Fertility Preservation for a Transgender Teenager

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In this article, we discuss a case in which a 16-year-old birth-assigned male came out to her parents as transgender. She is referred to the gender management program at a large pediatric academic center to discuss hormone therapy. She was initially evaluated by a psychiatrist, diagnosed with gender dysphoria and anxiety, and treated with medication and psychotherapy. When her anxiety was well controlled and she met eligibility and readiness criteria, she was referred to 1 of 2 pediatric endocrinologists in the gender management program to discuss hormone therapy. As part of the discussion about the risks/benefits of estrogen therapy, the pediatric endocrinologist discussed options for fertility preservation (FP) before potentially gonadotoxic therapy. The patient stated that she was not interested in FP. Her mother requested procedures to preserve the possibility that the daughter could have biological children someday. We asked experts in the care of transgender youth to discuss ways in which the doctor could respond to this disagreement between parents and a teenager about FP.

Pediatricians are only beginning to address the ethical issues surrounding transgender teenagers.[1] What exactly is the nature of gender dysphoria? Is it genetic, a normal variation, or a social construct? What are the possible physical or psychological side effects of early treatment? Or of delayed treatment? At what age do teenagers have the capacity to make decisions about medical or surgical treatment? In this Ethics Rounds, we address a different ethical dilemma: How should doctors address disagreements between parents and teenagers about the use of treatments that might preserve future fertility? We asked experts in the care of transgender teenagers to consider a case in which there was such a disagreement and to propose a course of action.

THE CASE

AB, a 16-year-old, is referred to a pediatric endocrinologist in a gender management program at a large pediatric academic center to discuss hormone therapy. AB was diagnosed 6 months ago with gender dysphoria by a child psychiatrist specializing in the care of gender diverse youth. AB was phenotypically male and had been raised as a boy, but at age 15, she came out to her parents as transgender.

The child psychiatrist also diagnosed her with anxiety. AB was started on anxiolytics and referred to a psychotherapist. At her visits with the psychiatrist and therapist, the potential risks/benefits of hormone therapy (estrogen) were mentioned but not discussed in detail. When her anxiety was well controlled and she met eligibility and readiness criteria, she was referred to 1 of 2 pediatric endocrinologists in the gender management program to discuss hormone therapy.

In the initial visit with the pediatric endocrinologist and a social worker,

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the parents described how they had initially struggled to accept the news that their child wanted to transition. Subsequently, they became more understanding and supportive.

As part of the discussion about the risks/benefits of estrogen therapy, the pediatric endocrinologist initiated a conversation about fertility. They discussed the following: (1) the potential risk of permanent infertility as a result of estrogen treatment, (2) management guidelines that urged doctors and patients to consider fertility preservation (FP) options before gonadotoxic therapy, and (3) the process, cost, and effectiveness of sperm banking. After this conversation, the patient responded, "I'm not interested. I'm not sure if I'll ever have kids. If I do, I'll just adopt." The father quickly chimed in, "When I was 16, I didn't think I wanted to have kids. I grew up, got married, and changed my mind." The mother addressed the providers, stating, "Are we really going to be relying on a 16-year-old child to make an accurate decision about whether they want to be a parent in 10 to 20 years? What if she grows up and regrets this decision? Doctor, shouldn't we tell her that we need to keep all her future options open?"

How should the doctor respond to this disagreement between parents and a teenager about FP?

Leena Nahata, MD, and Gwendolyn P. Quinn, PhD, Comment

There are several key questions that should be considered in this case: Are adolescents developmentally ready to consider future parenthood? Are there data to suggest that AB will desire biological children in the future and/or regret her decision to decline FP? How might AB's gender dysphoria and desire to start treatment impact her decision about FP? What are the potential risks/benefits of FP and/or delaying hormone treatment in adolescents with gender dysphoria? Could her history of anxiety be playing a role in her FP decision? Is AB well informed about what adoption entails? Because AB is a minor, who should be making the final decision about FP and the timing of hormonal treatment? What is the role of the provider in this shared decision-making process? Before the physician and/or care team can begin to address these questions, understanding what is known about fertility in general (in cisgender and transgender adults) and in other pediatric populations receiving gonadotoxic treatment (such as cancer and rheumatic conditions) is an important first step.

