Published in final edited form as:

Pediatr Blood Cancer. 2020 October ; 67(10): e28217. doi:10.1002/pbc.28217.

Parent Recommendation to Bank Sperm among At-Risk Adolescent and Young Adult Males with Cancer

Jessica S. Flynn, MS¹, Kathryn M. Russell, PhD¹, Vicky Lehmann, PhD^{1,2}, Lauren A.-M. Schenck, BA^{1,3}, James L. Klosky, PhD, ABPP^{1,4}

¹Department of Psychology, St. Jude Children's Research Hospital, Memphis, Tennessee

²Department of Medical Psychology, Amsterdam University Medical Center/University of Amsterdam, Amsterdam, The Netherlands ³Department of Psychology, University of Memphis, Memphis, Tennessee ⁴The Aflac Cancer and Blood Disorders Center at Children's Healthcare of Atlanta and Department of Pediatrics, Emory University School of Medicine, Atlanta, Georgia

Abstract

Background: Adolescent and young adult (AYA) males newly diagnosed with cancer are often faced with making quick decisions about whether to cryopreserve ("bank") sperm prior to treatment initiation. Given that parental influence is crucial among young patients, the present study examines the prevalence of and factors associated with parent recommendation to bank sperm.

Procedure: Parents of 13 to 21-year old males newly diagnosed with cancer and at-risk for infertility secondary to impending gonadotoxic treatment completed questionnaires typically within one week of treatment initiation. Medical and sociodemographic data, communication factors, and psychological factors were considered in a logistic regression model of parent report of parental recommendation to bank sperm (yes/no).

Results: Surveys from 138 parents (70.3% female) of 117 AYA males (M age = 16.1 years, SD = 2.0) were analyzed. Over half of parents recommended banking to their sons (N = 82; 59.4%). Parents who received a provider recommendation to bank sperm (OR = 18.44, 95% CI, 4.20-81.01, $p < 0.001$) or who believed in the benefits of banking (OR = 1.22, 95% CI, 1.02-1.47, $p = 0.03$) were significantly more likely to recommend sperm banking.

Conclusions: Given parents' role in influencing sperm banking outcomes, provider recommendation and promotion of banking benefits may influence parents and empower initiation of these sensitive discussions with their sons. Utilization of this approach should yield beneficial outcomes regardless of the banking decision.

Correspondence: Jessica S. Flynn, MS, CCRP, Department of Psychology, St. Jude Children's Research Hospital, 262 Danny Thomas Place, Mail Stop 740, Memphis, Tennessee 38105; phone: 901-595-7775; fax: 901-595-4701; jessica.flynn@stjude.org.

Conflict of interest: No authors have any conflicts of interest to disclose.

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

A meeting abstract with preliminary findings from the current study were published as part of the 2016 American Psychosocial Oncology Society's 13th Annual Conference, "Parental Predictors of Sperm Banking Recommendation among Adolescent Males with Impending Gonadotoxic Therapy," *Psycho-Oncology*, 25(Suppl. 2):137.

Keywords

Behavioral Studies; Late Effects of Cancer Treatment; Pediatric Oncology; Psychology; Quality of Life

Introduction

Survival rates of childhood cancer now exceed 85%,¹ making quality of life in survivorship a priority for both patients and providers. Infertility is a common consequence of childhood cancer treatment,^{2,3} with over half of male survivors experiencing suboptimal fertility and pregnancy outcomes.^{4,5} These findings have spurred the need for interventions at diagnosis, as well as targeted research on the factors which influence fertility preservation decision-making within this vulnerable group.⁶

Risk for infertility among males largely depends on the type of cancer therapy, with increased exposure to alkylating chemotherapies or radiation to the testes or hypothalamus/pituitary region of the brain conferring greatest risk.^{4,7,8} Thus, fertility preservation should ideally occur prior to the initiation of treatment.⁹ Among post-pubertal males diagnosed with cancer, sperm cryopreservation is considered the gold standard among fertility preservation options.¹⁰ Although the demands of collecting sperm are relatively low, the decision to bank is typically accompanied by time constraints, due to the urgency to initiate cancer therapy.¹¹ Despite valuing parenthood,¹² many adolescents do not bank sperm prior to initiation of gonadotoxic cancer treatment.^{11,13}

In the cancer setting, adolescents and young adults (AYA) often make medical decisions collaboratively with a parent^{14,15} and previous research indicates that parents have a critical role in AYAs' decision to bank sperm.¹⁶⁻¹⁸ AYAs whose parents recommend sperm banking are over twelve times more likely to make a collection attempt relative to those whose parents do not.¹⁶ Additionally, AYAs report that their family's support and influence significantly contributes to their banking decision.^{19,20}

