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Ethical Considerations in Fertility Preservation for Transgender Youth: A Case Illustration

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Abstract

Increasing numbers of transgender adolescents are presenting for transition-related medical care, including gender-affirming estrogen and testosterone. The decision to transition with hormones has long-term implications, including possible irreversible impairment of future reproductive functioning. The commentary by Hudson, Nahata, Dietz, and Quinn (2017) outlines the importance of fertility counseling for transgender adolescents and young adults as ethical, interdisciplinary practice. Key considerations raised include implementing shared decision-making strategies that account for youths' maturity and individual decisional capacity, evaluating co-occurring psychiatric conditions that could interfere with future-oriented decision-making, and considering benefits and harms of fertility preservation (FP) in the context of a youth's values, identity, and comfort. This report includes two case illustrations of transmasculine youth which highlight how ethical considerations emerge in clinical practice and underscore the nuance and complexity of fertility-related decision-making among transgender adolescents.

Keywords

Transgender youth; Gender-affirming hormone therapy; Fertility preservation; Reproductive health; Ethics

Increasing numbers of transgender adolescents are presenting for transition-related medical care (M. Chen, Fuqua, & Eugster, 2016). The decision to transition with gender-affirming hormones (estrogen and testosterone) has long-term implications, including possible irreversible impairment to reproductive functioning (Ikeda et al., 2013; Schulze, 1988). Thresholds for amount and duration of hormone exposure causing permanent negative effects on fertility have not been established. Thus, the World Professional Association of

Transgender Health and the Endocrine Society recommend fertility counseling prior to hormone initiation (Coleman et al., 2012; Hembree et al., 2017).

The commentary by Hudson, Nahata, Dietz, and Quinn (2017) emphasizes the responsibility of multidisciplinary providers, including pediatric psychologists, in ensuring transgender youth understand the reproductive health implications of medical transition and highlight unique clinical and ethical considerations of fertility counseling with transgender youth. First, Hudson et al. (2017) discuss clinical communication and shared decision-making. Authors recognize that adolescents may lack mature decisional capacity. Youth may be overly influenced by short-term consequences (e.g., delaying hormone initiation) versus long-term considerations (e.g., fertility). Thus, they recommend strategies to facilitate the informed consent process, including provider-facilitated discussions with patients and families and careful consideration of an adolescent's maturity and decisional capacity. Second, authors highlight the importance of assessing for psychiatric comorbidities that may interfere with the ability to consider future parenthood and fertility preservation (FP). Last, Hudson et al. (2017) emphasize that the potential benefits and harms of FP will vary depending on individual "values, identity, and comfort" (p.5). Thus, the goal of fertility counseling should be providing comprehensive information about fertility risk, FP options, risks of pursuing FP, and how to access FP, while preserving patient autonomy (Hudson et al., 2017).

Hudson and colleagues' recommendations are consistent with standard practice at the Gender & Sex Development Program (GSDP) at Ann & Robert H. Lurie Children's Hospital of Chicago, which has been offering treatment for transgender adolescents, including hormones and fertility counseling, since 2013. The goal of these two case illustrations is to expand the scope of Hudson and colleagues' paper by describing how clinical and ethical considerations regarding FP emerge in clinical practice, specifically for transgender young men (see Hudson et al., 2017 for a case of a transgender young woman). In the first case, the patient opted for oocyte cryopreservation. In the second case, the patient declined FP. These cases were chosen specifically to illustrate the decision-making process leading to distinct choices about FP. For context, just under 5% of youth initiating hormones in our clinic opted to preserve fertility between July 2013 and July 2016 (D. Chen, Simons, Johnson, Lockart, & Finlayson, 2017).

