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Fertility Preservation Practices at Pediatric Oncology Institutions in the United States: A Report From the Children's Oncology Group

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QUESTION ASKED: How do pediatric oncologists approach fertility conversations with patients newly diagnosed with cancer and their families at Children's Oncology Group (COG) institutions?

SUMMARY ANSWER: Few programs reported discussing fertility risk and preservation strategies with all new patients, and many lacked specific criteria for offering fertility preservation (FP) procedures. Additionally, many programs offered patients FP services not currently supported by national guidelines.

WHAT WE DID: A multidisciplinary group of experts in FP, including pediatric oncologists, endocrinologists, advanced practitioners, psychologists, and nurses, developed a survey that consisted of questions pertaining to institutional characteristics, presence and composition of designated FP person/team, FP services available to patients, practices concerning fertility risk assessment, counseling, and referral for preservation interventions, and barriers to FP. The survey was distributed to 220 COG member institutions between Mav-December 2018.

WHAT WE FOUND: Of the 144 (65.5%) programs that returned surveys, only 45.1% reported routine fertility discussions with all female patients and 38.5% with all male patients. Ninety-two (63.8%) reported no specific criteria for offering females FP, compared with 27.7% for males (P < .001). Program characteristics

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Natasha N. Frederick, MD, MPH, Center for Cancer and Blood Disorders, CT Children's Medical Center, 282 Washington St, Hartford, CT 06106; e-mail: nfrederick@connecticutchildrens.org associated with fertility discussions included on-site presence of reproductive endocrinology and infertility on site, mandated documentation of fertility discussions, and supportive infrastructure. Utilization of practices unsupported by guidelines included offering sperm banking after treatment initiation (28.9%), gonadotropin-releasing hormone analogs for FP (52.1%), ovarian tissue cryopreservation at diagnosis for patients with leukemia (29.7%), and testicular tissue cryopreservation (16.7%) not part of a clinical trial.

BIAS, CONFOUNDING FACTORS: The survey only represents two thirds of COG institutions and therefore may not be fully generalizable. Also, surveys were completed by one individual designated as either the site COG primary investigator or the one most familiar with FP at each institution, which could lead to inaccurate estimation of FP practices by other clinicians.

REAL-LIFE IMPLICATIONS: Despite national guidelines, these results suggest that many pediatric oncology patients may not receive appropriate fertility risk assessments and discussions of FP opportunities before initiation of treatment. Areas of focus for improving care include mandating documentation of discussions and widely disseminating the most current risk stratification models and intervention guidelines to maximize the provision of standardized care.



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CONTENT

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Fertility Preservation Practices at Pediatric Oncology Institutions in the United States: A Report From the Children's Oncology Group

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PURPOSE Fertility discussions are an integral part of comprehensive care for pediatric, adolescent, and young adult patients newly diagnosed with cancer and are supported by national guidelines. Current institutional practices are poorly understood.

METHODS A cross-sectional survey was distributed to 220 Children's Oncology Group member institutions regarding fertility discussion practices. Descriptive statistics were calculated for all variables. The association between specific practices and selected outcomes on the basis of sex was examined via multivariable logistic regression.

RESULTS One hundred forty-four programs (65.5%) returned surveys. Of these, 65 (45.1%) reported routine discussions of fertility with all female patients and 55 (38.5%) all male patients (P = .25). Ninety-two (63.8%) reported no specific criteria for offering females fertility preservation (FP), compared with 40 (27.7%) for males (P < .001). Program characteristics associated with fertility discussions included reproductive endocrinology and infertility on site (females odds ratio [OR], 2.1; 95% CI, 1.0 to 4.3), discussion documentation mandate (females OR, 2.3; 95% CI, 1.0 to 5.5; males OR, 3.5; 95% CI, 1.4 to 8.7), and cumulative institution-based FP infrastructure (which included [1] routine practice of documentation, [2] template for documentation, [3] mandate for documentation, and [4] availability of FP navigation; females OR, 1.6; 95% CI, 1.1 to 2.3; males OR, 2.3; 95% CI, 1.6 to 3.4). Utilization of practices unsupported by guidelines included offering sperm banking after treatment initiation (39/135 programs; 28.9%), gonadotropin-releasing hormone analogs for ovarian suppression/FP (75/144 programs; 52.1%), ovarian tissue cryopreservation at diagnosis for patients with leukemia (19/64 programs; 29.7%), and testicular tissue cryopreservation (23/138 programs; 16.7%) not part of a clinical trial.