Yet, it is unknown what factors may influence parents' decision to recommend banking. Perhaps parental recommendation is influenced by similar variables that differentiate banking outcomes among AYAs, such as medical (e.g., higher Tanner stage), communication (e.g., medical team recommendation), and/or psychological factors (e.g., self-efficacy to coordinate banking).¹⁶ In general, a lack of openness in family communication about this sensitive topic may be a hindrance for parents to recommend banking. Additionally, anxiety is common when a childhood cancer diagnosis is made, which may also influence parents' medical decision-making.¹⁹

However, as evidence is scarce, the objectives of this study were 1) to examine the prevalence of parents who recommend sperm banking to their adolescent sons newly diagnosed with cancer and 2) to determine medical/sociodemographic, communication, and psychological factors that associate with parent recommendation to bank sperm.

Methods

As part of a larger study investigating adolescent sperm banking factors,¹⁶ an observational, cross-sectional study design was utilized at eight institutions across the United States (US) and Canada ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01152268) Identifier: NCT01152268), where Institutional Review Board or Research Ethics Board approval was obtained. Additionally, research was performed in accordance with applicable federal rules and regulations.

Procedure

Caregivers were invited to complete a questionnaire only after their son consented/assented to the larger study. Of the 146 participating males, the majority ($n = 117$, 80.1%) had at least one caregiver provide written informed consent and return a completed survey. Caregivers were approached and consented (per enrolling site's ethical review board guidelines) typically within one week (M and $Mdn = 5.0$ days, $SD = 2.6$) post son's initiation of cancer therapy. As sperm banking should occur prior to the initiation of cancer therapy,⁹ caregivers completed this survey within days of fertility preservation decision-making to increase the temporal validity of self-report.²¹ Participants were provided with a \$12.50 gift card upon completion of the study measures as an incentive for participation and compensation for their time.

Participants

Participants were 138 caregivers (97 maternal, 41 paternal) of adolescents who had completed questionnaires within the larger study. Almost all caregivers self-identified as parents ($n = 136$, 98.6%; 2 were aunts), thus referred to as "parents." Per eligibility, participating parents had sons aged 13 - 21 years ($M = 16.1$, $SD = 2.0$) who were newly diagnosed with a first cancer (leukemia/lymphoma: $n = 73$, 52.9%; solid/brain tumor: $n = 65$, 47.1%), assessed by his oncologist/primary care team as being at increased risk for treatment-related fertility loss, at least Tanner Stage III ($n = 75$, 54.3% Tanner Stage V), proficient in speaking and reading English or Spanish, and cognitively capable of completing questionnaires. Parents ranged in age from 32 - 57 years ($M = 44.5$, $SD = 5.6$), were primarily White ($n = 99$, 71.7%), Christian ($n = 128$, 92.8%), married ($n = 100$, 72.5%), had less than a bachelor's degree ($n = 77$, 55.8%), and reported less than \$60 000 annual household income ($n = 40$, 47.8%). Notably, parents of younger ($M = 16.2$ years of age, $SD = 1.9$) or White (82 of 117) adolescents were more likely to participate than parents of older ($M = 17.8$ years of age, $SD = 1.9$; $t(144) = 4.2$, $p < 0.001$) or non-White (16 of 29; $X^2(1) = 6.5$, $p = 0.01$) adolescents. See Table 1 for full sociodemographics.

Measures

Primary Outcome—Parent sperm banking recommendation to their son was the primary outcome measure of this study, collected via parent report of sperm banking recommendation from either themselves or another parent (yes/no).

Medical and sociodemographic factors—Participants completed a series of standard sociodemographic questions as described above. Son's age, diagnosis, and Tanner stage were also captured from the medical record.

Communication—Parents were asked whether communication occurred (yes/no) regarding their son's fertility risk a) with their son's medical team or b) with family members or friends. They were also asked whether their son's medical team recommended sperm banking (yes/no).

Parents were then queried regarding their comfort in talking with their son about five sexual health topics, such as condom use and psychosexual development (1 = Very uncomfortable to 5 = Very comfortable) with total scores calculated by summing individual items (ranging from 5 - 25). Parents also completed the communication, problem solving, affective responsiveness, and general functioning subscales from the McMaster Family Assessment Device²² (Cronbach's $\alpha = 0.74 - 0.92$), which has frequently been used to measure family functioning among pediatric cancer populations, with higher scores suggesting greater communication problems within the family.²³