Gender & Sex Development Program Overview

GSDP is staffed by two adolescent medicine physicians, a pediatric endocrinologist, an advanced practice nurse, two clinical psychologists, and a licensed clinical social worker. Adolescents interested in hormones typically have their initial visit in our multidisciplinary clinic, where they are seen together by a medical and behavioral health provider. This is the first step in the process to making an informed decision about hormones and FP. We discuss adolescents' desires for hormones, their parents' level of support for medical transition, and our model of care (see D. Chen et al., 2016 for description of baseline psychological assessment). Subsequent medical follow-up includes a physical exam, labs, and education about the reversible and irreversible effects of hormones, including potential impact on fertility. Subsequent behavioral health follow-up includes an assessment of readiness for

hormones either conducted by a GSDP behavioral health provider or a youth's outside therapist in consultation with a GSDP provider. The assessment includes a diagnostic evaluation of gender dysphoria and co-occurring psychiatric conditions (and an assessment of their impact, if any, on decisional capacity). It also describes adolescents' understanding of hormone effects, including those on fertility, and provides an opportunity to explore parenthood desires. Our team introduces FP options and refers those desiring more information to Lurie Children's FP nurse navigator for specialized fertility counseling. Youth interested in FP are referred to adult specialists prior to initiating hormones. Once FP is completed or the youth/family declines FP, hormones are prescribed.

Oocyte Cryopreservation Overview

Understanding the oocyte cryopreservation process is necessary to grasp the physical and psychological demands of FP and potential barriers to FP. Oocyte harvesting requires 10–14 days of daily hormone injections to stimulate follicular development, monitoring via transvaginal ultrasounds, and ultrasound-guided oocyte retrieval (Wallace, Blough, & Kondapalli, 2014). Future use of cryopreserved oocytes requires partner or donor sperm and a recipient uterus, either a cisgender female partner or surrogate (De Sutter, 2001). Transmen also have the option of carrying a pregnancy, though this often undesired (Light, Obedin-Maliver, Sevelius, & Kerns, 2014). In addition to the physical and psychological demands of FP, cost is a universal barrier. Oocyte cryopreservation costs an average of \$5000 with an additional \$600 annual storage fee (Devine et al., 2015), and assisted reproductive technologies (ART) to utilize cryopreserved gametes ranges from \$1,000 to \$10,000 (Wahlert & Fiester, 2013). Ultimately, cost is a justice issue, as FP is likely to be limited only to those who can pay out of pocket (Campo-Engelstein & Chen, 2016). To date, there have been two documented cases of transmen undergoing oocyte cryopreservation *before* hormone therapy who have returned to use preserved gametes—each case has resulted in twin live births (Maxwell, Noyes, Keefe, Berkeley, & Goldman, 2017).

Developmental and Psychosocial Considerations

Transgender adolescents must consider desires for biological parenthood during a period in which thinking about family formation is developmentally non-normative, which some argue, calls into question youths' decision-making capabilities as they relate to FP. Transmasculine youth desiring biological parenthood must also weigh the benefits of FP against the risk that FP procedures will worsen gender dysphoria. Balancing beneficence and nonmaleficence in FP will differ depending on the value an individual places on preserving fertility potential, severity of gender dysphoria, individual adaptive strengths to cope with worsening dysphoria or decisional regret, and capacity for autonomous decision-making. Additionally, transgender adolescents may be making decisions about FP in the context of limited romantic and sexual experience. This potentially complicates considerations of using preserved gametes in the future if the physical anatomy of a likely co-parent is unknown. For instance, transmasculine youth attracted to cisgender females have the option to use donor sperm and have their partner carry the child to term. However, they will have to consider personal values related to biological parenthood in a situation in which it is not possible for the child to be biologically-related to both parents. On the other hand, transmasculine youth

attracted to cisgender males have the option to use partner sperm to form a child biologically-related to both parents. However, the cost of a gestational carrier—between \$50,000 and \$250,000 in the United States (Shetty, 2012)—must be weighed against the potential exacerbation of gender dysphoria associated with carrying a pregnancy (Light et al., 2014). Transmasculine youth primarily attracted to other transgender or non-binary individuals will need to consider their partner’s values, comfort, and identity in making decisions about family formation in the future.