CONCLUSION Despite recommended guidelines, fertility discussions with patients/families before treatment initiation are not routine at Children's Oncology Group institutions. Standard criteria to determine which options should be offered to patients are more common for males than females.

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INTRODUCTION

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Accepted on January 6, 2023 and published at ascopubs.org/journal/ op on February 10, 2023: D0I https://doi. org/10.1200/0P.22. 00349 Guidelines from the American Society of Clinical Oncology, National Comprehensive Cancer Network, American Academy of Pediatrics, and American Society of Reproductive Medicine (ASRM) recommend that all children, and adolescent and young adults (AYAs) newly diagnosed with cancer receive information about treatment-related risks to fertility and fertility preservation (FP) options, and to be referred, if interested, to reproductive specialists before the initiation of therapy.¹⁻⁴ For patients treated at Children's Oncology Group (COG) institutions, standard-of-care (SOC) interventions include sperm banking (SB)

before treatment initiation for postpubertal male patients and oocyte and embryo cryopreservation for postpubertal females. In December 2019, after completion of this survey, ASRM deemed ovarian tissue cryopreservation (OTC) a nonexperimental FP intervention for prepubertal and postpubertal females at high risk of infertility from cancer treatment.^{5,6} For prepubertal males, the only option to preserve reproductive germ cells is testicular tissue cryopreservation (TTC), which is experimental.⁷

Unfortunately, studies demonstrate that many young patients and their families are not provided with adequate information about the risk their treatment may

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pose to their future fertility or options for FP if risk exists.^{8,9} AYAs view conversations about fertility risk and preservation strategies as a priority before initiating treatment.¹⁰⁻¹² Appropriate fertility counseling for patients and families has been shown to positively affect quality of life (QOL) at diagnosis and after cancer treatment.¹³

As survival for children and AYAs with cancer continues to improve, clinical and research efforts must focus on mitigating late effects and improving QOL after treatment, including optimizing patients' ability to have future biological children.¹⁴ This necessitates fertility discussions with all patients and families in a time-sensitive manner at diagnosis, providing medically accurate information regarding risk and preservation strategies. The primary objective of this study was to describe current clinical practices regarding fertility risk assessment, patient counseling, and referral for FP across COG institutions.

METHODS

Fertility Survey

A cross-sectional survey distributed to COG member institutions collected data between May and December 2018 (Data Supplement, online only). A multidisciplinary group of experts in FP, including pediatric oncologists, endocrinologists, advanced practitioners, psychologists, and nurses, developed a survey in the absence of a validated instrument. The full survey consisted of 77 questions pertaining to institutional characteristics, presence and composition of designated FP person/team, FP services available to patients, practices concerning fertility risk assessment, counseling, and referral for preservation interventions, and barriers to FP (survey available as a Supplement). Four demographic and 30 practice-related questions form the basis of this report. Practice-related questions focused on which patients (all, post-pubertal, and/or at risk) routinely receive communications regarding treatment-related fertility risks and criteria for offering FP. FP interventions presented included SB, TTC, oocyte/ embryo cryopreservation, and OTC. TTC and OTC were classified as experimental procedures at the time of the survey. Use of gonadotropin-releasing hormone analogs (GnRHa) for FP, a nonstandard FP intervention, was also queried. Surveys were administered electronically through Research Electronic Data Capture (REDCap). Surveys were sent to the COG principal investigator (PI), or an individual identified by the PI as knowledgeable about FP at each of the 220 COG institutions. The study was approved by the institutional review board at the Fred Hutchinson Cancer Center. All respondents provided informed consent.