Psychological Factors—Five fertility and sperm banking-specific health belief scales were developed based on the Health Belief Model and specific to its application to sperm banking.²⁴⁻²⁸ Likert-type items examined parents' perceptions of 1) *vulnerability* regarding their son's fertility, 2) *severity* of infertility, 3) *barriers* to and 4) *benefits* of sperm banking, and 5) *self-efficacy* to facilitate the banking process. *Perceived vulnerability* was assessed using five items (e.g., "Compared to other males your son's age who have never been treated for cancer, what do you think your son's risk (or chances are) for developing fertility problems in the future?"), with response options ranging from 1 (Much lower) to 5 (Much higher). Another five items measured *perceived severity* (e.g., "Family would treat my son differently if he could not produce biological children"), with response options ranging from 1 (Strongly disagree) to 5 (Strongly agree). To measure *perceived benefits*, parents completed six items (e.g., "Having banked sperm makes an infertile man a more desirable spouse") on a 1 (Strongly disagree) to 5 (Strongly agree) Likert-type scale. *Self-efficacy* was measured by four items with response options ranging from 1 (Definitely no) to 5 (Definitely yes) regarding parent perceptions of their ability to assist their son with arranging an appointment at a fertility clinic, getting transportation to/from center, paying for sperm banking, and son's ability to produce sperm. To measure *perceived barriers*, parents rated the importance of 28 potential barriers to making the decision to bank a from 1 (Very unimportant) to 4 (Very important), which yielded seven factors including comfort and confidence, friends and extended family recommendations, medical recommendations, parent recommendation and concern, religion, treatment delay, and readiness, infertility risk and desire for children, and cost and availability.

Additionally, parents were asked if they believed their son's risk for infertility secondary to cancer treatment was high (3), moderate (2), low (1), or non-existent (0; another option "don't know" was coded as missing). Three questions querying parents' familiarity and beliefs about assisted reproductive technologies (ART) prior to son's cancer diagnosis contributed to a dichotomous composite ART score (1 = Familiar/positive, 0 = Not familiar/not positive). These questions were: 1) whether they themselves, a friend, or family member has ever attempted pregnancy through ART (yes/no); 2) "How familiar were you with fertility preservation methods?" (1 = Very familiar/familiar, 0 = Heard of/unfamiliar/

don't know); 3) "How did you feel about artificial means of achieving a pregnancy?" (1 = Positive, 0 = Neutral/negative/never thought about it).

Finally, the Symptom Checklist 90-R anxiety subscale²⁹ (Cronbach's $\alpha = 0.85$) was used to assess both parents' and sons' anxiety during the previous seven days (i.e., during the time when a sperm banking decision was likely made).

Statistical Analyses

Prevalence rates of parent sperm banking recommendations were computed using frequencies and proportions for categorical variables and means and standard deviation (SD) for continuous variables in order to describe these outcomes. Next, chi-square tests and univariate ANOVAs were used to identify medical/sociodemographic, communication, and psychological variables significantly associated with parental recommendation to bank (yes/no). Finally, a logistic hierarchical regression model was created to identify the multivariate associations between the statistically significant ($p < 0.05$) variables identified in univariate analyses with parent recommendation as a binary outcome. Specifically, step 1 included the medical and sociodemographic variables identified in univariate analyses to control for their effects and step 2 included the communication and psychological variables. The results of the final model are presented in odds ratios (OR), 95% confidence intervals (CIs), and the amount of variance explained in the overall model (Nagelkerke R^2).

Results

Of the 138 parents, over half ($n = 82$; 59.4%) recommended their son bank sperm. Based on chi-square tests and univariate ANOVAs, the only medical or sociodemographic variable identified as significantly associated with parent recommendation was higher income (Table 1). Moreover, there were three communication variables identified: fertility risk communication with the medical team and with family/friends, as well as recommendation to bank by medical team. Finally, six psychological variables were identified as significantly related to parent recommendation, including personal belief of son's infertility risk, familiarity with ART, the perceived barrier of infertility risk and desire for children, belief of son's vulnerability to infertility, perceived self-efficacy, and beliefs of benefits to banking (Table 2).

These factors were entered into the final logistic hierarchical regression model, with income in step 1 and the nine communication and psychological variables entered in step 2. Income was a significant factor in the first step, but only explained 8.3% of the variance and was ultimately not significant after adding the communication and psychological variables. The final model indicated two variables were positively and significantly associated with parent recommendation to bank: medical team recommendation for son to bank sperm (OR = 18.4, 95% CI: 4.20-81.01, $p < 0.001$) and parental perceived benefits to banking (OR = 1.22, 95% CI: 1.02-1.47 $p = 0.03$). This final model accounted for 62.5% of the variance in parent recommendation, $X^2(10) = 61.8$, $p < 0.001$ (Table 3).

