

Parental influences on sperm banking attempts among adolescent males newly diagnosed with cancer

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Objective: To investigate the influence of parental sociodemographic, communication, and psychological factors on sperm collection attempts among at-risk adolescent males newly diagnosed with cancer.

Design: Prospective, single group, observational study design.

Setting: Pediatric oncology centers.

Patient(s): Parents (N = 144) of 122 newly diagnosed adolescent males at increased risk for infertility secondary to cancer therapy.

Intervention(s): Survey-based assessment of parent factors associated with adolescent collection attempts.

Main Outcome Measure(s): Attempt of manual collection of sperm.

Result(s): Parental recommendation to bank sperm (odds ratio [OR] 3.72; 95% confidence interval [CI] 1.18–11.76) and perceived self-efficacy to facilitate banking (OR 1.20; 95% CI 1.02–1.41) were associated with an increased likelihood of making a collection attempt.

Conclusion(s): Parental recommendation to bank is a critical influence for sperm banking among adolescent males newly diagnosed with cancer. These findings highlight the importance of effective communication between parents, patients, and health-care teams when discussing preservation options. Parent perceptions of their ability to facilitate sperm banking at the time of diagnosis should also be targeted in future interventions.

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Key Words: Adolescent cancer, collection attempt, fertility preservation, infertility, sperm banking

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Survival rates among pediatric cancer patients have increased to greater than 80% since the 1960s, representing approximately 350,000 survivors of childhood cancer in the United States (1, 2). Despite this improvement, toxicities from cancer-

directed therapy have led to a variety of negative and potentially chronic health conditions, including infertility.

Results from the Childhood Cancer Survivor Study (CCSS) indicate that 46% of males surviving childhood cancer are infertile (3) with those

exposed to alkylating agents being at particularly elevated risk (i.e., 25% azoospermia, 28% oligospermia) (4). These rates of infertility and subfertility constitute a significantly increased risk relative to males in the general U.S. population (i.e., 9.5%) (5) and are concerning given that survivors place great importance on having children later in life and report psychological distress related to perceived or confirmed fertility loss (6–12). As early as adolescence, cancer patients prioritize fertility-related issues and report “having children” among their top three life goals (13).

Sperm banking (or cryopreservation) is the leading fertility preservation option for adolescent or adult males diagnosed with cancer. However,

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fertility preservation is underutilized in the pediatric setting (14–17), and factors associated with sperm banking in this population remain unclear.

Preliminary findings among adolescent and young adult cancer patients suggest that their parents have an important role in their decision-making specific to fertility preservation, as 58% of young males consult with their parents regarding their preservation options (18). Even young adults often choose to involve their parents in fertility consultation and appreciate shared decision-making (19). Yet parental attitudes and recommendations appear to be influenced by a number of factors, such as pressure from limited time for decision-making, potential for treatment delays, feeling overwhelmed by the son's cancer diagnosis, embarrassment discussing the process of sperm banking, and disbelief that infertility will be a consequence of their son's cancer treatment (18, 20–22). Importantly, parents of adolescents typically provide consent for sperm banking, coordinate banking appointments, or pay for the associated banking costs (14). This constitutes a unique situation in which adolescents rely on their parent's support, placing these adults in influential roles for facilitating or hindering sperm banking opportunities for their children. However, specific parental factors affecting sperm banking attempts among adolescent males remain understudied despite recent calls for more research on this topic (23–27).

In sum, a minority of at-risk adolescents with cancer bank sperm despite evidence that they desire children in the future. Therefore, it is important to examine the potential facilitators and barriers to banking. Although there are numerous possible reasons to bank or not to bank, one area that remains understudied is the influence of parents on adolescent sperm banking decision-making. Thus, the goal of this study was to examine the role of parental factors in association with attempts to bank sperm among at-risk adolescent males newly diagnosed with cancer.

