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 ($\pm$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