Case Illustration 1

“Ryan,” a European-American, birth-assigned female who identifies as male, was 17-years-old when he initially presented to GSDP. Ryan realized he was transgender at age 13. Despite identifying as male privately for four years, he had only recently disclosed his male gender identity to his parents at the urging of his girlfriend of two years, who was the only other person who was aware of his gender identity. Neither of Ryan’s parents (divorced but amicable) were surprised to learn that he “would feel more comfortable living as a man.” Ryan was a junior in high school and planned to transition socially and physically after graduation. While graduation was 18 months away, he and his parents sought care to discuss the process for starting hormones and obtain support for Ryan in navigating transition.

Clinical Communication and Shared Decision-Making

Ryan’s parents shared legal decision-making rights; however, Ryan’s desired timeline for transition meant he would be 18 and could legally consent for his own medical care. That said, Ryan relied heavily on his parents for both emotional and financial support, and both parents were actively involved in discussions about testosterone and FP. After his initial clinic appointment, Ryan had three appointments with a GSDP medical provider and 10 appointments with a GSDP psychologist over the course of 18 months, during which testosterone effects and FP options were discussed at length. As soon as Ryan learned there was an option for him to have biological children without physically carrying a child to term, he consistently expressed interest in pursuing FP. Ryan reasoned that because he was attracted exclusively to women, his future partner could serve as a gestational carrier. Both parents clearly communicated that they considered decisions about parenting and fertility to be personal. Thus, they deferred decisions about FP to Ryan, telling him they would fully support any decision he made, including financial support for FP. Ryan and his parents were referred for consultation with an adult reproductive endocrinologist who provided more detailed information about the oocyte harvesting process.

Psychological Comorbidities

Ryan met DSM-5 criteria for Gender Dysphoria, but otherwise did not present with psychological comorbidities. Ryan described periods of dysphoric mood and “feeling overwhelmed” triggered by unhappiness about his body. These feelings were most profound after menarche, after which he experienced heightened distress coinciding with each monthly cycle. He endorsed a history of passive suicidal ideation and one incident of cutting—both occurred more than a year before presenting for care. Ryan noted he “did not really want to die, just felt tired of being a girl.” Ryan’s mood improved after he came out as

transgender to his parents. He felt “excited” and “hopeful” when thinking about transitioning with hormones. Ryan’s desire to wait until after high school to pursue transition stemmed from anxiety about how his friends would respond to his transition and the desire to “have a fresh start” in college.

After Ryan had a consultation with an adult reproductive endocrinologist, he expressed significant anxiety about the invasiveness of FP procedures. He felt uncomfortable with the idea of hormone injections to stimulate follicular development and “hated” the thought of transvaginal monitoring and oocyte retrieval. Ryan shared that he had never been sexually active, had never had a pelvic exam, and could not even bring himself to use tampons during menses. The GSDP psychologist emphasized that Ryan could change his mind about FP if he felt the risks to his mental health outweighed the benefit (balancing beneficence and nonmaleficence). However, Ryan maintained his strong desire to “keep the option [of biological parenthood] open.” Therefore, to preserve Ryan’s autonomy to proceed with FP, subsequent therapy sessions included instruction of mindfulness-based approaches to manage anticipatory anxiety and distress associated with the oocyte harvesting cycle.

Ethical Considerations

Ryan demonstrated capacity to consent for treatment, which refers to the ability to (1) understand treatment information, (2) appreciate the situation and likely consequences, (3) weigh treatment options in terms of benefits and risks, and (4) reach a decision (Ruhe, Wangmo, Badarau, Elger, & Niggli, 2015). He articulated an accurate understanding of the effects of testosterone on fertility, oocyte cryopreservation procedure, need for ART to use gametes in the future, and cost of these treatments. He acknowledged the potential risk of FP on his mental health. Yet, he expressed a strong and unwavering desire to preserve fertility. Ryan presented for care with an 18-month timeline in mind for initiating testosterone; thus, there was sufficient time to prepare for FP. With regard to cost, parents were willing to allow Ryan to use his college savings account to pay for FP with the understanding that he may need student loans for college.