Data Analyses

Returned surveys were reviewed for completeness and confirmation that only one set of answers was received from each COG institution. Detailed institutional characteristics were not available for nonresponders, precluding direct comparison. As a surrogate, we examined the number of COG registrations and enrollments to therapeutic and nontherapeutic trials between responding and non-responding sites.

Standard descriptive statistics were calculated for all variables. The association (OR with 95% CI) between program characteristics and selected outcomes (discussion with all patients, discussion with postpubertal patients, and discussions with patients considered at risk for infertility) was examined for males and females separately using logistic regression. Factors found to have associations with P < .1were then included in adjusted models. To assess the cumulative impact of division-based infrastructure (specifically, [1] having a routine practice of documentation, [2] a template for documentation, [3] a mandate for documentation, and [4] availability of FP navigation), each factor was assigned a value of 1, and a separate logistic regression model evaluated the impact of 0 to \geq 3 factors. P values were two-sided, with values < .05 considered statistically significant. All analyses were conducted using Stata (version 16, College Station, TX).

RESULTS

One hundred forty-four institutions completed the survey for an overall response rate of 65.5%. Of the respondents, 89 (61.8%) self-identified as part of academic medical centers and 53 (36.8%) reported a dedicated FP team or individual. Based upon number of new cancer diagnoses per year, 56 (38.9%) identified as small (< 60 new patients/year), 50 (34.7%) as medium (61-120 new patients/year), and 39 (26.4%) as large (> 120 new patients/year) programs.¹⁵ Responding sites had higher COG registrations and enrollments to therapeutic and nontherapeutic clinical trials compared with nonresponders (P < .001).

Practices for Female Patients

Fertility-risk discussions. Discussions of treatment-related risk for infertility were reported to occur routinely before initiating cancer-directed therapy among all female oncology patients, all postpubertal patients, and all patients considered to be at risk for infertility at 65/144 (45.1%), 94/144 (65.3%), and 113/144 (78.5%) programs, respectively (Table 1). In adjusted models, discussions of FP with all patients were associated with the presence of reproductive endocrinology and infertility (REI) within the institution (OR, 2.1; 95% CI, 1.0 to 4.3), routine documentation of FP discussions in the medical record (OR, 2.3; 95% CI, 1.0 to 5.5), and an institutional mandate to document FP conversations (OR 2.3; 95% CI, 1.0 to 5.5), although estimates were imprecise (Table 2). As the cumulative number of division-based FP infrastructure components increased from 0 to 4, the association with universal discussion increased (OR, 1.6; 95% CI, 1.1 to 2.3). Discussions were not associated with type of program, program size, or the presence of an FP navigator/team alone.

TABLE 1. Fertility-Focused Conversation Practices With New Pediatric,Adolescent, and Young Adult Oncology Patients at Children's Oncology Group Sites(N = 144)

Fertility Conversation Practice	Females, No. (%)	Males, No. (%)	Р
Fertility routinely discussed with patients before the start of cancer-directed treatment ^a	N = 144	N = 143	.250
All patients	65 (45.1)	55 (38.5)	.060
All postpubertal patients	94 (65.3)	108 (75.5)	.100
Patients considered to be at risk for infertility	113 (78.5)	100 (69.9)	.770
No routine practice	6 (4.2)	5 (3.5)	
Embryo and/or oocyte cryopreservation (females) or SB (males) services are available	n = 135 95 (70.4)	n = 138 135 (97.8)	< .001
Criteria used when considering offering standard-of care FP methods to postpubertal patients starting cancer treatment ^{b,c}	n = 95	n = 138	
Offered to all postpubertal patients	21 (22.1)	88 (63.8)	< .001
Specific criteria guides who is offered FP	12 (12.6)	9 (6.5)	.110
No specific criteria guides who is offered FP	59 (62.1)	37 (26.8)	< .0010
Question not answered	3 (3.2%)	4 (2.9)	
Decision making about who is offered standard-of-care FP when there are no specific criteria ^{a,c}	n = 58	n = 37	
Individual basis by the medical staff	41 (70.7)	33 (89.2)	.040
Individual basis based on patient characteristics	28 (48.3)	18 (48.6)	1.00
Assessment by FP team	24 (41.4)	3 (8.1)	< .0001

Abbreviations: FP, fertility preservation; OTC, ovarian tissue cryopreservation; SB, sperm banking; TTC, testicular tissue cryopreservation.

