

The Ethical Need for a Fertility Decision Aid for Transgender Adults of Reproductive Age

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ABSTRACT

Current studies show that about half of transgender and gender-diverse (TGD) people wish to have children in the future. TGD patients who pursue gender-affirmation interventions must be aware of the impact that various treatments can have on fertility, as gender-affirming care through medical or surgical treatment can limit or alter reproductive potential. Many medical professional societies encourage providers to educate and counsel patients about the consequences of treatment and viable options for fertility preservation (FP) as early as possible, though patients may not be aware of all the family formation methods available. There is a significant need for a tool that thoroughly details not only the various opportunities for parenthood but the perceived cost, rates of success, and risks associated with each option. A fertility decision-aid would allow for a more robust informed consent process and shared decision-making for all individuals pursuing gender-affirming care.

Keywords: Transgender, Fertility Treatment, Informed Consent, Decision-Making, Parenthood, Fertility Preservation

INTRODUCTION

Over 1.6 million adults and youth in the United States, or about 0.6 percent of those age 13 and over, identify as transgender, according to a report released by The Williams Institute in June 2022.¹ Current studies show that approximately half of transgender and gender-diverse (TGD) people wish to have children in the future, which aligns with the rate of cisgender individuals who desire parenthood in some form.² Studies on parenthood show improved quality of life and mental health in TGD adults and decreased incidence of suicide in TGD women.³ In one study, almost half of the TGD individuals who indicated an interest in parenthood said they wanted genetically related offspring.⁴ However, medical or surgical therapies can limit reproductive potential.⁵ Recent findings indicate that some TGD adults who underwent medical or surgical paths to affirmation regret decisions that may have led to their inability to have genetic children. Perhaps they did not know it was an option, faced barriers to care, or were not interested at the

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time.⁶ Many medical professional societies, including the World Professional Association for Transgender Health (WPATH), the Endocrine Society, and the American College of Obstetrics and Gynecology, encourage providers to educate and counsel patients about the consequences of treatment and viable options for fertility preservation as early as possible.⁷ This paper argues that TGD patients who pursue gender-affirmation interventions must be aware of the impact treatments can have on fertility and, ultimately, parenthood and that a design tool may help them understand the risks and make informed decisions.

I. Gender Affirmation Options

Some TGD individuals do not use medical or surgical therapies to feel affirmed in their identity.⁸ Non-medical paths to affirmation include social and legal measures.⁹ These reversible paths do not impact the individual's future fertility potential. TGD individuals can follow different paths of gender-affirming care through social, legal, medical, and surgical affirmation.¹⁰ Social affirmation can include using gender-affirming pronouns, names, and clothing.¹¹ Legal affirmation can include changing the gender and name on a birth certificate and other records in states where this is permissible.¹² Social and legal affirmations are reversible and do not impact fertility potential.

Medical affirmation involves the use of gender-affirming hormone therapy. Feminizing or masculinizing hormone therapy allows for the development of secondary sex characteristics that more closely align with the individual's gender identity.¹³ No set regimen for treatment exists, as a patient's goals will determine their individualized plan.¹⁴ Some standard feminizing agents include estrogen, androgen-reducing medications, and progestins, while the common masculinizing agent is testosterone.¹⁵ Gender-affirming hormone therapy is not currently seen as a definitive cause of infertility, as it is possible to discontinue treatment and see a noted reversal of intended effects.¹⁶ Research findings suggest that hormone therapy should stop for a minimum of three months to reverse any treatment effects.¹⁷ The only available data on long-term hormonal therapy use is inconsistent, based on observational studies with varying duration and doses.¹⁸ Individuals can stop gender-affirming hormone therapy, but its lasting impact on fertility is unknown.¹⁹

A TGD individual may choose to undergo surgical interventions that do not impact fertility. These interventions can masculinize or feminize body parts to allow a patient's physical appearance to align with their gender identity.²⁰ This care could include breast augmentation for TGD women and Adam's apple reduction or breast reduction for TGD men.²¹ Other surgical interventions will impact TGD individuals' fertility. Genital surgery for a TGD woman can include the removal of the penis and scrotum (penectomy and orchiectomy) and the construction of a vagina and labia (vaginoplasty and vulvoplasty).²² A TGD man can have removal of the ovaries and uterus (oophorectomy and hysterectomy) and construction of a penis and scrotum (metoidioplasty, phalloplasty, and scrotoplasty).²³ Following these gender-affirming surgeries, individuals are infertile due to the removal of their reproductive organs.²⁴ These procedures are irreversible and directly impact reproductive capacity in TGD individuals.

