“We Can Always Adopt”: Perspectives of Adolescent and Young Adult Males with Cancer and Their Family on Alternatives to Biological Parenthood

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Purpose: Approximately half of male childhood cancer survivors experience impaired fertility, which is known to cause psychological distress. Yet, less than 50% of at-risk adolescent and young adult (AYA) males pursue fertility preservation (FP) at diagnosis. Alternatives to biological parenthood (e.g., adoption/sperm donation) may be considered, but little is known about perspectives regarding these alternatives among AYA males and their families.

Methods: Families of AYAs were recruited for a mixed-method study examining FP decisions at cancer diagnosis. One month later, 48 participants from 20 families (18 male AYAs, 12–22 years of age, 19 mothers, 11 fathers) completed semistructured interviews, including two questions about: (a) alternative routes to biological parenthood, and (b) their knowledge about the processes involved and/or challenges associated with such alternatives. Verbatim transcripts were coded for thematic content using the constant comparison method.

Results: Three main themes were identified, of which two represent both ends of considering alternative parenthood: (a) Willingness to consider alternatives to biological parenthood, primarily adoption; (b) No consideration/discussion of alternative family building options; and (c) Variable knowledge of alternatives and/or associated challenges. Notably, more AYAs than parents mentioned a specific preference for biological children.

Conclusions: One-month postcancer diagnosis, most parents reported willingness to consider alternatives to biological parenthood for their sons, while AYA males were less knowledgeable or open to these options. Future research should prospectively examine how these attitudes affect FP decisions before treatment. Medical and psychosocial providers should counsel patients and survivors accordingly to optimize reproductive outcomes and prevent psychosocial distress if parenthood goals are unfulfilled.

Keywords: cancer, adoption, fertility, parenthood, adolescent/young adult, oncology

Introduction

APPROXIMATELY HALF OF male childhood cancer survivors experience infertility as a late effect of treatment,^{1–3} yet having children ranks as a “top 3” life goal for adolescent males newly diagnosed with cancer.⁴ Research with adult survivors has shown most want to have a child and

view both the idea of parenthood and themselves as parents positively.^{5,6} Failure to meet parenthood goals and anxiety about fertility status are sources of distress for many survivors.^{7,8}

Sperm banking is an established, effective, and generally noninvasive fertility preservation (FP) procedure for adolescent and young adult (AYA) males.^{4,9} Despite expanding

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access to fertility-related care at the time of cancer diagnosis,^{10–12} sperm banking rates remain under 50% at many pediatric medical centers.^{11,13} Recent research has shown parents may defer banking decisions to the AYA despite their known challenges in making future-oriented decisions.^{14,15} Parents also underestimated the distress their son would feel if unable to have a biological child.⁶ Families identified cost of FP, time constraints, and religious beliefs as barriers to sperm banking.¹⁶

For survivors experiencing fertility impairment, alternative approaches to having biological children include assisted reproductive technologies (ART) like *in vitro* fertilization, third-party reproduction (e.g., egg or sperm donation), and adoption.^{17,18} While some survivors embrace a life without children and do not seek alternative options,¹⁹ others have pursued alternatives to biological children and reported challenges involved. For example, financial burden is frequently cited as a major barrier to both ART and adoption.²⁰ Additionally, due to a lack of overarching federal regulations in the United States, each adoption agency has their own set of regulations and criteria.²¹ Moreover, potential adopters may worry about how to broach the topic of the child's origin, fear they will be unable to love their child as their own, or their child will reject them in favor of a birth parent.¹⁷ Survivors of cancer may face additional barriers to adoption, such as ambiguous health criteria for potential adopters and/or open discrimination from adoption agencies due to their medical history.²¹

It remains unclear whether AYAs and families consider alternative parenthood options and/or have knowledge of associated challenges at the time of a new cancer diagnosis, which may be an important consideration in the decision about FP. Thus, the goal of this qualitative study was to identify knowledge and perspectives of AYA males and their family toward alternatives to biological parenthood when faced with a new cancer diagnosis.

Methods

Data were collected as part of a larger IRB-approved pilot study examining FP decisions (October 2017 to October 2019) at a pediatric academic center in the Midwest. AYA males were eligible if they were: 12–25 years of age; scheduled for adjuvant therapy (chemotherapy and/or radiation) due to newly diagnosed cancer; pubertal/eligible for sperm banking (as determined in a routine clinical fertility consult); developmentally/cognitively fit, and proficient in English. Up to two parents/caregivers for each AYA were recruited, who had to be proficient in English. Twenty families ($N=48$ participants, including 18 AYAs, 19 mothers, and 11 fathers) were included and demographic information is presented in Table 1.