MATERIALS AND METHODS

Procedure

A prospective, single group, observational study design was used to include adolescents and their caregivers treated at eight leading pediatric oncology institutions in the United States and Canada (28). Eligible patients were male, newly diagnosed with cancer for the first time, 13 to 21 years of age, Tanner stage ≥ 3 , and at increased risk for treatment-related fertility loss (as determined by the patient's attending oncologist). The patients also had to be proficient in speaking and reading English, and cognitively able to complete questionnaires. The study team members screened daily patient lists of new patients diagnosed with cancer for eligibility requirements. Once initial eligibility was met, the adolescent's oncologist was contacted to confirm patient's increased risk of infertility secondary to impending cancer treatment. The patients were approached for study participation and enrolled 1 through 7 days after initiation of cancer therapy (or up to day 14 at our Canadian site). As sperm banking should ideally occur before initiation of cancer treatment (29), the timing of assessment was decided upon

to increase the validity of self-report regarding factors that influenced sperm banking outcomes, including collection attempt (30). Once patients were consented, their caregivers were invited to participate as well, and all procedures were approved by participating sites' institutional review boards. All consenting participants were given pen-and-paper questionnaires. Upon completion, participants were each provided with a \$12.50 gift card as a compensation for their time and effort.

Participants

Of the 156 enrolled adolescent males, 146 completed surveys, and an additional 144 caregivers (101 maternal, 42 paternal, 1 survey completed collaboratively by both parents) returned surveys as well. It should be noted caregivers of younger adolescents (mean age 16.2 years \pm 1.9 standard deviation [SD]) were more likely to enroll than caregivers of older adolescents (mean age 18.0 \pm 2.1 SD; $t = 4.2$, $P < .001$). Almost all caregivers were parents ($n = 142$), and two were aunts, thus referred to as "parents." The parents were on average 44.5 years of age (± 5.6 SD), 70.1% female ($n = 101$), primarily white ($n = 100$, 69.4%), Christian ($n = 133$, 92.4%), and married or living as married ($n = 103$, 71.5%). Based on sensitivity analyses and given that 70.1% of surveys were maternal reports, in cases where adolescents had two caregiver reports ($n = 22$) the maternal values were used for categorical variables; an aggregate of maternal and paternal score was used for continuous variables. Analyses were also conducted for mothers and fathers separately. This approach yielded 122 paired parent-adolescent reports for the primary study analyses (see Table 1 for demographics). The 122 corresponding adolescents were diagnosed with leukemia/lymphoma ($n = 65$, 53.3%), solid tumor ($n = 48$, 39.3%), or brain tumor ($n = 9$, 7.4%).

Measures

Primary outcome. The primary study outcome was a sperm collection attempt (yes/no) in the context of fertility preservation, and reports were obtained from the parent and/or adolescent questionnaires. An affirmative collection attempt was counted if a parent (and/or adolescent) answered the question of whether their son (or they) had banked sperm with "Yes," "No, he (or I) provided a sample but there was no sperm in it to bank," or "No, he (or I) tried to but wasn't able to provide a sample." As there was 100% agreement between adolescent and parent reports, the validity of the primary attempt outcome is considered robust.

Parental sociodemographic factors. Parents responded to a series of standard sociodemographic questions (i.e., age, race/ethnicity, education, job status, household income, resident status, religion, and marital status) for our investigating of the potential influence of these factors on banking attempt.

Parental fertility-related communication factors. Parents were asked a series of binary questions (yes/no) about whether someone from their son's medical team had talked with them or their son regarding his fertility risk as well as whether they and/or other family members/friends had talked with their son regarding his risk. Parents were also asked to rate their

TABLE 1

Parent sociodemographic variables by son's sperm banking attempt.