Discussion

Given that parent recommendation to sperm bank is robustly related to adolescent banking outcomes and is more influential than other factors related to banking (i.e., medical team recommendation, risk of infertility, and Tanner Stage),¹⁶ parental recommendations and beliefs need to be considered in clinical practice and research. This study demonstrates that parent recommendations to bank sperm are most strongly influenced by their communication with the medical team and their personal beliefs. Communicating with parents, including directly recommending sperm banking prior to treatment and addressing their beliefs, is easily implementable in clinical practice. Importantly, such modifications by providers could increase rates of fertility preservation among AYAs at-risk for infertility due to cancer treatment. The present study is meaningful because previous research has found that AYAs want their parents involved and report that parental influence is the second most important factor when making a decision to bank (behind “doing what’s right for me”).^{20,30} AYAs are even more likely to refuse sperm banking if making this decision alone.²⁰ Post-hoc analyses of our data also support this finding, as patients whose parents were available and willing to participate in our study were more likely to bank sperm than patients whose parents did not complete a survey, $X^2(1) = 3.8$, $p < 0.05$. This study demonstrates that over half of parents (59%) support sperm banking, which is important when other research reports up to 80% of AYAs engage in a shared banking decision-making process with their parents²⁰ and our previously published results demonstrate that 80% of these AYA males who receive a parent recommendation make a collection attempt (57/71) and over 75% of those without a recommendation fail to make an attempt (36/46).¹⁷ As such, efforts to investigate factors that encourage or discourage parent recommendation to sperm bank are warranted and should remain a target for intervention when working with families in pediatric and/or young adult oncology.

The motivation behind parental recommendation is multifold and may include a desire for their son to maintain the option of biological parenthood or their own chance of becoming a grandparent, but parents also encourage their sons to bank sperm to avoid future decisional regret.^{31,32} Regardless of intent, parents frequently struggle to initiate and manage these sensitive fertility-related discussions with their son, particularly at the time of a new cancer diagnosis.^{33,34} AYAs also prioritize parenthood at the time of diagnosis¹² and want to be informed of fertility preservation options.²⁰ Despite AYAs’ desire to be involved in these conversations,³⁵ fertility-related communication may occur between parents and providers, outside of their presence, especially when the adolescent is very young or due to cultural/religious influences.^{11,36} Such isolated parent-provider discussion is inadvisable for many reasons,³⁷ as the results of our study indicate that medical team recommendation to a family for the son to bank sperm is associated with increased parental recommendations for banking.

This raises the question as to whether these discussions improve parental attitudes/beliefs toward the benefits of banking and as our study results indicate, also increase parental recommendation. Although 43% of parent participants self-report a basic familiarity of how sperm is utilized in ART, misunderstandings may remain, and the inclusion of information tailored to young patients may also be beneficial during discussions. Many sources may

contribute to parental beliefs of banking benefits, such as misperception of son's infertility risk,³⁸ but providers can target misbeliefs and counsel parents, which may increase parental recommendation or at least improve decisional satisfaction. Study results suggest medical team intervention, including recommendation and psychoeducation, are necessary to promote parental recommendation for banking, which in turn is associated with increased sperm banking.¹⁶ Providers should highlight the benefits of fertility preservation, such as relieving fertility-related distress by allowing AYAs to maintain options for biological parenthood, while lowering the risk for decisional regret in the future. Providers should also give families appropriate privacy and time to discuss the decision on their own in order to provide more opportunities for parental recommendation to occur and to promote decisional satisfaction.³⁴ Future research should examine the efficacy of such interventions targeting provider recommendation, whether parents and providers have the same perception of provider recommendation, and whether such intervention outcomes (i.e., higher rates of parental support, higher rates of banking) vary by provider type or institution and whether they result in improved banking outcomes. Preliminary findings from our study also point to likely financial barriers, with less than half of parents (48.5%) who report an annual income under \$60,000 recommending banking, versus 77.2% of parents who report an annual income of \$60,000 or more. Most of our participants (54.3%) disclose that cost is an important consideration when making a fertility preservation decision. Although income did not remain a significant predictor of parent recommendation in this study's final model, previous research has found prohibitive costs and lacking health insurance coverage are often cited as barriers to banking³⁹ and could be a factor to explore further in future research.

Apart from providing new insights, certain limitations of this study should be considered. The cross-sectional design of this study limits conclusions regarding the proposed temporal sequence of parents' decision-making process, and because both communications were measured by parent self-report, parent-son and provider-family discussions cannot be confirmed and should be the focus of future research. Additionally, few medical factors were collected as part of the study and therefore we are unable to determine any potential association of factors such as patient acuity, stage of disease, or comorbidities with parent recommendation. Moreover, our measurement of banking recommendation does not allow for the differentiation of an active recommendation for or against banking versus a passive, more neutral, lack of recommendation, and this differentiation could be useful in future research. Most importantly, given our limited sample size, we did not statistically account for potential nesting within families (i.e., for AYAs with two participating parents). Yet, two separate post-hoc analyses were completed with only one parent per AYA and yielded similar results (provider recommendation: OR = 17.01, 95% CI, 3.19-90.58, $p = .001$ [including mothers of AYAs with two participating parents] and OR = 26.39, 95% CI, 3.75-185.82, $p = .001$ [including fathers]; benefits to banking: OR = 1.27, 95% CI, 1.04-1.56, $p = .02$ [mothers] and OR = 1.39, 95% CI, 1.03-1.88, $p = .03$ [fathers]). Notably, when both parents participated in the study, almost all dyads (20/21) agreed on the presence or absence of a parental sperm banking recommendation. Overall, the small number of participating fathers ($n = 41$) and dyads ($n = 21$) limits our ability to differentially examine potential maternal versus paternal influences, as well as associations of within-family