Procedures

Visit 1. If eligible, AYA males and their parents were approached in the hospital before starting cancer treatment and immediately after their fertility consult; this consult is part of the routine procedures/electronic orders at our institution for all patients newly diagnosed with cancer.¹¹ Once consent (and assent if <18 years) was obtained, a questionnaire examining demographic characteristics and parenthood goals/FP decision making was administered to each AYA and

parent(s) separately (10–15 minutes); each participant received a \$5 meal card. A standardized form was used to collect diagnosis/treatment-related information from medical records.

Visit 2. Study staff recontacted families at the hospital or through telephone 1–2 months later. Each participant was invited to complete a semistructured, one-on-one interview with trained study staff to explore perspectives on having biological children, their conversations with family and providers about FP, and how they ultimately made decisions regarding FP. Each participant received a \$20 gift card. Interview responses were audiorecorded and transcribed verbatim.

Data used for this article were derived from the following questions about alternative routes to biological parenthood. *Part 1: Some families tell us about discussions they have had about alternatives to having biological (genetically related) children, while some have told us they have not had these discussions. What alternative routes to parenthood would you consider or have you considered?* *Part 2: What do you (your son) know about what is involved in the process of these options, and who have you talked to about it? How did you (your son) get this information?*

Analysis

Using the iterative process of the constant comparison method,²² four members of the research team (T.L.M., K.G.L., B.P.Y.) independently analyzed the data as participants were interviewed.^{23–25} Transcripts were reviewed starting with the largest sample (mothers), followed by fathers and AYAs, while study staff continued data collection. Analysis began with reading 10 transcripts to gain a gestalt of the issue, followed by rereading to identify emergent themes and codes. 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 the other groups (fathers, AYAs). The researchers then collectively reviewed the initial code book, extracted quotes, and discussed reasoning for emerging themes. Discrepancies were resolved by group discussion, and a final code book was created. The code book was applied to 10 new transcribed interviews to determine fit with the existing categories. Researchers kept notes of questions, potential comparisons, and leads for follow-up,²⁶ then repeated this process until saturation was reached ($n=30$). All additional transcripts were reviewed ($n=48$) to confirm saturation and that no new themes emerged. Inter-rater reliability was calculated between the three coders by identifying the number of times each comment was rated as fitting with one of the themes/subthemes. The level of agreement was 0.88 (kappa coefficient).²⁷

Results

Qualitative interview themes

Thematic content analysis of all 48 interviews identified three major themes (Table 2): (a) willingness to consider alternatives to biological parenthood, primarily adoption; (b) no consideration/discussion of alternative family building options; and (c) variable knowledge of alternatives and/or

TABLE 1. DEMOGRAPHIC CHARACTERISTICS OF THE WHOLE SAMPLE (N=48)

	AYA (n=18)		Mothers (n=19)		Fathers (n=11)	
Age, <i>M (SD), range</i>	15.5 ± 2.3, 12–22		43.5 ± 6.8, 33–59		46.7 ± 7.4, 36–62	
	n	%	n	%	n	%
Marital status						
Engaged/married	—	—	12	63.2	7	63.6
Single	14	77.8	3	15.8	1	9.1
In a serious relationship	3	16.7	—	—	—	—
Separated/divorced	—	—	3	15.8	3	27.3
Unknown	1	5.6	1	5.3	—	—
Race						
White	13	72.2	17	89.4	9	100.0
Black or African American	3	16.7	1	5.3	—	—
Other	2	11.1	—	—	—	—
Unknown	1	5.6	1	5.3	—	—
Ethnicity						
Non-Hispanic	17	94.0	18	94.7	10	90.9
Unknown	1	5.6	1	5.3	1	9.1
Religion						
Christian	10	55.6	15	78.9	6	54.5
Catholic	1	5.6	—	—	1	9.1
None	5	27.8	2	10.5	1	9.1
Agnostic	—	—	—	—	3	27.3
Muslim	—	—	1	5.3	—	—
Other	1	5.6	—	—	—	—
Unknown	1	5.6	1	5.3	—	—
Highest level of education completed						
Some high school	8	44.4	—	—	—	—
High school diploma or GED	4	22.2	4	21.1	—	—
Some college, no degree	—	—	4	21.1	5	45.5
Associate degree	—	—	3	15.8	1	9.1
Bachelor's degree	—	—	4	21.1	4	36.4
Graduate or professional degree	—	—	2	10.5	1	9.1
Other	5	27.8	1	5.3	—	—
Unknown	1	5.6	1	5.3	—	—
Total household income						
Less than \$25,000	2	11.1	1	5.3	—	—
\$25,000 to \$49,999	2	11.1	4	21.1	—	—
\$50,000 to \$74,999	—	—	6	31.6	4	36.4
\$75,000 to \$99,999	—	—	3	15.8	2	18.2
\$100,000 to \$149,000	—	—	3	15.8	3	27.3
\$150,000 or more	1	5.6	1	5.3	1	9.1
Unsure	12	66.7	—	—	—	—
Unknown	1	5.6	1	5.3	—	—
Diagnosis type						
Brain and spinal cord tumors	2	10.0	—	—	—	—
Leukemia	6	30.0	—	—	—	—
Lymphoma	5	25.0	—	—	—	—
Other solid tumors	7	35.0	—	—	—	—