Variable	All parents (N = 122) ^a	Adolescent banking	
		No attempt n (%)	Attempt n (%)
Race/ethnicity			
White	83 (68.0)	37 (44.6)	46 (55.4)
Non-white	36 (29.5)	16 (44.4)	20 (55.5)
Religion			
Christian	111 (90.9)	50 (45.0)	61 (55.0)
Non-Christian	8 (6.6)	2 (25.0)	6 (75.0)
Education			
Less than HS diploma	12 (9.8)	7 (58.3)	5 (41.7)
HS diploma or GED	23 (18.9)	15 (65.2)	8 (34.8)
Post-HS training/no bachelor's degree	32 (26.2)	12 (37.5)	20 (62.5)
Bachelor's degree	35 (28.7)	15 (42.9)	20 (57.1)
Post-graduate education	17 (13.9)	4 (23.5)	13 (76.5)
Job status			
Full-time	57 (46.7)	20 (35.1)	37 (64.9)
Part-time or unemployed	61 (50.0)	31 (50.8)	30 (41.2)
Annual household income, \$			
≤19,000	12 (9.8)	7 (58.3)	5 (41.7)
20,000–39,999	25 (20.5)	15 (60.0)	10 (40.0)
40,000–59,999	21 (17.2)	10 (47.6)	11 (52.4)
60,000–79,999	9 (7.4)	4 (44.4)	5 (55.6)
80,000–99,999	14 (11.5)	2 (14.3)	12 (85.7)
≥\$100,000	25 (20.5)	6 (24.0)	19 (76.0)
Marital status			
Single, never married	7 (5.7)	4 (57.1)	3 (42.9)
Married, or living as married	85 (69.7)	34 (40.0)	51 (60.0)
Divorced, separated, or widowed	28 (23.0)	15 (53.6)	13 (46.4)
Son's age, mean (±SD)	16.2 (1.9)	15.8 (1.9)	16.4 (1.8)
Parent age, mean (±SD)	44.2 (5.8)	42.3 (5.3)	45.8 (5.7)

Note: Data presented as n (%), unless stated otherwise. GED = general equivalency diploma; HS = high school; SD = standard deviation.

^a Totals may not equal 100% due to missing data.

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son's perceived fertility risk as assigned from 0 to 3 (i.e., none, low, moderate, or high) as estimated by 1) the medical team, 2) the involved family members/friends, and 3) their son. Parents were also asked a series of binary questions (yes/no) about whether someone from their son's medical team had recommended sperm banking to their son as well as whether they and/or other family members/friends had made a patient recommendation to bank.

Parental health beliefs. Fertility and banking-related health beliefs (i.e., perceived vulnerability, severity, barriers, benefits, self-efficacy, and cues to action) were measured via sets of Likert-type items which were adapted from previous research specific to the Health Belief Model (31–35). Perceived vulnerability was assessed using a five-item scale, which included content such as "Compared to other males your son's age who have never been treated for cancer, what is your son's risk of developing fertility problems in the future?" with responses ranging from 1 (much lower) to 5 (much higher). Perceived severity was also measured using a five-item scale that instructed the adolescents to rate how

much they agreed/disagreed with statements such as "I would be disappointed if my son could not produce biological children" (1 = strongly disagree to 5 = strongly agree).

To measure perceived barriers, parents rated the importance of 28 potential barriers, such as "oncologist recommendation" and "your family's religious beliefs," from 1 (very unimportant) to 4 (very important). To measure perceived benefits, parents completed six items on a 1 (strongly disagree) to 5 (strongly agree) scale in response to statements such as "A woman can get pregnant from banked sperm." Self-efficacy was measured via four items regarding perceptions of their and their son's ability to complete aspects of sperm banking, with response options ranging from 1 (definitely no) to 5 (definitely yes). Finally, cues to action were measured by asking parents to endorse sources of fertility-related information, choosing from 7 medical, 12 family/friends, and 6 media sources. The number of sources endorsed were summed for a total score.

In addition to health beliefs, anxiety during the previous 7 days (i.e., during the interval in which their son's diagnosis and sperm banking decision-making were presumably made) was measured using the anxiety subscale of the Symptom Checklist 90-R (36). Parents also completed the communication, problem solving, affective responsiveness, and general functioning subscales from the McMaster Family Assessment Device (37).