dynamics, on banking recommendation. However, the low ratio of fathers may indicate a more influential role of mothers in the medical setting, as parents were approached during hospital visits and mothers were more often present and/or willing to participate. Thus, these potential intra-family differences should be further explored, as previous research suggests within-family differences in messages, influences, and priorities in the sperm banking decision-making process and related factors.^{12,38,40}

Overall, this study identifies two novel factors contributing to parent recommendation of banking sperm: medical team recommendation and perceived benefits of banking. Both factors are modifiable and can be targeted in psychoeducational and communication-based interventions with oncology staff. Although sperm banking may not be suitable and desirable for all young cancer patients or their families, improving timely communications, direct recommendations, and accurate information and resources by medical team members, promoting intra-familial discussion around sperm banking, and allowing parents to make appropriate fertility preservation recommendations is advised. Implementing such measures will not only facilitate the familial decision-making process at the time of diagnosis but will also promote decisional satisfaction regardless of the families' final decision or banking outcome.

Acknowledgements:

This work was supported by the National Institute of Child Health and Human Development (HD-06126, Klosky - PI), and National Cancer Institute (CA-21765, Roberts – PI), with support provided to St. Jude Children's Research Hospital by the American Lebanese Syrian Associated Charities (ALSAC).

Abbreviations Table

ART	Assisted reproductive technologies
AYA	Adolescent and young adult
CI	Confidence interval
M	Mean
Mdn	Median
OR	Odds ratio
SD	Standard deviation
US	United States

References

1. Howlader NA, Krapcho M, Miller D, et al., editors. SEER Cancer Statistics Review, 1975-2016 [Internet]. Bethesda, MD: National Cancer Institute Based on November 2018 SEER data submission, posted to the SEER web site, 4 2019 [cited 2019 Oct 16]. Available from: https://seer.cancer.gov/csr/1975_2016/.
2. Hudson MM, Ness KK, Gurney JG, et al. Clinical ascertainment of health outcomes among adults treated for childhood cancer. JAMA. 2013;309(22):2371–2381. [PubMed: 23757085]