Not all mothers, fathers, and AYA from each family participated (e.g., a parent could participate irrespective of whether their son had participated); thus, there are missing demographic data from families.

AYA, adolescent and young adult; M, mean; SD, standard deviation.

TABLE 2. MAJOR THEMES OF QUALITATIVE INTERVIEWS

1. Willingness to consider alternatives (44% AYAs, 70% parents)	a. Have discussed it (22% AYAs, 50% parents)
2. No consideration/discussion of alternative family building options (56% AYAs, 30% parents)	b. Have deferred the decision until a. future time (17% AYAs, 27% parents)
3. Knowledge about the processes involved and/or associated challenges (28% AYAs, 63% parents)	c. No information (33% AYAs, 17% parents)
	d. Some information from others that have adopted (22% AYAs, 60% parents)
	e. Acknowledging challenges (costs, pathways) (6% AYAs, 27% parents)

associated challenges. Themes are described in greater detail below, accompanied by representative quotes.

Willingness to consider alternative options. Nearly one-half of AYAs and most parents said they had considered or would be willing to consider alternatives to having biological children. Adoption was the most common alternative mentioned by mothers, fathers, and AYAs. Approximately one-quarter of AYAs and one-half of parents reported they had discussions within the family and/or with family friends about alternative pathways to having biological children.

I told him...if you can't have children, you can always adopt...I told him I will love whatever you bring me home. Girl, boy, doesn't matter (Mother of 13-year-old, Hodgkin lymphoma).

We did tell him...if it does [make him infertile] you can always adopt children or you know there's other...choices too (Mother of 14-year-old, acute myeloid leukemia).

That was one thing I did want him to fully understand...if you can't have a child of your own, then so what? There's plenty of children out there that need a loving home (Father of 16-year-old, embryonal rhabdomyosarcoma).

When we were going through this, then my parents, we also talked about foster care, adopting, stuff like that. Those were the two that we really thought about (17-year-old, chronic myeloid leukemia).

Me and my dad talked a little bit about adopting...he told me about some of his friends that I know that were adopted that I had no idea. I thought it was cool to just know that they were adopted...they're cool guys...shows me that adopting is like okay, and if I can't have kids down the road, I can always adopt (16-year-old, embryonal rhabdomyosarcoma).

Fewer participants (primarily mothers) mentioned sperm donation as another alternative route to parenthood.

He knows other options that people do, like they use someone's egg and someone's sperm, but I have not been specific with him (Mother of 12-year-old, intracranial germ cell tumor).

We considered adoption and sperm donors... (12-year-old, Ewing sarcoma).

No consideration/discussion of alternative family building options. In contrast to the first theme, more than half of AYAs and approximately one-third of parents reported they had not considered alternatives to having biological children. Notably, one-quarter of AYAs (but few parents) reported a preference for biological children.

It's not anything...right now he's thinking about, or I mean you know, that we're discussing as a family (Mother of 18-year-old, lymphoma).

I haven't considered any alternatives for him (Father of 13-year-old, acute lymphocytic leukemia).

I haven't really considered parenthood at the moment... I'm living my life. I got other things to worry about (19-year-old, Burkitt's lymphoma).