Statistical Approach

To build a logistic regression model with the most appropriate parental variables selected as covariates, a three-step statistical strategy was employed incorporating multiple imputation for managing missing data, elastic net for selection of important covariates, and finally building the multivariable logistic regression model. After eliminating variables that had ≥ 20% missing data, a Markov Chain Monte Carlo method was employed to impute other missing values, working from an assumption of arbitrary missing pattern and the multivariate normal distribution of factors (38, 39). The elastic net method was used in each of the 20 imputed data sets to select final factors. Covariates selected by Bayesian information criteria 19 times or more (≥ 95% chance) were retained and tested in the final model (40, 41). Finally, the multivariate logistic models were fitted using these selected covariates from the 20 imputed data sets. These results were combined, and aggregated statistical inferences were generated. The final results are presented in odds ratios (OR) and 95% confidence intervals (CIs).

RESULTS

More than half of adolescents attempted to bank sperm (n = 68, 55.7%) by the time of survey administration, and 57 (83.8%) of those attempts were successful (see sample descriptives of all parents combined and grouped by son's banking attempt outcome in Tables 1 and 2).

Following the statistical approach outlined above, the final logistic model included the following four variables (which were statistically significantly related to banking attempt at the univariate level): parent communication of

TABLE 2

Variable	All parents (N = 122) ^a	Adolescent sperm banking	
		No attempt	Attempt
Communication, n (%)			
Fertility risk communication			
Parent to son			
No	21 (17.2)	20 (95.2)	1 (4.8)
Yes	96 (78.7)	30 (31.2)	66 (68.8)
Medical team to parent or son			
No	20 (16.4)	18 (90.0)	2 (10.0)
Yes	101 (82.8)	35 (34.7)	66 (65.3)
Other family/ friends to son			
No	92 (75.4)	48 (52.2)	44 (47.8)
Yes	26 (21.3)	4 (16.4)	22 (84.6)
Sperm banking recommendation			
Parent			
No	46 (37.7)	36 (78.3)	10 (21.7)
Yes	71 (58.2)	14 (19.7)	57 (80.3)
Medical team			
No	36 (29.5)	28 (77.8)	8 (22.2)
Yes	82 (67.2)	22 (26.8)	60 (73.2)
Other family/ friends			
No	89 (73.0)	46 (51.7)	43 (48.3)
Yes	22 (18.0)	2 (9.0)	20 (91.0)
Perceived son's fertility risk			
None	10 (8.2)	6 (60.0)	4 (40.0)
Low	38 (31.1)	17 (44.7)	21 (55.3)
Moderate	52 (42.6)	21 (40.4)	31 (59.6)
High	12 (9.8)	2 (16.7)	10 (83.3)
Psychological, mean (\pm SD)			
Health beliefs			
Vulnerability	18.1 (5.6)	16.1 (5.5)	19.5 (5.2)
Severity	9.6 (3.5)	9.5 (3.4)	9.7 (3.6)
Benefits	21.8 (3.9)	19.8 (4.2)	23.2 (2.9)
Barriers	82.0 (16.1)	82.29 (15.5)	81.9 (16.7)
Self-efficacy	15.6 (3.8)	13.5 (3.7)	17.0 (3.1)
Cues to action	3.1 (2.3)	2.5 (2.0)	3.7 (2.4)
McMaster Family Assessment Device			
Communication	17.1 (2.0)	17.6 (2.2)	16.7 (1.8)
Problem solving	16.3 (2.0)	16.7 (2.0)	16.0 (1.9)
Affective responsiveness	18.7 (3.1)	18.6 (3.3)	18.9 (3.1)
General functioning	39.1 (4.9)	39.3 (5.7)	38.9 (4.2)
Anxiety (SCL-90-R)	62.6 (11.8)	64.9 (11.8)	60.8 (11.5)

Note: SCL-90-R = Symptom Checklist-90 Revised (36); SD = standard deviation.