3. Chemaitilly W, Cohen LE. Diagnosis of endocrine disease: endocrine late-effects of childhood cancer and its treatments. *Eur J Endocrinol*. 2017;176(4):R183–R203. [PubMed: 28153840]
4. Green DM, Liu W, Kutteh WH, et al. Cumulative alkylating agent exposure and semen parameters in adult survivors of childhood cancer: a report from the St. Jude Lifetime Cohort Study. *Lancet Oncol*. 2014;15(11):1215–1223. [PubMed: 25239573]
5. Wasilewski-Masker K, Seidel KD, Leisenring W, et al. Male infertility in long-term survivors of pediatric cancer: a report from the Childhood Cancer Survivor Study. *J Cancer Surviv*. 2014;8(3):437–447. [PubMed: 24711092]
6. Skinner R, Mulder RL, Kremer LC, et al. Recommendations for gonadotoxicity surveillance in male childhood, adolescent, and young adult cancer survivors: a report from the International Late Effects of Childhood Cancer Guideline Harmonization Group in collaboration with the PanCareSurFup Consortium. *Lancet Oncol*. 2017;18(2):e75–e90. [PubMed: 28214419]
7. Green DM, Zhu L, Wang M, et al. Effect of cranial irradiation on sperm concentration of adult survivors of childhood acute lymphoblastic leukemia: a report from the St. Jude Lifetime Cohort study. *Hum Reprod*. 2017;32(6):1192–1201. [PubMed: 28444255]
8. Green DM, Kawashima T, Stovall M, et al. Fertility of male survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. *J Clin Oncol*. 2010;28(2):332–339. [PubMed: 19949008]
9. Leonard M, Hammelef K, Smith GD. Fertility considerations, counseling, and semen cryopreservation for males prior to the initiation of cancer therapy. *Clin J Oncol Nurs*. 2004;8(2):127–131, 145. [PubMed: 15108413]
10. Loren AW, Mangu PB, Beck LN, et al. Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. *J Clin Oncol*. 2013;31(19):2500–2510. [PubMed: 23715580]
11. Barlevy D, Wangmo T, Ash S, Elger BS, Ravitsky V. Oncofertility decision making: findings from Israeli adolescents and parents. *J Adolesc Young Adult Oncol*. 2019;8(1):74–83. [PubMed: 30153089]
12. Klosky JL, Simmons JL, Russell KM, et al. Fertility as a priority among at-risk adolescent males newly diagnosed with cancer and their parents. *Support Care Cancer*. 2015;23(2):333–341. [PubMed: 25082365]
13. Klosky JL, Randolph ME, Navid F, et al. Sperm cryopreservation practices among adolescent cancer patients at risk for infertility. *Pediatr Hematol Oncol*. 2009;26(4):252–260. [PubMed: 19437327]
14. Mack JW, Fasciano KM, Block SD. Adolescent and young adult cancer patients' experiences with treatment decision-making. *Pediatrics*. 2019;143(5).
15. Robertson EG, Mitchell R, Wakefield CE, et al. Enrolment in paediatric oncology early-phase clinical trials: the health-care professionals' perspective. *J Paediatr Child Health*. 2019;55(5):561–566. [PubMed: 30288839]
16. Klosky JL, Wang F, Russell KM, et al. Prevalence and predictors of sperm banking in adolescents newly diagnosed with cancer: examination of adolescent, parent, and provider factors influencing fertility preservation outcomes. *J Clin Oncol*. 2017;35(34):3830–3836. [PubMed: 28976795]
17. Klosky JL, Flynn JS, Lehmann V, et al. Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer. *Fertil Steril*. 2017;108(6):1043–1049. [PubMed: 29202957]
18. Klosky JL, Lehmann V, Flynn JS, et al. Patient factors associated with sperm cryopreservation among at-risk adolescents newly diagnosed with cancer. *Cancer*. 2018;124(17):3567–3575. [PubMed: 29975417]
19. Achille MA, Rosberger Z, Robitaille R, et al. Facilitators and obstacles to sperm banking in young men receiving gonadotoxic chemotherapy for cancer: the perspective of survivors and health care professionals. *Hum Reprod*. 2006;21(12):3206–3216. [PubMed: 16887922]
20. Ginsberg JP, Ogle SK, Tuchman LK, et al. Sperm banking for adolescent and young adult cancer patients: sperm quality, patient, and parent perspectives. *Pediatr Blood Cancer*. 2008;50(3):594–598. [PubMed: 17514733]