I haven't really considered. That's kind of like the main reason why we [banked sperm], because I wouldn't really want to like, adopt or anything. I'd want to have my own biological children (18-year-old, germinoma).

I mean, I never really considered having another child, like, if it's not like my blood (15-year-old, Hodgkin lymphoma).

Some participants also mentioned deferring the decision about parenthood and alternative routes to parenthood for later in life.

We haven't considered anything at all at this point. I mean it's not come up in discussion again about the sperm banking and his choice not to do it, and again, it probably could be years down the road before we know where we stand on that. If he has that ability or not (Mother of 16-year-old, Hodgkin lymphoma).

Well, there's always adoption or other...I don't know. At this point he's not interested in any of that right now. That's not a major thing for him right now (Mother of 17-year-old, chronic myeloid leukemia).

[He] doesn't even know if he wants to have kids! He's got nobody to raise it with him yet, so he's not there yet...This is not on his mind (Father of 19-year-old, Burkitt's lymphoma).

Sadly, I did not think about my future... I'm leaving that spot open for my future self so I don't get overconfident now thinking oh yes I'm going to do this, but then find out never mind (13-year-old, acute lymphocytic leukemia).

Variable knowledge about alternatives and/or associated challenges. Perceived knowledge about alternative pathways to parenthood varied widely among mothers, fathers, and AYAs. Mothers and fathers more frequently reported having some knowledge about alternative options in comparison to AYAs. Some participants mentioned that they or their son had no knowledge about alternatives to having biological children.

We have some friends that have adopted, but I don't know a lot personally (Mother of 14-year-old, acute myeloid leukemia).

I don't think he knows squat. I really don't. That is certainly a topic we need to discuss (Father of 16-year-old, embryonal rhabdomyosarcoma).

I have no idea how you get adopted (18-year-old, lymphoma).

More than one-half of parents and one-quarter of AYAs noted having some knowledge based on family/friends that had fostered or adopted.

I mean we have family members and other people in our lives that have been adopted (Mother of 16-year-old, embryonal rhabdomyosarcoma).

I do know that our family friends adopted, so I asked them about what the process was (12-year-old, Ewing sarcoma).

Approximately one-quarter of parents, but few AYAs, noted specific considerations or barriers to these alternatives, including pathways to adoption, high costs, and other challenges.

I have another friend that just adopted a little boy from a foreign country, and that was pretty much the price of a brand new car. It was like \$40,000 (Mother of 13-year-old, acute lymphocytic leukemia).

I know [adoption] is a pain in the butt. From people that I know that have actually had to go to another country to pick up a child and sign all the forms and pay and stuff, and I've heard that it's definitely difficult, especially if you do it from a different country (17-year-old, Hodgkin lymphoma).

[Adoption] is definitely a long and difficult process. I know people that have actually had to go to another country to pick up a child and sign all the forms and pay and stuff, and I've heard that it's definitely difficult, especially if you do it from a different country (17-year-old, Hodgkin lymphoma).

Discussion

Our findings suggest about half of male AYAs newly diagnosed with cancer and most parents would be willing to consider alternatives to biological children in the future. Specifically, most parents mentioned they would be open to adoption. Some participants (primarily mothers) also reported considering sperm donation as a potential alternative. Although none of the AYAs reported not wanting future children, some who did not consider alternatives said they were deferring the issue until they were older.

Our findings are similar to prior research showing survivors would prefer to have a biological child.²⁸ In a recent study, childhood cancer survivors reported they would adopt if they could not have biological children, but no survivor had gone through the whole process, and most seemed unaware of potential obstacles (e.g., costs). More importantly, some survivors reported that, in hindsight, adopting a child would be less satisfying than having a biological child.¹⁹ Parents in our sample said they would be as happy with an adopted grandchild, which is consistent with prior literature showing parents may underestimate their son's desire to have a biological child over an adopted child.⁶

In addition to preferences for biological versus alternative pathways to parenthood, another major theme was related to knowledge, which again differed between parents and AYAs. More parents than AYAs reported having knowledge about challenges involved in the process of adoption (e.g., time, money). No participant mentioned having cancer as a potential barrier to adoption. Research suggests potential parents who have medical conditions, such as cancer, face discrimination from adoption agencies in the United States and internationally.²¹ Additionally, cancer organizations, intra- and international adoption agencies, and adoption specialists reported concerns regarding the welfare of a child adopted by a cancer survivor and were hesitant to discuss the potential for cancer survivors to become adoptive parents.¹⁷

In addition, adoption, particularly international, can be expensive and families often feel they would not be able to afford this option.^{20,29} However, lack of awareness of these potential challenges may lead to future disappointment for those experiencing infertility.