Impaired fertility has a significant and often devastating effect on many individuals and families in the United States.[2] Although historically thought of as an "adult issue," an emerging body of literature over the past decade has shown many childhood medical conditions and associated treatments lead to infertility,[3–5] necessitating discussions about future parenthood and FP with youth and caregivers. Although these discussions tend to be more challenging in younger adolescents,[6] there has been at least 1 study which revealed that young, otherwise healthy, teen-aged girls had already thought about future parenthood.[7]

The majority of fertility-related research in pediatrics has been done in childhood cancer,[4] leading to recommendations to discuss infertility risk and FP options, including sperm and oocyte and/or embryo cryopreservation for postpubertal youth and ovarian or testicular tissue cryopreservation in prepubertal children, with families before initiation of gonadotoxic therapy.[8] With only ~25% of male adolescents pursuing sperm cryopreservation (which is generally noninvasive) before cancer therapy and lower rates of use of more invasive FP methods, there are multiple studies in which researchers show the distress about potential infertility and regret about missed FP opportunities among childhood cancer survivors.[9–12] Most commonly reported barriers to FP in this population include inadequate counseling, urgency to start cancer treatment, and cost.[10,13] This work has set the stage for examining fertility-related practices and outcomes in other at-risk pediatric populations, including youth with rheumatic diseases, nonmalignant conditions leading to bone marrow transplantation, differences of sex development, genetic disorders, and gender dysphoria.[3]

The American Society for Reproductive Medicine Ethics Committee published a statement in 2013 stating that transgender patients have the same desires for biological children as other individuals and should thus be counseled about infertility risk associated with hormone therapies and FP options before starting treatment.[14] The 2009 Endocrine Society guidelines and 2011 World Professional Association for Transgender Health Standards of Care outline the potential risks of infertility associated with masculinizing and feminizing regimens and state that discussions about reproductive options should occur even if patients are not interested in these issues at the time of treatment.[15,16] However, few studies have been conducted among transgender adults to examine parenthood goals and fertility-related attitudes. According to 2 survey studies in Belgium, 51% of the transgender women would have considered sperm banking if it had been offered,[17] 54% of transgender men reported a desire for children, and 37.5% of transgender men would have considered freezing germ cells had it been offered.[18] At that same center, 15% of transgender women had banked their sperm.[19] Three recent studies revealed mixed results, with researchers in 2

studies suggesting that transgender adults and others in the lesbian, gay, bisexual, transgender, and questioning community were less likely to envision biological parenthood[20,21] and researchers in the other study showed that biological parenthood was a common desire among transgender adults.[22] Given these limited and conflicting data, the World Professional Association for Transgender Health guidelines state that "lessons should be learned" from those who have suffered fertility impairment because of cancer therapy.[14]

We agree with informing youth like AB about fertility-related data in cancer survivors, although considerations may be different in these 2 groups. In 2 recent studies conducted at large pediatric gender management programs, researchers showed <5% of transgender youth attempted FP before hormone therapy,[23,24] which is significantly lower than the preservation rates among adolescents with cancer described above.[10,11] Given the retrospective nature of both studies, it is difficult to assess perceived benefits and barriers; although gender and body dysphoria were not discussed specifically, urgency to start hormonal treatment was mentioned by some youth.[22,23]

Similar to AB's response, 40% of transgender youth in a recent retrospective study reported a plan to adopt in the future as a reason for declining FP.[22] The desire to adopt and the consideration of adoption as a family building option are certainly common. However, adoption is not simple, it can be expensive, and may be even more challenging for a transgender individual. The average cost of adoption is ~$30 000, which is slightly higher than the costs associated with FP.[25] The requirement of a letter from a physician showing a clean bill of health is a deterrent for some attempting to adopt. In some adoption settings, the biological mother has a choice about the future adoptive parents and may or may not welcome the opportunity for the infant to be placed in a home with a transgender parent or cancer survivor.[26] These cautions are not meant to deter transgender individuals from considering adoption but rather to inform, as part of shared decision-making, that there are challenges and expenses with this option, as there are for FP options as well.

AB's family and provider face a difficult dilemma. On 1 hand, it is important to create some time and space for her to think about the risks and options presented during the encounter before starting hormone therapy. On the other hand, there is evidence that hormonal interventions are associated with positive psychosocial outcomes in youth with gender dysphoria,[27] so a prolonged delay in starting treatment may cause harm. Additionally, especially because mental health conditions are prevalent in youth with gender dysphoria,[28,29] it is important to consider the possible impact of anxiety or depression on AB's ability to form romantic relationships and/or envision future parenthood, and conversely, it is also important to consider the potential impact of pursuing or declining FP on her mental health. AB's medical and mental health providers should talk with AB and her parents separately about parenthood goals, logistics of sperm banking, and potential benefits and barriers. In addition, her entire care team should talk as a group to optimize support for AB and her family during this challenging process.

Lisa Campo-Engelstein, PhD, Comments

The first step the doctor should take is to talk to AB alone to better understand the reasons why she is opposed to FP. The patient's initial refusal should be taken as a starting point for a dialogue rather than blithely accepted by the doctor.[30] Although AB states she is not sure if she will want to have kids in the future, there may be other factors at play in her decision. There may be good reasons for AB refusing FP, and there may be concerns AB has that can be successfully addressed.