21. Agarwal A, Ong C, Durairajanayagam D. Contemporary and future insights into fertility preservation in male cancer patients. *Transl Androl Urol*. 2014;3(1):27–40. [PubMed: 26816750]
22. Epstein NB, Baldwin NB, Bishop DS . The McMaster Family Assessment Device. *J Marital Fam Ther*. 1983;9(2):171–180.
23. Bishop DS, Epstein NB, Keitner GI, Miller IW, Baldwin LM, Minden SL. McMaster Family Assessment Device and its use in rehabilitation, psychiatric and normal-populations. *Arch Phys Med Rehabil*. 1983;64(10):504–504.
24. Janz NK, Becker MH. The Health Belief Model: A decade later. *Health Educ Q*. 1984;11(1):1–47. [PubMed: 6392204]
25. Booth RE, Zhang Y, Kwiatkowski CF. The challenge of changing drug and sex risk behaviors of runaway and homeless adolescents. *Child Abuse Negl*. 1999;23(12):1295–1306. [PubMed: 10626612]
26. Lollis CM, Johnson EH, Antoni MH. The efficacy of the health belief model for predicting condom usage and risky sexual practices in university students. *AIDS Educ Prev*. 1997;9(6):551–563. [PubMed: 9451482]
27. Schover LR, Brey K, Lichtin A, Lipshultz LI, Jeha S. Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors. *J Clin Oncol*. 2002;20(7):1880–1889. [PubMed: 11919248]
28. Watt LD. Pregnancy prevention in primary care for adolescent males. *J Pediatr Health Care*. 2001;15(5):223–228. [PubMed: 11562639]
29. Derogatis LR, & Unger R. Symptom checklist-90-revised In: Weiner IB, Craighead WE, editors. *Corsini encyclopedia of psychology*, 4th edition. Hoboken, NJ: Wiley; 2010.
30. Chapple A, Salinas M, Ziebland S, McPherson A, MacFarlane A. Fertility issues: the perceptions and experiences of young men recently diagnosed and treated for cancer. *J Adolesc Health*. 2007;40(1):69–75. [PubMed: 17185208]
31. Quinn GP, Murphy D, Knapp C, et al. Who decides? Decision making and fertility preservation in teens with cancer: a review of the literature. *J Adolesc Health*. 2011;49(4):337–346. [PubMed: 21939862]
32. Stein DM, Victorson DE, Choy JT, et al. Fertility preservation preferences and perspectives among adult male survivors of pediatric cancer and their parents. *J Adolesc Young Adult Oncol*. 2014;3(2):75–82. [PubMed: 24940531]
33. Ellis SJ, Wakefield CE, McLoone JK, Robertson EG, Cohn RJ. Fertility concerns among child and adolescent cancer survivors and their parents: a qualitative analysis. *J Psychosoc Oncol*. 2016;34(5):347–362. [PubMed: 27269305]
34. Li N, Jayasinghe Y, Kemertzis MA, Moore P, Peate M. Fertility preservation in pediatric and adolescent oncology patients: the decision-making process of parents. *J Adolesc Young Adult Oncol*. 2017;6(2):213–222. [PubMed: 27906588]
35. Crawshaw MA, Glaser AW, Hale JP, Sloper P. Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years. *Eur J Cancer Care (Engl)*. 2009;18(4):381–390. [PubMed: 19594609]
36. Panagiotopoulou N, van Delft FW, Hale JP, Stewart JA. Fertility preservation care for children and adolescents with cancer: an inquiry to quantify professionals' barriers. *J Adolesc Young Adult Oncol*. 2017;6(3):422–428. [PubMed: 28186840]
37. Fallat ME, Hutter J, American Academy of Pediatrics (AAP) Committee on Bioethics, AAP Section on Hematology/Oncology, AAP Section on Surgery. Preservation of fertility in pediatric and adolescent patients with cancer. *Pediatrics*. 2008;121(5):e1461–1469. [PubMed: 18450888]
38. Lehmann V, Flynn JS, Foster RH, Russell KM, Klosky JL. Accurate understanding of infertility risk among families of adolescent males newly diagnosed with cancer. *Psychooncology*. 2018;27(4):1193–1199. [PubMed: 29351367]
39. Omesi L, Narayan A, Reinecke J, Schear R, Levine J. Financial assistance for fertility preservation among adolescent and young adult cancer patients: a utilization review of the Sharing Hope/ LIVESTRONG Fertility Financial Assistance Program. *J Adolesc Young Adult Oncol*. 2019.

40. Nahata L, Morgan TL, Ferrante AC, et al. Congruence of reproductive goals and fertility-related attitudes of adolescent and young adult males and their parents after cancer treatment. *J Adolesc Young Adult Oncol*. 2019;8(3):335–341. [PubMed: 30817225]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

TABLE 1

Medical and sociodemographic factors among parents of at-risk adolescents and young adults newly diagnosed with cancer; and separated by parent sperm banking recommendation^a

	All parents N=138 n (%)	Recommended sperm banking		
		No n=56 n (%)	Yes n=82 n (%)	p
Sex				0.61
Female	97 (70.3)	38 (39.2)	59 (60.8)	
Male	41 (29.7)	18 (43.9)	23 (56.1)	
Race				0.57
White	99 (71.7)	39 (39.4)	60 (60.6)	
Other	38 (27.5)	17 (44.7)	21 (55.3)	
Annual Household income				< 0.01
< \$60 000	66 (47.8)	34 (51.5)	32 (48.5)	
\$60 000	57 (41.3)	13 (22.8)	44 (77.2)	
Education				0.10
Less than Bachelor's	77 (55.8)	35 (45.5)	42 (54.5)	
Bachelor's or higher	57 (41.3)	18 (31.6)	39 (68.4)	
Religion				0.10
Christian	128 (92.8)	54 (42.2)	74 (57.8)	
Other	8 (5.8)	1 (12.5)	7 (87.5)	
Marital status				0.31
Married	100 (72.5)	43 (43.0)	57 (57.0)	
Not married	36 (26.1)	12 (33.3)	24 (66.7)	
Son's diagnosis				0.41
Leukemia or lymphoma	73 (52.9)	32 (43.8)	41 (56.2)	
Brain or solid tumor	65 (47.1)	24 (36.9)	41 (63.1)	
Son's Tanner stage				0.35
Stage 3	15 (10.9)	8 (53.3)	7 (46.7)	
Stage 4	44 (31.9)	20 (45.5)	24 (54.5)	
Stage 5	75 (54.3)	27 (36.0)	48 (64.0)	
	M(SD)	M (SD)	M (SD)	p
Parent age	44.5 (5.6)	44.0 (5.4)	44.9 (5.7)	0.31
Son's age	16.1 (2.0)	16.1 (1.9)	16.1 (2.0)	0.72

^a May not equal 100% due to missing data.