Clinical Decision

Ultimately, Ryan elected to move forward with FP and successfully cryopreserved 19 oocytes one month following high school graduation. Ryan began the process of coming out as transgender to his friends and extended family and transitioned socially. He started testosterone one month after completing FP. Now, at age 20, Ryan is doing well. He is attending community college with plans to transfer to a 4-year university. He has had regular medical follow-up for testosterone management, but has not needed ongoing therapy. Ryan was seen by a GSDP psychologist for one session recently to support his pursuit of gender-affirming chest surgery. He continued to express satisfaction with his decision to preserve fertility.

Case Illustration 2

“Peter,” a European-American, birth-assigned female who identifies as male, was 16-years-old when he initially presented to GSDP. Peter realized he was transgender and disclosed his

identity to his parents two months prior to his first clinic visit. Peter was reserved during this initial meeting and struggled to articulate his goals. Parents were seeking information about how best to support Peter's ongoing gender exploration given his recent realization that he was transgender and was still using feminine pronouns and legal name. At this initial appointment, Peter wanted to delay social and physical transition until after high school graduation but did have several questions for the GSDP physician about testosterone. Parents felt Peter needed more time to explore gender identity before making any decisions about medical transition.

Peter was referred to a GSDP psychologist to support gender exploration. His first session was two weeks after his initial GSDP appointment, and the change in Peter's appearance was striking. Peter was dressed in masculine clothing, and his previously long hair had been cut and styled in a masculine manner. He also wanted to be addressed using his preferred name and masculine pronouns. Parents noted "things moved quickly" following their initial appointment, and Peter now wanted to transition socially for his senior year of high school and start testosterone as soon as possible. Parents expressed full support of Peter transitioning socially and were not opposed to discussing testosterone initiation. However, they reiterated their desire for Peter to have ongoing therapy to ensure transitioning with hormones was in his best interest.

Clinical Communication and Shared Decision Making

At age 16, Peter's parents had legal decision-making rights, and there were no concerns related to their capacity to consent for treatment. Over the course of 5.5 months, Peter had 16 sessions with a GSDP psychologist and three sessions with a GSDP physician. During this time, parents were consistent in their support for Peter's desires for transition, while relying heavily on the treatment team's ongoing assessment of Peter's readiness for testosterone. Specifically, as it related to fertility and parenting desires, Peter's parents deferred decision-making to Peter entirely, stating, "whether he's cis or trans, being a parent was always going to be his decision."

Peter's desires for future parenthood were explored across several sessions. Peter stated that while he "liked kids" and would like to have children in the future, he had not given much thought to the importance of biological parenthood to him personally. Different family formation options, including adoption and biological parenthood, were introduced. Options for FP including detailed information about the process and cost were discussed with Peter and his parents. Upon learning the invasiveness of the oocyte harvesting procedure, Peter stated he was not interested in FP and would instead adopt. Peter's parents emphasized that the decision about FP was one they felt strongly should be deferred to him, despite his minor status. Conversations about fertility and future parenting desires occurred almost exclusively in the therapy room with the GSDP psychologist taking care to balance Peter's stated disinterest in FP with the possibility that his desires for biological parenthood could change with age and experience.

Psychological Comorbidities

Peter's psychological history was significant for generalized anxiety disorder and oppositional defiant disorder diagnosed at age 8. He was referred for neuropsychological testing at age 9 due to academic decline and concerns for inattention. Results revealed above average IQ and mostly above average academic skills with weaknesses noted in math fluency and written expression. Results also identified problems with inattention and executive functioning. Peter was subsequently diagnosed with ADHD, inattentive type, and learning disabilities in math and writing. He met with a psychologist for therapy as needed from age 8 to 15 and was prescribed stimulant medication by a child psychiatrist starting at age 12.