First, AB may be eager to medically transition. Although this might be dismissed as adolescent impatience, research in adults has revealed that many transgender individuals prefer a fast transition over delaying their transition for FP.[19] If AB's desire for a quick transition is the reason she is refusing sperm banking, her doctor should explain to her that sperm retrieval can be done immediately via masturbation so there will not be a significant delay.[31]

Second, AB may be uncomfortable with masturbation. Although masturbation poses no physical risks, there can be psychological harm associated with it. Depending on the teenagers' age and sexual maturity, they may not have experimented with masturbation and may not feel comfortable performing it. Discussing masturbation may be embarrassing to the point that it may stifle further conversation about sperm banking. For transgender teenagers experiencing gender dysphoria, masturbation may be too distressing to even consider. Indeed, sexually engaging with anatomy that is incongruent with their gender identity may exacerbate their gender dysphoria.[32] Thankfully, there are alternative methods for sperm retrieval, such as electroejaculation, testicular sperm extraction, and microscopic epididymal sperm aspiration. These other methods are more invasive and carry physical risks. They can also be psychologically stressful.[31] If AB is uncomfortable with masturbation, informing her of these alternate methods may alleviate her concerns and allow her to pursue FP.

Third, AB's gametes will not match her gender identity. Although research on this topic is limited, researchers in 1 study found that FP of discordant gametes made it more difficult for transgender individuals to let go of their assigned gender identity.[17] If AB is worried that FP may be a reminder of gender dysphoria or that it will prevent her from moving forward, it may be in her best interest to forgo FP, even if biological parenthood is important to her. However, she should be counseled that infertility may also affect her psychosocial health.

Fourth, AB's sexual orientation may be a factor. In some studies, researchers have shown transgender women who identify as lesbians or bisexual are more likely to bank sperm before transitioning,[19] probably because they would be able to use their frozen gametes with future partners. If AB identifies as a lesbian or bisexual, then she should be informed that she and a future partner would be able to use their gametes to create a biological child, which may be an attractive reason to undergo FP. If AB identifies as heterosexual, then it will not be possible for her to use her gametes and her future partner's gametes to create a biological child, which may lead her to conclude that it is not worth undergoing sperm banking. Regardless of her sexual orientation, the doctor should have a detailed conversation about all her reproductive options so she can adequately assess them.

If after a thorough discussion, the doctor concludes the main reason AB is refusing sperm banking is in fact because she is unsure whether she will have children, the doctor should let her know that it is fine, and even normal, for her to not know right now whether she will want children in the future. Moreover, the doctor should assert it is her choice whether to have children, either adopted or biological, or not have children, and any choice she makes is a good one. The doctor should emphasize the goal of FP is not to pressure her into making a choice right now but instead that it is a way to maintain the option of biological parenthood so as to enhance her future reproductive autonomy. AB should be told that some states and adoption agencies discriminate against transgender individuals,[33] which may make it difficult for her to adopt in the future. Additionally, she should be aware that private adoption can cost tens of thousands of dollars and can be a long and difficult process.[34] Sperm banking can also be an expensive option, not only because of the costs of storage but also because of the costs incurred through using assisted reproductive technologies to conceive and the potential cost of hiring a gestational carrier.

Ultimately, the decision of whether to bank sperm belongs to AB. Forcing an elective medical procedure on her against her wishes would be a violation of nonmaleficence and autonomy. At age 16, AB is likely emotionally mature enough to make her own reproductive decisions. Furthermore, minors are legally permitted to make their own medical decisions about their reproductive and sexual health in most cases. Given that AB is making her own medical decisions about gender-affirming treatment, it would be hypocritical to deny her decision to refuse FP, which is a component of her gender-affirming treatment.

Although the decision about FP rests with AB, the physician should not take her initial "no" as a final answer and should instead initiate an involved conversation about the advantages and disadvantages of FP. Only after such a conversation should AB be able to make her decision.

Amy Tishelman, PhD, Comments

The topic of FP in transgender youth is complex and timely. Referrals for medical treatments have increased dramatically in recent years.[35] This trend brings with it a need for guidelines and optimal approaches related to important collateral issues. One of the most profound of these involves best practices in counseling and decision-making regarding FP for transgender youth.

