be made to obtain both informed consent and assent.⁴⁶ In this context, it is important to note that none of the participants in this study (mothers, fathers, or AYAs) reported negative effects of completing the decision tool or study participation. Rather, many participants reported a neutral effect, and as described above, most shared positive effects during their interviews. The fact that all of the families enrolled in visit 1 completed visit 2 is also suggestive of a positive experience with engaging in the research. However, future studies could explicitly assess whether increased anxiety or distress related to fertility may occur in the setting of research participation. A next step will also be to conduct cognitive interviews to ensure parents and AYAs understand the items as written, and explore preferences regarding mode of delivery for the intervention.

There are several study limitations that should be noted. First, this study was not designed a priori to assess the impact of research participation at diagnosis per se, rather qualitative interviews were added post hoc to explore the family experience. Participants were mostly white and were recruited at a single site. The sample also included only AYA males; their reactions to research participation may not reflect other pediatric/adolescent populations. Additionally, while recruitment and retention rates for this study have been high (> 90%), not all family members completed interviews. Consistent with prior fertility-related research in this population,¹⁷ participation was highest among mothers. More than half of fathers participated, which is a strength given recent research suggesting fathers may have a stronger influence on males' banking decisions.²⁰ Future research using a larger sample could also identify differences in perceptions based on age, disease type, and respondent (patient vs mother vs father).

In summary, this study demonstrates AYA males and their families perceive FP research as beneficial or neutral at the time of a new cancer diagnosis, before treatment begins. Mothers, fathers, and AYAs (12–25 years of age) noted participation helped them focus on and discuss FP. This builds on recent research highlighting the important influence of parents on FP decisions in AYA males with cancer and provides a foundation for future family-centered interventions for this population.¹⁷

CONFLICTS OF INTEREST

None.

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DATA AVAILABILITY

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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