II. Fertility Counseling to Explain Paths to Parenthood

Patients receiving gender-affirming care should have the opportunity to learn about the various ways to achieve parenthood, including fertility preservation. Family formation methods include sexual intercourse, artificial insemination, surrogacy, and adoption or foster care.²⁵ These methods apply to non-TGD people as well. Patients may not be aware of the various means of family-building, so accurate and expansive fertility counseling is essential before initiating medical or surgical affirming care. The frequency with which TGD individuals receive fertility counseling and how thorough it is, is unclear. When surveyed about fertility

preservation, healthcare providers reported a lack of confidence in discussing fertility preservation with patients due to gaps in their knowledge on best practices, success rates, and regret rates in patients who did not preserve fertility. They also had varied perceptions of their role in treating patients and whether they should discuss family planning.²⁶ Patients have reported receiving an overview of fertility options from their primary transgender-healthcare providers before being referred to reproductive specialists.²⁷ While this is an essential step for patients seeking more information about their opportunities for parenthood, only 16 percent of Society for Assisted Reproductive Technology member clinics share information about options for transgender individuals on their websites.²⁸

Many organizations recommend discussing the risk of infertility. Providers of transgender health care do not, and may not be trained to, provide adequate counsel to patients. Patients also cannot give informed consent for fertility or gender-affirming care interventions without more information on the benefits and burdens of all available treatments. Current literature demonstrates a need for a decision aid that thoroughly details not only the opportunities for parenthood but the perceived cost, rates of success, and risks associated with each option.²⁹ This tool could foster a more informed dialogue between an individual and their care team. A fertility decision aid would also allow for a more robust informed consent process for all individuals pursuing gender-affirming care.

Regardless of the affirmation path chosen, a TGD individual should have early and frequent conversations with their care team regarding fertility. The World Professional Association for Transgender Health (WPATH) asserts that healthcare professionals should discuss fertility preservation options before initiating gender-affirming hormone therapy or surgery. The American College of Obstetrics and Gynecology states that “fertility and parenting desires should be discussed early in the process of transition, before the initiation of hormone therapy or gender affirmation surgery.”³⁰ The Endocrine Society writes that “all individuals seeking gender-affirming medical treatment should receive information and counsel on options for fertility preservation prior to initiating puberty suppression in adolescents and prior to treating with hormonal therapy in both adolescents and adults.”³¹ These conversations are essential even if the patient is not interested in parenthood at the time. WPATH addresses the potential for regret, as cases of individuals who received hormone therapy and genital surgery and later desired genetically related children have been identified.³²

TGD patients pursuing gender-affirming care should assess their individual fertility goals to better understand the many ways to build a family. Surveys of TGD adults show that participants want to become parents in various ways. In one study, 31.3 percent of those surveyed wanted to become parents through adoption, 25 percent wanted children through sexual intercourse, 15.6 percent through surrogacy, 12.5 percent using donor sperm, 9.4 percent using a known sperm donor, and 6.3 percent through the foster care system.³³ TGD women showed a significant interest in adoption (75 percent of participants), whereas more than half of TGD men wanted to become parents through sexual intercourse or pregnancy (58.3 percent).³⁴ These fertility goals should be acknowledged and discussed with the care team to guide decision-making about fertility preservation.