^aParticipants could choose more than one response for each question in the table.

^bAt the time of the survey, standard-of-care FP opportunities included oocyte and/or embryo cryopreservation for female patients and SB for male patients; respondents to this question were limited to those sites that reported providing embryo/oocyte cryopreservation (n = 95 of 144) and SB (n = 138 of 144); total values are smaller if a site skipped this follow-up question.

^cAt the time of the survey, experimental FP opportunities included OTC for female patients and TTC for male patients.

SOC FP referrals. Oocyte/embryo cryopreservation was reported as available at 95/135 (70.4%) institutions. Among these 95 sites, 21 (22.1%) offered oocyte/embryo cryopreservation to all postpubertal females, 12 (12.6%) reported specific criteria guiding which patients are offered these interventions, 59 (62.1%) reported no specific criteria, and 3 (3.2%) did not answer the question (Table 1). Where no specific criteria were identified, 41 (70.7%) reported medical staff made the decision on an individual basis, 28 (48.3%) reported decisions were made on the

basis of individual patient characteristics, and 24 (41.4%) reported decisions were made on the basis of assessment by the FP team. Institutions were allowed to select more than one option for this question. Although the survey included questions on what types and doses of treatment exposures were used to determine who was offered SOC interventions, only 12 institutions provided any information.

OTC. Still considered experimental at the time of the survey, OTC was available at 64 of 134 (47.8%) responding institutions, either under an IRB protocol (18/64; 28.1%), as a clinical service (12/64; 18.8%), or by referring to another institution (34/64; 53.1%). Of the 44 programs that answered how eligibility for OTC was identified in a clinical setting, 26 programs (59.1%) noted this was determined by the medical team, 18 (40.9%) reported that the decision was made individually considering patient characteristics, and 15 (34.1%) reported that the decision was made after assessment by the FP team.

Practices for Male Patients

Fertility risk discussions. For male patients, routine discussions of treatment-related risk for infertility at diagnosis were reported to occur with all oncology patients (55/143 [38.5%]), all postpubertal patients (108/143 [75.5%]), and all patients considered to be at risk for infertility (100/143 [69.9%]; Table 1). Programs with a mandate to document FP discussions were more likely to report routine discussion with all male patients (OR, 3.5; 95% CI, 1.4 to 8.7; Table 2). As the cumulative number of division-based FP infrastructure components increased from 0 to 4, the association with universal discussion increased (OR, 2.3; 95% CI, 1.6 to 3.4). Discussions were not associated with program type, program size, or the presence of an FP navigator/ team.

FP options. SB was as available at 135/138 (97.8%) of institutions. One hundred thirty-four institutions provided information on selection of patients offered sperm banking. It was offered to all postpubertal males at 88/134 (65.7%) institutions, 37/134 (27.6%) reported no specific criteria guiding which patients are offered SB, and 9/134 (6.5%) reported specific criteria (Table 1). Thirty-seven programs answered a question about how decisions were made regarding which patients were offered FP. Of these, 33/37 (89.2%) reported decisions were made on an individual basis by clinicians and 18/37 (48.6%) on the basis of individual patient characteristics. Questions designed to identify what types and doses of treatment exposures were used to determine who was offered SOC interventions were only answered by nine institutions.