Transgender adolescents generally decline fertility-sparing treatments.[23,24] Nahata et al[23] found that only 2 out of 72 patients attempted FP, although information was provided to all patients about the potential detrimental impacts of medical intervention for gender dysphoria. Chen et al[24] likewise reported a low rate of follow-through with FP interventions among transgender adolescents. Some of the reasons youth cited for rejecting interventions included concerns about delaying hormonal treatment, cost, the invasiveness of FP procedures, disinterest in having biological children, intention to adopt, and discomfort with masturbation (birth-assigned boys only). In both studies, transgender girls were more likely to attempt preservation, possibly because of the more onerous nature of FP for transgender men.

The fact that transgender adolescents are generally disinterested in fertility-sparing interventions is not necessarily of concern. There are certainly many diverse adult goals with regard to family construction, and all can be considered of value, such as being a foster parent, adopting, or choosing to not have children. However, it is suggested in some research that a significant number of transgender adolescents may be interested in having biological children.[36] Of more concern, many transgender teenagers report they had never been counseled by their doctors about FP. Low rates of fertility counseling are concerning because transgender adults often do have interest in having biological children.[17,18] Thus,

the dilemma is how to counsel youth about a desire that may not be present in the moment but may become extremely important in the future.

Numerous ethical and clinical considerations are relevant to this case. These include the rights of an adolescent to be involved in medical decision-making versus parental rights, the ability of adolescents to make short- and long-term decisions, mental health factors that can impact decision-making capacity, the context in which transgender youth are approached (eg, awaiting medical intervention), general best practice models for engaging with adolescents in informed clinical decision-making, and the challenges of integrating these practices into an often busy clinic setting and/or within the context of an interdisciplinary team. The additional factor of family discord is another dimension that can confound attempts to implement a straightforward protocol for complex decision-making.

Most current professional policies and guidelines embrace inclusion of adolescents in important clinical decision-making. The American Academy of Pediatrics recommends that health care providers should create a collaborative environment "to resolve any conflicts between the parents and adolescent" and that "the clinicians should generally advocate for the adolescent's wishes if they represent an ethically acceptable treatment option."[7]

In this case, it would be important to understand this adolescent's full spectrum of considerations and why this patient expressed disinterest in having biological children. A single meeting for fertility discussions may preclude sufficient reflection and may serve to reinforce an adolescent's proclivity to engage in impulsive decision-making. Members of an interdisciplinary team can help slow the process and foster a discourse that enables a teenager to think carefully about options. Discussion may need to persist over time and occur with adolescents and parents separately and together. In a medical setting this can be complicated when teenagers may feel anxious to receive treatment and other mental health issues may be pulling toward the quick elimination of all barriers to treatment.

Studies reveal that positive communication involves professionals who are prepared in advance for important conversations and who can display empathy, compassion, and support during meetings. This involves some simple (but often overlooked) strategies, such as listening to patients, appropriate nonverbal behavior (eg, eye contact), and using technology responsibly and not as a barrier between the patient and provider.[8,37]

A critical element in discussions of FP involves sensitivity to cultural beliefs and assumptions,[7] including understanding the meaning of having biological children within a cultural framework. Transgender females may be embarrassed by discussions of masturbation. With transgender youth, the difficulties can be compounded by sometimes significant discomfort with aspects of their bodies or reproductive physiology and a desire to feel better quickly, with medical treatment as the avenue to reduced dysphoria.

Often, interdisciplinary teams can function to provide optimal strategies to communicate with transgender youth about fertility options, integrating the information provided above. A team can develop a structure and protocols for integrating best practices for fertility counseling with transgender youth. Psychologists and other mental health professionals can assess the mental health and cognitive capacity of both youth and their parents or guardians, address cultural issues that might impact decision-making, and engage in conversations with adolescents about their goals and hesitancies, as relevant. Reproductive endocrinologists and other medical specialists can take a lead in discussions of medical options. All family member perspectives should be treated with respect. Parents also may need to process emotional responses, which can include the grief of relinquishing the likelihood of becoming biological grandparents. With thoughtful planning, colleagues working together can develop team approaches that work well to assist patients and families to resolve conflicts and engage in thoughtful decision-making about fertility treatments.

John D. Lantos, MD, Comments

Disagreements between parents and teenagers are common. Usually, they can be resolved with a little patience, a little sensitivity, and a little goodwill. But emotions run high when the issues concern sexuality, gender identity, sexual preference, and procreation. The stakes get even higher when a doctor must prescribe an irreversibly gonadotoxic therapy as a part of the treatment of gender dysphoria. Such situations may lead to long-term regrets no matter which course of action is chosen. All that any professional can hope to do in this situation is to try as hard as humanly possible to address all the medical and psychological concerns as patiently and as conscientiously as possible, and then hope that in the years to come the patient will be content with the choices she made, the process by which the choices were made, and the consequences of those choices. The alternative, to force a FP treatment on an already fragile teenager, would be even worse.

ABBREVIATION

FP: fertility preservation

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