III. Fertility Preservation

Individuals who wish to share their genetic makeup with their child will usually need to speak with a reproductive specialist about fertility preservation options. They are the same as those for cisgender individuals using fertility services before cancer treatment or elective preservation.³⁵ For TGD adults with ovaries, this includes freezing embryos (using donor or partner sperm) or ovarian tissue.³⁶ While no longer viewed as an experimental treatment, professionals offer tissue freezing to few patients due to a lack of

data on its safety and efficacy.³⁷ For TGD adults with testicles, freezing sperm and preserving testicular tissue can preserve the ability to have biological children.³⁸

Fertility preservation numbers for TGD adults remain low. A study showed that 76.6 percent of TGD men and 76.1 percent of TGD women considered fertility preservation, but only 3.1 percent and 9.6 percent, respectively, initiated it.³⁹ Success rate, cost, need for travel, and elevated risk of gender dysphoria likely lead to lower use of fertility preservation.⁴⁰ According to the American Society for Reproductive Medicine, the average cost of an IVF cycle in the US is \$12,400.⁴¹ Intrauterine insemination can range in cost from a few hundred dollars to \$2,000 per cycle.⁴² There are also associated costs to freeze and store sperm and eggs.⁴³ Insurance coverage and physical location impact the costs and how the patient bears the costs.⁴⁴ For those who do not have sufficient or any insurance coverage, fertility preservation may not be feasible.

Of additional significance for this population, fertility preservation techniques can exacerbate gender dysphoria as the patient must produce gametes associated with the gender they do not recognize.⁴⁵ For TGD women, masturbating in a clinical setting or sperm banking for sperm cryopreservation can cause severe distress.⁴⁶ Furthermore, fertility preservation for TGD men can be challenging and invasive. A transvaginal ultrasound exam is a requirement for the cryopreservation of embryos and oocytes.⁴⁷ This exam can cause significant distress as the procedure does not align with their male identity.⁴⁸ Controlled ovarian stimulation cycles require two weeks of daily gonadotropin injections, and the patient is given anesthesia for oocyte retrieval.⁴⁹ Furthermore, TGD men undergoing fertility preservation must discontinue testosterone use, and menstruation can resume.⁵⁰

IV. Other Paths to Parenthood

a. Adoption

TGD adults can also pursue parenthood through adoption systems, though foster care is a temporary option. While almost one-third of surveyed TGD adults consider adoption a means to parenthood, cost and fear of discrimination can prevent them from following through.⁵¹ TGD individuals have expressed a reluctance to pursue adoption due to the fear of discrimination by adoption agencies, attorneys, or families.⁵² Nineteen states in the US allow child welfare agencies to refuse to provide services to LGBTQ+ families if it conflicts with the religious beliefs of the relevant people in the agency.⁵³ Nineteen states have no laws about discrimination during the adoption process based on sexual orientation or gender identity.⁵⁴ Only 29 states have statutory or regulatory protections against discrimination based on orientation and gender identity.⁵⁵

b. Surrogacy

There are two types of surrogacies: traditional and gestational.⁵⁶ In traditional surrogacy, professionals fertilize the surrogate's egg by the sperm of an intended parent or a sperm donor through intrauterine insemination. In gestational surrogacy, the surrogate undergoes IVF to implant the fertilized embryo.⁵⁷ Egg donation can be used for gestational surrogacy if necessary. Those considering surrogacy need to understand the specific laws in their state, as they can differ significantly.⁵⁸

c. Intercourse

TGD individuals who have not undergone genital surgery can have intercourse with the intention of causing pregnancy. TGD men who have not had genital surgery can bear children. For those who have initiated hormonal therapy, limited data has been collected on the impact of gender-affirming hormone therapy on

conception.⁵⁹ TGD men have gotten pregnant after discontinuing testosterone use.⁶⁰ TGD women who have not had genital surgery can have intercourse with a person with ovaries and produce sperm to fertilize an egg. Gender-affirming hormone therapy possibly affects sperm viability.⁶¹