At the time of presentation to GSDP, many of Peter's past diagnoses had resolved—he met criteria for Gender Dysphoria and ADHD, predominately inattentive presentation. While Peter had recently realized his transgender identity, he had a longstanding history of gender nonconformity and gender questioning since childhood. Peter shared that he “felt more like a guy” during elementary school but did not share these feelings because “I was really shy at the time and thought that my feelings weren't normal.” He “hated” wearing girls' swimsuits and yearned to wear swim trunks and “go topless.” Peter also consistently assumed male gender roles online, choosing male avatars for videogames since age 14. Shortly after realizing his transgender identity and seeing his parents' support, Peter had the opportunity to experience life “as a guy” during a 2-week summer camp with peers who were unaware of his gender history. After this experience, Peter had no desire to “hide” who he was any longer, and amended his initial timeline for transition from after high school graduation to “as soon as possible.”

Peter's co-occurring ADHD was effectively managed by stimulant medication and did not challenge his decisional capacity. While he was diagnosed with learning disabilities in math and writing, we did not expect this to compromise his decision-making ability. In fact, past cognitive testing revealed above average IQ, which is positively correlated with decisional capacity (Elbogen et al., 2007). Discussions about hormones, parenting desires, and FP procedure and costs occurred over multiple sessions across several months with both medical and behavioral health providers. Peter demonstrated an accurate understanding of the potential long-term impact of testosterone on fertility.

Ethical Considerations

Potential harms and benefits of FP were carefully considered with a focus on maintaining Peter's autonomy. While Peter clearly expressed an interest in parenting in the future, he also conveyed his discomfort with the invasiveness of oocyte harvesting. He shared, “even if biological parenthood were really important to me, I don't think I could do it without making the dysphoria worse,” communicating that the risks of FP (nonmaleficence) outweighed the benefit (beneficence) for him. As Peter expressed interest in adoption, the GSDP psychologist discussed cost and potential complications associated with adoption (e.g., long waitlist, birth parents changing their minds, etc.) to ensure that Peter also was weighing the benefits and risks of adoption. Peter reasoned that there also is significant expense associated with oocyte cryopreservation and future use of ART. Peter's parents

deferred fertility-related decision-making to him, but were in a position to financially support FP efforts if desired. Deferring the decision to pursue FP to Peter is in accordance with American Academy of Pediatrics Committee of Bioethics guidelines that state that minors who are judged to have decisional capacity are entitled to the same degree of autonomy as an adult patient (1995). Thus, in Peter's case, his decision to pursue or decline FP should be prioritized as he demonstrated the ability for autonomous decision-making.

Clinical Decision

Ultimately, Peter decided that biological parenthood was not something he strongly valued or desired. Therefore, he was not willing to risk worsening his dysphoria and delay hormone initiation, which he felt would significantly alleviate his gender dysphoria. Parents supported his decision to decline FP and consented for hormones. Peter started testosterone 5.5 months after his first GSDP appointment. Peter, now 19-years-old, has had 23 sessions with a GSDP psychologist since testosterone initiation for support around transition, ongoing body dysphoria, and adjustment to college. He underwent gender-affirming chest reconstruction at age 18, which further alleviated dysphoria. Peter also has had two romantic relationships with young women. Approximately two years after starting testosterone, Peter expressed some regret during a therapy session that he had not pursued FP. He shared that since his body dysphoria improved, he has felt more comfortable exploring his sexuality and developed more serious romantic relationships that involved "thinking about the future." In particular, Peter's girlfriend at the time expressed interest in the possibility of using the same sperm donor to fertilize both Peter's and her own oocytes in the future. This way, any future children she and Peter shared would both be biologically related to one another, as well as to one parent. The GSDP psychologist discussed the option of discontinuing testosterone for a period of time to attempt FP, should Peter so desire. Over the course of several sessions, FP options and Peter's desires for biological parenthood were reconsidered. Again, Peter decided that the oocyte cryopreservation would be too invasive and would negatively impact his mental health.

