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Original article

Low Fertility Preservation Utilization Among Transgender Youth

Leena Nahata, M.D.^{a,b,*}, Amy C. Tishelman, Ph.D.^{c,d}, Nicole M. Caltabellotta, B.A.^b,
 and Gwendolyn P. Quinn, Ph.D.^{e,f}

^a Division of Endocrinology, Department of Pediatrics, Nationwide Children's Hospital, The Ohio State University College of Medicine, Columbus, Ohio

^b Center for Biobehavioral Health, The Research Institute at Nationwide Children's Hospital, Columbus, Ohio

^c Harvard Medical School, Boston, Massachusetts

^d Departments of Psychiatry, Urology, and Endocrinology, Boston Children's Hospital, Boston, Massachusetts

^e Health Outcomes and Behavior Program, Moffitt Cancer Center, Tampa, Florida

^f Morsani College of Medicine, University of South Florida, Tampa, Florida

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A B S T R A C T

Purpose: Research demonstrates a negative psychosocial impact of infertility among otherwise healthy adults, and distress among adolescents facing the prospect of future infertility due to various medical conditions and treatments that impair reproductive health. Guidelines state that providers should counsel transgender youth about potential infertility and fertility preservation (FP) options prior to initiation of hormone therapy. The purpose of this study was to examine the rates of fertility counseling and utilization of FP among a cohort of adolescents with gender dysphoria seen at a large gender clinic.

Methods: An Institutional Review Board–approved retrospective review of electronic medical records was conducted of all patients with ICD-9/10 codes for gender dysphoria referred to Pediatric Endocrinology for hormone therapy (puberty suppression and/or cross-sex hormones) from January 2014 to August 2016.

Results: Seventy-eight patients met inclusion criteria. Five children were prepubertal, no hormone therapy was considered, and they were therefore excluded. Of the remaining 73 patients, 72 had documented fertility counseling prior to initiation of hormone therapy and 2 subjects attempted FP; 45% of subjects mentioned a desire or plan to adopt, and 21% said they had never wanted to have children.

Conclusions: Utilization rates of FP are low among transgender adolescents. More research is needed to understand parenthood goals among transgender youth at different ages and developmental stages and to explore the impact of gender dysphoria on decision-making about FP and parenthood. Discussions about infertility risk, FP, and other family building options should be prioritized in this vulnerable adolescent population.

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IMPLICATIONS AND CONTRIBUTION

About 98.6% of transgender adolescents (n = 72) at a large pediatric academic center were counseled about infertility risk due to hormone treatment yet only two attempted fertility preservation. Parenthood goals need to be explored among transgender youth at different ages/developmental stages, to optimize care and prevent potential regret about missed opportunities.

Conflicts of Interest: The authors have no conflicts of interest to disclose.

* Address correspondence to: Leena Nahata, M.D., Nationwide Children's Hospital, 700 Children's Dr., Columbus, OH 43205.

E-mail address: leena.nahata@nationwidechildrens.org (L. Nahata).

Approximately 6.7 million women and 3.3–4.7 million men in the United States experience fertility impairment [1], which has been shown to negatively impact quality of life and psychosocial well-being [2,3]. Although the majority of research regarding fertility in pediatrics has been conducted in oncology, a significant subset of fertility problems may result from other

pediatric medical conditions and/or therapies prescribed in childhood/adolescence as well, including cross-sex hormone therapy for transgender youth. In this context, there is an emerging need for pediatric providers to initiate discussions about infertility risk and fertility preservation (FP) options with these at-risk or high-risk youth and their families [4]. Established FP methods exist for postpubertal males (sperm cryopreservation) and postmenarchal females (oocyte and embryo cryopreservation), with experimental options available for younger children (e.g., testicular and ovarian tissue cryopreservation) [5,6]. Several groups, including the American Academy of Pediatrics, American Society for Reproductive Medicine, and American Society of Clinical Oncology, have published guidelines urging providers to counsel patients about fertility risks and refer to reproductive specialists to discuss FP options prior to initiation of treatment [6–8].