TTC. For the prepubertal male population, 37/138 programs (26.8%) reported TTC as available either under an IRB protocol, a non–evidence-based clinical service, or by referral to an outside institution. Of the 23 programs with TTC available as a non–evidence-based clinical service only, two programs (8.7%) reported planned exposures

TABLE 2. Program Characteristics Associated With Fertility Discussions

	All Female Patients		All Male Patients	
Program Characteristics	OR _{unadjusted} (95% CI)	$OR_{adjusted}$ (95% CI) ^a	OR _{unadjusted} (95% CI)	$OR_{adjusted}$ (95% CI) ^a
REI on site	2.0 (1.0 to 4.0)	2.1 (1.0 to 4.3)	—	—
Urology on site	_	—	1.9 (0.6 to 5.6)	—
Division-based factors supporting FP discussions				
Presence of FP navigator/team v none	1.1 (0.6 to 2.2)		1.9 (0.9 to 3.8)	1.4 (0.6 to 3.0)
FP discussion routinely documented in the medical record	2.9 (1.3 to 6.2)	2.3 (1.0 to 5.5)	3.9 (1.6 to 9.2)	2.1 (0.8 to 5.3)
Template for FP documentation	1.5 (0.6 to 3.3)		2.8 (1.2 to 6.5)	1.4 (0.5 to 3.6)
Documentation of FP discussions mandated by institution	3.0 (1.4 to 6.7)	2.3 (1.0 to 5.5)	5.3 (2.3 to 12.2)	3.5 (1.4 to 8.7)
Cumulative division-based FP infrastructure ^b	1.6 (1.1 to 2.2)	1.6 (1.1 to 2.3)	2.3 (1.6 to 3.4)	2.3 (1.6 to 3.4)

Abbreviations: FP, fertility preservation; OR, odds ratio; REI, reproductive endocrinology and infertility.

^aAdjusted models included concurrent adjustment of all factors shown, except cumulative division-based FP infrastructure was modeled separately without concurrently adjusting for its component factors; factors without an adjusted OR were those whose unadjusted association's *P* value was > 0.1 and therefore not included in the multivariable models.

^bThe presence of FP navigator/team, routine documentation of FP discussions, availability of FP documentation template, and FP discussion mandate were summed for each institution (0 to \geq 3 factors), and modeled as a linear term; unadjusted and adjusted results were nearly identical.

(chemotherapy, radiation therapy, and surgery), diagnosis, and/or age as criteria to inform who was offered TTC. The decision to offer TTC was made by the treating medical team (13; 56.5%), on an individual basis secondary to patient characteristics (6; 26.1%), or on the basis of assessment by FP team (7; 30.4%).

Comparison of Practices for Females Versus Males

There were no differences in rates of FP discussions at diagnosis between males and females (Table 1). Sites were more likely to offer SOC practices to all postpubertal males compared with all females (63.8% v 22.1%; P < .001). In the absence of specific criteria, males were more likely to be offered SOC FP by medical staff on an individual basis (89.2% v 70.7%; P = .0431) and females were more likely to be offered SOC FP only after assessment by the FP team (41.4% v 8.1%; P < .001).

Non–evidence-based FP practices. Seventy-five/144 programs (52.1%) reported using GnRHa for ovarian suppression/FP; while 63 (44%) of these also reported use for menstrual suppression and/or contraception, the remaining 12 (8.3%) used it for ovarian suppression/FP alone (Fig 1). Of the institutions with SB available, 39/135 (28.9%) reported offering SB after start of treatment. Of 64 programs with OTC available, 19 (29.7%) offered it to female patients with leukemia at diagnosis. Twenty-three of 37 (62.1%) programs offering TTC did so as a non–evidence-based clinical practice and not part of a clinical trial.