Conclusions

These two cases illustrate the complexity of fertility-related decision-making among transgender adolescents pursuing hormone treatment. Autonomy to make reproductive health decisions are complicated by each adolescent's desire for physical transition and the immediacy of transition needs. Indeed, gender-affirming hormones may represent life-saving treatment for transgender people, who, as a population, experience alarmingly high rates of attempted suicide. In one national survey, 41% of transgender adults attempted suicide, compared to a national average of 4.6% (Herman, Haas, & Rodgers, 2014). Research suggests that treatment with hormones can improve mental health functioning and alleviate gender dysphoria (Costa & Colizzi, 2016). Thus, compromising future fertility may be an acceptable risk in the context of immediate relief from dysphoria. However, research on transgender adults suggests that about half desire biological children (De Sutter, Kira, Verschoor, & Hotimsky, 2002; Wierckx et al., 2012), and over a third would have considered FP had such technologies been available at the time of their transition (Wierckx et al., 2012).

Transgender adolescents pursuing hormones may be at particularly high risk for prioritizing short- versus long-term outcomes, putting them in jeopardy for later experiencing regret.

The potential risk of exacerbating gender dysphoria by undergoing oocyte cryopreservation must also be underscored. In case 1, Ryan was unwavering in his desire for FP and aside from gender dysphoria, did not exhibit psychological comorbidities. In many ways, Ryan's circumstance was "ideal" for someone interested in FP in the sense that he was psychologically stable, possessed intact decisional capacity and was not in a rush to start hormones. His family also was in a financial position to support his pursuit of FP. Moreover, Ryan's transition timeline allowed for an extended therapeutic period to prepare for an invasive procedure. While Ryan was satisfied with his decision to cryopreserve oocytes, the process was both physically and emotionally taxing. Thus, even individuals who are motivated and desire FP have concerns about these procedures and need support through the process. In case 2, Peter ultimately decided that the mental health risks associated with FP outweighed the benefit of keeping an "open future" with regard to biological parenthood. The opportunity to transition (medically and surgically) greatly reduced gender dysphoria and enabled Peter to explore fertility desires in a way he could not, prior to transition. It was only after he felt more comfortable with his body that he was able to explore romantic relationships. And it was the experience of being in a relationship that raised the possibility that Peter's fertility status could impact not only himself, but a future partner. This realization led Peter to reconsider his decision not to pursue FP, before ultimately coming to the same conclusion that the risks outweighed the benefits.

It is difficult to know whether the fertility counseling process could have been approached differently to minimize Peter's decisional conflict, as it was his lived experience as a young man that provided the context and perspective that prompted him to re-evaluate his decision not to pursue FP. More specific discussion around the possibility of changing his mind about biological parenthood in the future or considering the desires of a future partner may have been helpful. However, it is important to note that just because Peter experienced decisional conflict and expressed regret does not mean that he made a "wrong" decision initially. That Peter came to the same conclusion that the risks of FP to his mental health outweighed the benefit of preserving fertility, even after gender-affirming hormone and surgical treatment, suggests that declining FP was the "right" decision for him.

The challenges discussed in these two cases highlight the need for transgender healthcare providers, particularly those who see adolescents, to be knowledgeable and comfortable discussing complex issues related to fertility and reproductive health. These core competencies are critical to enable providers to support adolescents in weighing risks and benefits of hormones and FP. It is unclear whether comprehensive fertility counseling is routinely implemented as part of standard-of-care protocols for initiating hormones. What is clear is that such counseling is needed to facilitate informed, autonomous decision-making, and minimize reproductive health disparities for this vulnerable population of youth. Future research should evaluate whether current fertility counseling approaches are effective in improving knowledge of reproductive health options and satisfaction with decision-making.

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