Long-term follow-up studies show childhood cancer survivors express distress about potential infertility due to cancer treatment and regret about missed opportunities for FP [9–11], leading to initiatives designed to improve access to FP for newly diagnosed cancer patients [12]. As guidelines have recently been updated to expand fertility counseling beyond cancer [6,13,14], one area of particular emphasis has been on youth with gender dysphoria because these individuals often experience discrimination, limited access to medical services, and psychosocial difficulties [15,16]. Gender dysphoria is a condition in which an individual experiences distress due to discordance between the gender assigned at birth and the gender with which he or she identifies; many of these individuals identify as transgender. Mental health conditions including depression, anxiety, post-traumatic stress disorder, self-harm, and suicidal ideations/attempts are commonly seen in transgender youth [15,17]. Hormone therapy is used to help alleviate gender dysphoria and allow transgender youth to achieve physical changes consistent with their affirmed gender, with puberty blockers initiated in early puberty, and then cross-sex hormone therapy (testosterone or estrogen) in later puberty [18]. Long-standing exposure to these hormones may impact both spermatogenesis and oocyte production and may be followed by surgery to remove reproductive organs; thus, the Endocrine Society, World Professional Association for Transgender Health, and American Society for Reproductive Medicine guidelines emphasize the importance of counseling about infertility risk and offering FP prior to therapy [7,18–20].

Despite emerging literature about family planning among transgender individuals, little is known about fertility-related attitudes and parenthood goals among transgender youth or adults [21]. Two survey studies were conducted among transgender adults in Belgium, in which both transgender males and females expressed a desire for biological children and many stated that they would have considered FP had it been offered [22,23]. However, other smaller studies suggest that transgender adults and others in the sexual and gender minority community are less likely to envision biological parenthood [24,25]. Notably, there have been no studies among transgender youth with regard to attitudes toward fertility, parenthood, and FP. With puberty blockers often prescribed at the onset of puberty, as early as 8–11 years of age, and an increasing number of clinical programs offering cross-sex hormone therapy at 13–14 years of age [26], it remains unclear if and how transgender youth consider future parenthood and whether or not they choose to utilize FP technologies prior to hormone therapy. The goal of this study was to

assess FP utilization/consideration among transgender youth prior to starting hormone therapy at a large pediatric academic center.

Methods

An Institutional Review Board–approved retrospective review of electronic medical records was conducted at a single large pediatric academic center, of all patients with ICD-9/10 codes for gender dysphoria referred to Pediatric Endocrinology for hormone therapy (puberty suppression and/or cross-sex hormones), from January 2014 (when a structured gender management program was established) to August 2016. Because of the nature of the study, informed consent was waived. A standardized abstraction form was used by a trained investigator and physician to collect the following information from documentation in the patients' electronic medical records: age and Tanner stage at the Endocrinology visit where hormone therapy was discussed, gender assigned at birth, affirmed gender, initiation of hormone therapy (GnRH analogue and/or cross-sex hormone), documentation of fertility counseling including whether FP had been offered and pursued, reasons for declining FP (if available), mental health morbidities, and information about legal guardians/adoptive status. When abstracting information, the study team reviewed all clinical encounters and medication orders in each patient's chart.

Fertility counseling practices

All patients were diagnosed with gender dysphoria by a child psychiatrist and subsequently referred to one of two pediatric endocrinologists specializing in care of transgender youth. During each new patient visit, the pediatric endocrinologist and a social worker met with the patient and family to review risks/benefits of hormone therapy and provide comprehensive fertility counseling, including discussions about potential risk of infertility due to hormone therapy, a review of established FP options including sperm banking or oocyte preservation, and an estimated cost of these options (including the fact that procedures may not be covered by insurance). For pubertal transgender females, a referral to the local sperm bank was offered for collection of a semen sample via masturbation. In cases where an adolescent expressed interest in FP but discomfort with masturbation, testicular sperm extraction was also offered. Postmenarchal transgender males were offered a referral to a reproductive endocrinologist at a nearby practice to discuss oocyte preservation in more detail. All youth were informed that pursuing FP after beginning puberty blockers or cross-sex hormone therapy would require cessation of hormone therapy and may require further progression of natal puberty. At the end of the visit, a summary of information was provided in writing (treatment consent forms to be signed by patients and parents). If within the next 2–4 weeks, the adolescent declined FP and wished to start hormone therapy, the appropriate treatment was prescribed, and signed treatment consent forms were scanned into the medical record.

Data analyses

Data analyses were performed using SPSS version 21.0 (IBM Corp, 2012). Descriptive statistics were used to summarize characteristics of the study sample, documentation of fertility counseling prior to treatment (yes vs. no), and utilization of FP (yes vs. no). Pearson's chi-square test and Fisher's exact test were used to

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