DISCUSSION

Since 2006, national guidelines have recommended routine discussion of fertility risk and FP options before the start of therapy for all newly diagnosed patients with cancer.¹⁻⁴ This recommendation is driven by data showing that lack of discussion at diagnosis is a source of distress affecting survivors' QOL, that survivors both underestimate and overestimate their risk for infertility, and that survivors often do not know what their risk or lack thereof is.¹⁶⁻¹⁹ Unfortunately, fewer than 50% of COG institutions surveyed report routine fertility counseling for all pediatric and AYA patients at diagnosis. Most sites have no standard criteria guiding which female patients are offered SOC FP interventions, relying instead on individual decisions driven by medical staff or patient characteristics. Two thirds of sites indicated that SB is offered to all postpubertal males with individual assessments guiding the other third. This individualized approach to FP discussions creates the potential for future patient regret, distress, and provider legal liability, as well as potentially promoting inequitable care or health disparities.²⁰⁻²³ Controversial practices including the use of GnRHa for FP, SB after initiation of chemotherapy, OTC at diagnosis for patients with leukemia, and TTC not on a clinical trial are common, despite lack of support among leading national governing societies.²⁴⁻²⁶ As the majority of patients with childhood cancer in North America are treated at a COG-affiliated institution, this study provides the most comprehensive overview of the current landscape of FP practice for this population and presents an opportunity to improve universal discussions among patients, standardize criteria for FP referrals, and optimize evidencebased practices.²⁷

Routine discussions about fertility were most common with female patients considered to be at risk for infertility (78.5% of institutions), followed by postpubertal males (75.5%), males considered to be at risk for infertility (69.9%), and all post pubertal females (65.3%). Although similar numbers of institutions cite routinely discussing fertility with male and female postpubertal patients, three times as many programs offer SOC FP interventions to postpubertal males (66%) compared with females (23%). We hypothesize this

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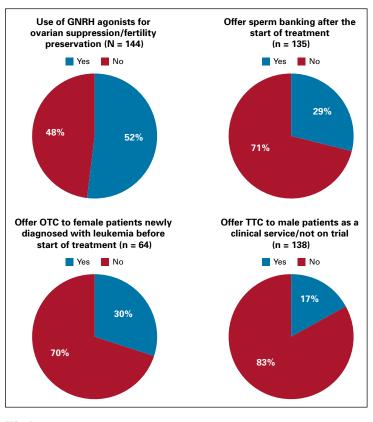


FIG 1. Use of non-evidence-based fertility preservation practices. GNRH, gonadotropin-releasing hormone; OTC, ovarian tissue cryopreservation; TTC, testicular tissue cryopreservation.

occurs because SB is almost universally available, is far less expensive and invasive, has been available far longer, and is quicker to complete compared with options available to females.^{15,28,29}

Although recommendations for offering SB may be riskindependent for postpubertal males,³⁰ risk for infertility drives recommendations to pursue FP for other patients. Survey questions designed to better understand whether specific criteria, such as exposure to chemotherapy, radiation, and/or surgery, were used to guide which patients are offered FP went unanswered by 92% of institutions. We suspect this reflects a lack of standardized criteria used to stratify who and when FP is offered. Indeed, prior research has consistently identified health care providers' lack of knowledge about fertility risk assessment as a barrier to providing FP services.^{15,31} Offering FP interventions on the basis of individual interpretations of patient risk or other patient factors instead of standardized criteria raises ethical concerns including loss of patient/parent autonomy for decision making and non-malfeasance.³²⁻³⁵ Patients and families cannot make informed decisions if not provided with clear and comprehensive information on their risk of future infertility, even if only to advise that their risk is low or negligible.⁴ To some degree, institutions cannot be faulted for lacking rigorous guidelines as clarifying who is at increased risk for fertility impairment can be challenging. A recent risk stratification system, published after this survey was undertaken, by the Oncofertility Consortium's Pediatric Initiative Network, was developed to improve consistency in risk assessment for both clinical and research purposes.³⁶ The PanCareLife Consortium and the International Late Effects of Childhood Cancer Guideline Harmonization Group established consensus recommendations on appropriate FP strategies to offer patients on the basis of individual risk status to facilitate consistency in clinical practice.^{37,38} It is unclear how well known these resources are across institutions.