^aTotals may not equal 100% due to missing data.

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infertility risk with son, parent recommendation to bank sperm, medical team recommendation to bank sperm, and parental self-efficacy to coordinate and facilitate banking and perceptions of their son's ability to physically provide a sample in the context of a new cancer diagnosis. The two emerging factors in the final collection attempt model included parent recommendation to bank (OR 3.7; 95% CI 1.2–11.8; $P=.03$) and

parental self-efficacy to coordinate/facilitate banking (OR 1.2; 95% CI 1.0–1.4; $P=.02$), both of which were statistically significantly associated with a greater likelihood of adolescent attempt to bank sperm (Table 3). Although not statistically significant, there was also a trend for parent communication of fertility risk to their sons. Specifically, those parents who reported communicating this risk were more likely to have sons who made a sperm banking attempt (OR 8.7; 95% CI 0.9–83.8; $P=.06$).

Using the same statistical approach, separate models were built using maternal and paternal data separately. In both cases, parent recommendation to bank was identified as the most robust predictor associated with adolescent sperm banking attempt. Specifically, maternal recommendation (OR 3.0; 95% CI 1.9–4.8; $P<.001$) and paternal recommendation to bank (OR 8.2; 95% CI 3.0–22.8; $P<.001$) were associated with a greater likelihood of adolescent attempts to bank sperm.

DISCUSSION

The current study enhances the limited body of literature assessing factors that influence sperm banking outcomes among at-risk adolescent males newly diagnosed with cancer, focusing on the role of parents in adolescent fertility preservation. Parent recommendation to their son to bank sperm along with parent self-efficacy to coordinate and facilitate banking at the time of diagnosis were the most salient factors associated with sperm banking attempts among adolescents.

Parents who recommended sperm banking were almost four times more likely to have sons who made a banking attempt. Parental influence in this regard may seem obvious, but it highlights a valuable target for future intervention. Parent attitudes toward banking and subsequently communicating a recommendation to bank to their son may be modified by assessing and intervening upon any reservations or barriers parents may have to communicating with their sons on such a sensitive topic. Additionally, addressing worries and educating parents about the details of sperm banking (including costs, sperm storage, future utilization of materials, etc.) as well as the potential benefits it may have for their son's future could translate to increased parent recommendations of banking to their sons as well.

Notably, mother and father recommendation to bank were separately identified as influencing adolescent sperm banking attempts, highlighting the importance of both parents in their sons' fertility preservation process. However, it should also be noted that paternal influence, at least of those who were involved in their sons' care, may have a stronger influence relative to maternal influence, as indicated by an almost three times larger likelihood to attempt sperm banking by their sons (i.e., OR 8.3 vs. 3.0).

Parent self-efficacy regarding the coordination and facilitation of sperm banking was also statistically significantly associated with adolescent collection attempt. This construct specifically relates to parents' perceptions of their ability to facilitate sperm banking, such as scheduling the consultation and collection encounters, transporting the patient to associated appointments, and managing the financial aspects of

TABLE 3

Parent-reported variable	OR	95% CI	P value
Parent communicated fertility risk			
No	1.0		
Yes	8.7	0.9–83.8	.06
Parent recommend banking			
No	1.0		
Yes	3.7	1.2–11.8	.03
Medical team recommend banking			
No	1.0		
Yes	2.0	0.6–7.0	.27
Parent self-efficacy ^a	1.2	1.0–1.4	.02

Note: CI = confidence interval; OR = odds ratio.

^a Continuous variable, with 1 OR indicating 1 unit increase.

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sample preparation, cryopreservation, and storage, as well as their perception of whether their son would be able to produce a sample as a newly diagnosed cancer patient. Accordingly, the parents who believed the practicalities of the banking process can be completed in this difficult context had sons that were more likely to attempt to bank sperm. This finding again offers opportunities for health-care providers to assist in educating parents about this unique process so that parents feel more prepared and engaged in providing banking opportunities for their son, as appropriate. However, previous research also indicated that although parents' ability to facilitate banking is crucial, the physical presence of a parent at the sperm banking facility can be undesirable (42) and can potentially inhibit adolescent males in their provision of a sperm sample (43). These data were not assessed in this study but should be considered when providers prepare and educate families for the banking visit.