While most parents in this study had considered alternatives, most AYAs said they had not. Many participants, particularly AYAs, said they were not thinking about alternatives to biological parenthood until they (their son) were ready for that stage of life. A previous study showed some survivors of childhood cancer, who reported no firm desire for children at diagnosis, changed their mind in the subsequent 3–7 years.⁸ Due to adolescents having limited ability to engage in future-oriented thinking,^{13,30} parental input is paramount. Recent research indicates the important influence of parental recommendation on FP decisions among male AYAs newly diagnosed with cancer.^{13,31} Furthermore, fertility counseling and both declining or completing FP before treatment decrease future regret.³² Thus, communication about FP and alternatives to biological parenthood should begin at the time of a new cancer diagnosis between physicians, parents, and AYAs at risk for future infertility. Families should discuss future parenthood goals (including adoption logistics, sperm donation, or a life without children) to make optimal decisions about FP and mitigate future regret or disappointment. Additionally, acceptance and access to alternative methods of parenthood may alter the degree of distress in survivorship if fertility is impaired.

This study should be considered within the context of several limitations. Participants were mostly White and recruited at a single pediatric cancer center. Due to our small sample size, we were unable to analyze subgroups based on age/development stage, although our sample was unique in that many younger adolescents (12-year-olds) were included. We were also unable to examine correlations between subject characteristics and themes, which would be an interesting future direction. Recruitment rates were high, however not all family members completed interviews. Fewer fathers participated, which is important to consider as fertility-related research has shown fathers have a significant influence on FP decisions among AYA males.³¹ It is also important to consider that perspectives on alternative routes to parenthood may be biased based on the FP decisions made 1 month prior (upon beginning treatment). Furthermore, variable knowledge was a salient theme that emerged, but we did not have an objective measure to assess knowledge about adoption, which is an area for future research. Finally, this sample consisted of only AYA males; their thoughts about parenthood may not generalize to other populations (e.g., females). Despite these limitations, our findings may help inform future research on understanding AYA and family perceptions about alternative methods to parenthood.

Our findings have clinical implications for medical and psychosocial care before, during, and after cancer treatment. Although counseling about infertility risk and FP options is recommended by several organizations,^{33,34} providers have reported barriers to initiating these discussions during a new cancer diagnosis (i.e., provider personal discomfort, perceived lack of finances and insurance).^{35,36} Families are understandably focused on curative treatments and may not prioritize future quality of life in that context.³⁶ Having the ability to consult a team that is dedicated to fertility and

reproductive health can facilitate more comprehensive discussions about infertility risk, FP options, alternatives to biological parenthood, and other aspects of family planning. Ongoing discussions (from time of diagnosis through survivorship) and provision of written materials about these reproductive health topics would optimize comprehension and retention of information.

As was noted in this study and prior research,^{4,37} AYAs and their families may have differing goals and attitudes regarding parenthood and FP,⁶ increasing the complexity of these discussions. When opinions differ, parents may ultimately defer decisions about FP to the AYA,¹⁴ which may be problematic if AYAs do not have adequate information and/or foresight about this topic.³⁸ Developing family-centered interventions and decision aids may facilitate these discussions. Recent research suggests these are of benefit and are not overly burdensome.³⁹ AYA and family perspectives may change over time, warranting ongoing fertility and reproductive health counseling.

In summary, many families are open to alternatives to biological children, but perspectives of AYAs and parents may differ. Both groups (especially AYAs) may lack information about what is involved in these processes. Clinicians should prioritize communication with AYAs and parents to help them reach consensus and make FP decisions that will prevent future regret. Additionally, health care providers discussing FP with patients and families should be well equipped to address potential options and challenges associated with alternatives to biological parenthood, such as adoption. Future research should be conducted on the optimal time and approach to give families adequate information and facilitate communication, without overly burdening them during the stressful and brief period near a new cancer diagnosis.

Author Disclosure Statement

No competing financial interests exist.

Funding Information

(1) Clinical and Translational Intramural Funding Program (#1K08CA237338-01), The Abigail Wexner Research Institute at Nationwide Children's Hospital. (2) The National Cancer Institute.

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