Our data suggest that an institutional mandate to document FP discussions, a factor that can be modified through institutional policies, electronic medical record best practice advisories, or as opt-outs on new patient order sets, could help to improve FP discussion rates.^{39,40} Documentation has additional benefits of ensuring survivorship care planning can address the use of stored gametes, assessment of future fertility, and medicolegal protection for the institution or provider.^{20,21,41} More division-based infrastructure, with a heavy emphasis on documentation, increased the likelihood that universal discussions of fertility took place. Improvement in discussion rates may also be possible by using trainees, navigators, or telehealth interventions.^{42,45} Having an REI team located within the institution was associated in an adjusted multivariable model with having discussions with all female patients. A similar association was not seen between having urology located within the institution and having discussions with all male patients. We hypothesize that this gender discrepancy may be related to the critical role that REI plays in FP for females, whereas for males, a referral to a sperm bank can be made by any member of the oncology or FP team. Although REI availability within an institution is difficult to modify for the purposes of improving FP, institutions without REI on site might need to establish external relationships with this service. It is worth further investigation to understand what options are available to access REI services when they are not available within a given institution.

We also identified FP clinical practices that are not recommended by current guidelines. Almost 30% of institutions reported offering SB to postpubertal male patients after the initiation of chemotherapy. Because of concerns about DNA damage and increased likelihood of azoospermic samples after treatment initiation, strong recommendations exist for SB before initiating treatment.46-48 More than half of the institutions reported use of GnRHa for FP, a practice endorsed only in breast cancer, where studies have demonstrated efficacy.24,49 These findings have not been replicated in other oncologic patient populations or in young patients, highlighting an important area of future research.⁵⁰⁻⁵² Among programs with the capacity to offer OTC, almost one third noted that they offer OTC to patients with leukemia at diagnosis. Although deemed nonexperimental by ASRM in 2019, concerns remain about OTC in patients with leukemia, given that the ovaries are contaminated by leukemia at diagnosis and therefore cannot be used for reimplantation.⁴ Since all contemporary upfront acute lymphoblastic leukemia protocols contain $\leq 3 \text{ g/m}^2$ of alkylating agents, placing pediatric and adolescent patients at low risk for impaired fertility, OTC can be performed in the setting of relapse when a negative MRD state is attained. Of the programs that offered TTC, more than 60% reported doing so outside of a clinical trial. This impedes data collection on an experimental technique not yet tested in humans, including enhancing overall understanding of potential side effects.

The data reported from this survey have limitations. The survey only represents two thirds of COG institutions and therefore may not be fully generalizable. We hypothesize that the survey data may over-represent FP practices as institutions responding may be more likely to have established programs.¹⁵ Additionally, the institutions that did not respond to the survey enrolled fewer patients to COG clinical trials compared with respondents, raising the possibility that they are smaller centers that may also be less well equipped to support FP strategies. Importantly, the status of OTC changed from experimental to nonexperimental in December 2019 after completion of data collection, limiting interpretation of responses in relationship to this procedure. Of note, surveys were completed by one individual designated as either the site PI or the one most familiar with FP at each institution, which could lead to inaccurate estimation of FP practices by other clinicians. Finally, the survey was not designed to capture the quality of the discussions that took place or the impact of these discussions on FP outcomes. Nonetheless, the survey does establish a baseline for monitoring the evolution of FP practices in the pediatric and adolescent cancer population.

In conclusion, more than 16 years have elapsed since the initial publication of guidelines aimed at integrating FP into comprehensive cancer care, yet significant numbers of pediatric and AYA oncology programs do not meet these practice recommendations and/or practice FP interventions that are not recommended or supported by data. Although improvements have certainly been made across the years, our results suggest that much work remains to make universal discussions of fertility and referral for FP interventions feasible across institutions. Areas of focus for improving care include mandating documentation of discussions and widely disseminating the most current risk stratification models and intervention guidelines to maximize the provision of standardized care.

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EQUAL CONTRIBUTION

E.J.C. and J.L. contributed equally as cosenior authors to this work.

PRIOR PRESENTATION

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Fertility Preservation Practices at Pediatric Oncology Institutions in the United States: A Report From the Children's Oncology Group

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