Although this is the largest study on the behavioral features of sperm banking among parents of adolescent males newly diagnosed with cancer, some limitations should be taken into account. Sperm banking attempt, the primary outcome, was based on self-report as opposed to being abstracted from the medical record. However, the 100% agreement on the attempt outcome between parents and adolescents mitigates this concern. Furthermore, administration of the study surveys before the initiation of cancer therapy would have been most advantageous with regard to examining the factors truly predictive of making a banking attempt. Unfortunately, this methodology was not feasible given the short time interval between diagnosis and treatment for many represented cancers, including leukemia. Additionally, mothers were overrepresented relative to fathers in this study; however, this sampling is representative of who was present with the patient at the hospital. Previous research has suggested that mothers more frequently influence fertility preservation decision-making among their sons relative to fathers (19). Yet the magnitude to which either parent may influence this decision appears to differ when examined by mothers and fathers separately. Finally, although this study focused on parental factors

influencing adolescent sperm banking, it should be noted that a variety of other factors influence fertility preservation, including patient, provider, hospital system, medical, and developmental variables that also contribute to this decision-making process (28). Nevertheless, considering and showcasing parental factors is important, as parents play a crucial role in communicating with and facilitating sperm banking attempts for their adolescent and young adult sons, regardless of age, and could be an important target for interventions designed to increase collection attempts.

CONCLUSIONS

Various practice guidelines recommend fertility preservation among adolescent patients diagnosed with cancer (23, 26, 44, 45), but sperm banking remains underutilized in the pediatric setting. This study has demonstrated that parents play an important role in sperm banking attempts among adolescent males, and they constitute a valuable target for intervention. All adolescents who are treated for pediatric cancer are not at risk for infertility, but within our sample of at-risk patients, approximately half engaged in a collection attempt, and the majority of those patients successfully banked samples. Therefore, the providers' timely communication of fertility risk, family counseling, and recommendations for preservation options are important, irrespective of the estimated risk or prognosis. By participating in such discussions, providers will empower parents and adolescents during the fertility preservation decision-making process while promoting engagement within the family to steer this aspect of care.

Communication of fertility risk and/or fertility preservation options (as appropriate) should be a fundamental feature of comprehensive childhood cancer care. Youths depend on their parents for support when making decisions regarding fertility preservation, and parents rely on their health-care team to provide accurate information regarding treatment-related infertility risk in addition to options for fertility preservation.

To offer the most appropriate care for these patients and families, a multidisciplinary team approach is ideal. In addition to medical providers (e.g., reproductive endocrinologists, urologists, oncologists, and nurse practitioners), it is important that mental health professionals (e.g., psychologists, social workers, and psychiatrists) trained in working with adolescents and families on fertility preservation are part of the treatment team and allowed to provide specialty care in this sensitive context. For example, a psychologist may take the lead in assessing sperm banking candidacy (such as assessing a patient's psychosexual development, history of masturbation, desire for future children, facilitation of fertility preservation decision making near the time of diagnosis, or provision of developmentally appropriate psycho-education specific to the procedural demands/process of sperm banking), whereas a social worker, for example, may contribute by identifying funds or other resources for families to assist with the financial costs associated with cryopreservation.

Specific to parents (and the findings from this study), mental health professionals can also provide interventions for promoting parental self-efficacy/confidence in managing sperm banking discussions and the logistical demands of the banking process. Psychosocially trained professionals can also offer strategies to parents for articulating sperm banking recommendations to their sons as appropriate. Using this approach to approach families, the patients will receive the necessary comprehensive care that is needed when making timely sperm banking decisions, and the parents can maintain an active/influential role in supporting their child during this difficult and important process.

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