V. A Decision Aid to Support Informed Consent and Shared Decision Making

For individuals pursuing gender-affirming care, time is of the essence when considering fertility preservation. In one review, transgender health doctors reported that most patients did not want to postpone treatment for fertility preservation procedures, even if they wanted children;⁶² any delay in treatment can be distressing for those with gender dysphoria.⁶³

Providers face several challenges when counseling patients about fertility. The WPATH guidelines pose an ethical dilemma for transgender health providers as limited data offers guidance about discussing fertility risks and recommendations with patients.⁶⁴ For TGD patients, limited and contradictory data about fertility outcomes before, during, and after gender affirmation exists, particularly for the lasting impact of gender-affirming hormone therapy.⁶⁵ For TGD women who have taken estrogen and stopped to pursue fertility preservation, data on sperm quality is mixed.⁶⁶ The data on when normal ovarian function resumes is variable for TGD men using testosterone who have stopped to pursue fertility preservation.⁶⁷ Much data comes from the oncofertility literature, which indicates that when providers use standardized counseling practices when discussing fertility with their patients, more patients undergo fertility preservation, and patient satisfaction increases.⁶⁸

For individuals seeking gender-affirming care, there is a need for a decision aid that providers can utilize across multiple clinics and programs.^{69,70} Patients must be aware of the benefits, risks, and alternatives of any intervention to provide truly informed consent. When discussing fertility for TGD patients, this includes which fertility options are available at each stage of transition and the potential for a live birth with each option.⁷¹ Furthermore, a decision aid would allow for shared decision-making, where the patient is an active participant and co-designer of their treatment plan.⁷² Shared decision-making acknowledges the healthcare provider's beneficence, knowledge, and experience while equally valuing the right to patient autonomy and respecting the ability of the patient to inform the provider.⁷³ A decision aid can help initiate the conversations between a patient and their provider that allow for a true partnership in decision-making.

A recent study investigated the efficacy and impact of a web-based fertility decision aid targeted at TGD adolescents and young adults.⁷⁴ This tool, titled Aid for Fertility-Related Medical Decisions (AFFRMED), significantly increased fertility knowledge in both youth and their parents while improving youth's perceived ability to make fertility decisions.⁷⁵ Youth participants and their parents found the tool "feasible, acceptable, and usable."⁷⁶ This initial study was small, with only eight adolescents or young adults and seven parents participating.⁷⁷ At large, the effectiveness of the trial will be the next step in determining the legitimacy of the aid for clinical use.⁷⁸

A similar decision-making tool designed for TGD adults would also be useful. The tool can present an average range of expected costs as much variability exists and costs change over time. This tool should also include general information on what is required to pursue each path to parenthood. For example, a patient undergoing fertility preservation needs to know what steps are necessary after the cryopreservation of gametes for live birth.⁷⁹

CONCLUSION

Individuals pursuing gender-affirming care must closely consider the impact of their medical and surgical care on their desire to become parents as early in their affirmation journey as possible. A decision aid can be helpful if it outlines the risks to fertility and options to preserve fertility, with the specific data necessary to make an informed choice. The tool should include the methods of fertility preservation, each step of the protocol and respective risks for each method, the expected timeline from initiation to completion, general success rates, options for remaining gamete disposition, and the average cost of treatment. This should include a list of steps to initiate the process for each method and any potential barriers or obstacles. For surrogacy, the tool should include the two types and the average cost. For intercourse, the aid should include information on risks for discontinuing gender-affirming hormone therapy and general success rates. Clinics and providers could elect to tailor the decision aid for their population to include specific information about local laws and the availability of services.

With a standardized fertility decision aid, TGD individuals can have a more thorough understanding of the opportunities and limitations placed on their reproductive capacity. Healthcare providers can feel more confident that their patients have access to relevant information regarding family-building before initiating medical or surgical affirmation. This allows for a more substantial informed consent and shared decision-making process, regardless of the decision made. A trial-tested decision-making tool for TGD adolescents and young adults exists that can serve as a model for creating aid for TGD adults of all ages. A fertility decision aid designed explicitly for TGD adults of reproductive age would be invaluable to support patients and healthcare providers in transgender health.

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