TABLE 2

Communication and psychological factors among parents of at-risk adolescents and young adults newly diagnosed with cancer; and separated by parent sperm banking recommendation^a

	All parents N=138 n (%)	Recommended sperm banking		
		No n=56 n (%)	Yes n=82 n (%)	p
Provider recommended sperm banking				< 0.001
Yes	93 (67.4)	19 (20.4)	74 (79.6)	
No	44 (31.9)	36 (81.8)	8 (18.2)	
Provider communicated infertility risk				< 0.001
Yes	116 (84.1)	37 (31.9)	79 (68.1)	
No	22 (15.9)	19 (86.4)	3 (13.6)	
Communicated infertility risk with friends/family				< 0.01
Yes	27 (19.6)	4 (14.8)	23 (85.2)	
No	107 (77.5)	51 (47.7)	56 (52.3)	
Familiar/positive attitude toward ART^b				< 0.01
Yes	88 (63.8)	27 (30.7)	61 (69.3)	
No	48 (34.8)	28 (58.3)	20 (41.7)	
	M(SD)	M (SD)	M (SD)	p
Sexual communication	21.9 (5.3)	22.0 (5.1)	21.8 (5.5)	0.79
McMaster Family Assessment				
Affect response	18.8 (3.1)	18.3 (3.1)	19.1 (3.0)	0.09
Communication	17.1 (2.1)	17.4 (2.0)	16.9 (2.1)	0.11
Problem solving	16.4 (2.0)	16.5 (2.0)	16.3 (2.0)	0.90
General functioning	39.2 (4.8)	38.4 (5.5)	39.7 (4.2)	0.44
Perceived infertility risk	1.6 (0.8)	1.4 (0.8)	1.8 (0.8)	< 0.01
Fertility Health Beliefs				
Self-efficacy	15.4 (3.9)	13.1 (4.2)	16.8 (3.0)	< 0.001
Severity	9.5 (3.5)	9.2 (3.8)	9.8 (3.3)	0.54
Vulnerability	18.3 (5.8)	15.8 (6.3)	19.9 (4.8)	0.02
Benefits	21.7 (4.1)	19.5 (4.6)	23.2 (3.1)	< 0.001
Barriers:				
Comfort, confident	21.7 (5.0)	21.3 (4.6)	21.9 (5.2)	0.55
Friend/family recommendation	15.3 (5.3)	16.0 (4.8)	14.9 (4.7)	0.17
Medical recommendation	12.1 (2.9)	12.4 (3.3)	12.0 (3.3)	0.45
Parent recommendation, concern	12.0 (3.2)	12.3 (3.0)	11.9 (3.2)	0.86
Religion, readiness	8.4 (2.5)	8.4 (2.4)	8.3 (2.5)	0.44
Fertility desire, risk	7.3 (1.1)	6.9 (1.2)	7.6 (1.0)	< 0.01
Cost, availability	5.5 (1.8)	5.6 (1.8)	5.5 (1.8)	0.71
Anxiety				
Parent	63.0 (12.2)	64.8 (11.5)	61.9 (12.6)	0.28

	All parents	Recommended sperm banking		<i>p</i>
	N=138	No n=56	Yes n=82	
	n (%)	n (%)	n (%)	
Son	56.6 (14.0)	58.2 (13.0)	55.6 (14.6)	0.41

^aMay not equal 100% due to missing data.

^bART = assisted reproductive technologies

TABLE 3

Multivariate logistic hierarchical regression on parent sperm banking recommendation among parents of at-risk adolescents and young adults newly diagnosed with cancer

	β	SE	OR	95% CI	<i>p</i>	Nagelkerke R^2
Step 1					0.01	0.08
Annual household income	1.09	0.44	2.97	1.25 – 7.03	0.01	
Step 2					< 0.001	0.63
Annual household income	1.15	0.73	3.17	0.75 – 13.33	0.12	
Provider recommended sperm banking	2.91	0.76	18.44	4.20-81.01	< 0.001	
Provider communicated infertility risk	2.03	1.17	7.61	0.76-75.83	0.08	
Communicated infertility risk with friends/family	0.52	0.85	1.68	0.32-8.84	0.54	
Familiar/positive attitude toward ART ^a	-0.24	0.76	0.78	0.18 – 3.46	0.75	
Perceived infertility risk	0.38	0.53	1.46	0.52 – 4.10	0.47	
Perceived benefits	0.20	0.09	1.22	1.02 – 1.47	0.03	
Self-efficacy	0.14	0.11	1.16	0.92 – 1.45	0.20	
Perceived vulnerability	0.01	0.07	1.01	0.87 – 1.16	0.94	
Barriers: fertility desire, risk	0.13	0.34	1.13	0.58 – 2.23	0.72	

^a ART = assisted reproductive technologies