

Ethical Issues in Gender-Affirming Care for Youth

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Transgender and gender-nonconforming (TGNC) youth who suffer from gender dysphoria are at a substantially elevated risk of numerous adverse physical and psychosocial outcomes compared with their cisgender peers. Innovative treatment options used to support and affirm an individual's preferred gender identity can help resolve gender dysphoria and avoid many negative sequelae of nontreatment. Yet, despite advances in these relatively novel treatment options, which appear to be highly effective in addressing gender dysphoria and mitigating associated adverse outcomes, ethical challenges abound in ensuring that young patients receive appropriate, safe, affordable treatment and that access to this treatment is fair and equitable. Ethical considerations in gender-affirming care for TGNC youth span concerns about meeting the obligations to maximize treatment benefit to patients (beneficence), minimizing harm (nonmaleficence), supporting autonomy for pediatric patients during a time of rapid development, and addressing justice, including equitable access to care for TGNC youth. Moreover, although available data describing the use of gender-affirming treatment options are encouraging, and the risks of not treating TGNC youth with gender dysphoria are evident, little is known about the long-term effects of both hormonal and surgical interventions in this population. To support ethical decision-making about treatment options, we encourage the development of a comprehensive registry in the United States to track long-term patient outcomes. In the meantime, providers who work with TGNC youth and their families should endeavor to offer ethically sound, patient-centered, gender-affirming care based on the best currently available evidence.

The Williams Institute on Sexual Orientation and Gender Identity Law and Public Policy estimates there are ~150 000 adolescents between the ages of 13 and 17 who identify as transgender in the United States.¹ Although there is no reliable estimate of the worldwide population of transgender youth, the Joint United Nations Programme on HIV/AIDS approximates that between 0.1% and 1.1% of the worldwide population of reproductive age is transgender.² Gender-affirming care for children and adolescents may include social

transition; puberty suppression; gender-affirming hormone treatment; surgical interventions; mental health treatment; and consultation with families, schools, and medical environments. As the number of children and adolescents in the United States who publicly identify as transgender and gender-nonconforming (TGNC) continues to increase,¹ it is critical to address ethical issues related to the provision of appropriate, patient-centered care and the challenges that TGNC individuals and their families face

abstract

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in accessing care that meets their needs. In this review, we explain and evaluate an overview of the most pressing of these issues using the foundational bioethics principles of beneficence, nonmaleficence, autonomy, and justice. There are additional ethical issues, such as fertility preservation and clinical approaches to treating nonbinary presentations of gender dysphoria, that are reviewed in detail elsewhere.³

Medical and psychosocial care designed to affirm individuals' gender identities has been demonstrated to mitigate many of the negative effects of gender dysphoria, or the distress that frequently accompanies a discrepancy between one's assigned gender at birth and one's gender identity. Such care appears to satisfy the principles of beneficence (the obligation to provide benefit to patients) and nonmaleficence (the avoidance of unnecessary harm). Indeed, emerging evidence suggests that a lack of access to appropriate gender-affirming care may lead to TGNC youth being at greater risk of harm, including violence, sexually transmitted infections (such as HIV), depression, anxiety, and suicide.⁴⁻⁷ Moreover, TGNC individuals are subject to profound and pervasive social stigma, which likely contributes to poor psychosocial functioning and the adverse psychological outcomes experienced by those who are unable to access gender-affirming care.⁸ At the same time, because of its relative novelty and a lack of research into practices and outcomes, gender-affirming care raises risks that have yet to be fully understood and evaluated. This has implications for autonomy (a comprehensive understanding of all risks and benefits and the ability to decide freely) because patients and families sometimes must make decisions based on limited or low-quality information.

With regard to justice (the equal distribution of benefits and burdens among social groups), access to care is currently inequitable. Barriers to appropriate medical care for TGNC adults and youth include geographic disparities in the availability of qualified medical and mental health providers who are willing and able to offer appropriate gender-affirming care, fear of discrimination from members of the health care community, and disparities in health insurance coverage that render certain procedures and interventions unaffordable for many.^{5,9-13} In areas of the world where being transgender is criminalized, providers have been known to report TGNC adults to the police for seeking care, essentially barring them from accessing health care providers.¹³

Our goal is to demonstrate that TGNC youth face substantial barriers to accessing affordable and appropriate care and to elucidate the special ethical concerns that providers of gender-affirming care to youth should consider when treating this population. Many of the issues identified can be addressed by better tracking and understanding outcomes among those receiving gender-affirming treatment. We conclude that a comprehensive outcomes registry in the United States in which patient-centered outcomes are used can help guide the future of ethical, patient-centered, gender-affirming care.

HARMS ASSOCIATED WITH NONTREATMENT

Exposure to Trauma: Poverty, Homelessness, Violence, and Sexual Exploitation

As a result of their marginalized status, TGNC youth are more likely than their non-TGNC peers to experience a number of trauma-related risk factors associated with poor physical and mental health outcomes, including poverty,

homelessness, and violence. Even with gender-affirming treatment, TGNC youth may be at an elevated risk of harm. According to a 2015 survey of TGNC people in the United States, 29% of respondents were living in poverty, which is more than twice the rate of the rest of the American population.¹⁴ Along with other lesbian, gay, bisexual, transgender, and queer and/or questioning youth, TGNC youth experience homelessness at alarming rates, together making up 20% to 40% of the >1.6 million homeless youth in the United States today.¹⁵ Often as a result of discrimination, rejection, and/or violence at home, TGNC youth are unable to remain in their family homes.^{15,16} Once homeless, they are more likely to interact with the juvenile criminal justice system¹⁷ and are at an increased risk of physical abuse or assault, mental health issues, engagement in transactional sex, and substance use than are those who do not identify as members of sexual or gender minority groups.^{18,19}

Poor Mental Health Outcomes and Suicide

As a result of profound stigma, TGNC youth may be less likely to seek and obtain professional medical care for gender-affirming procedures or other health issues, which in turn places them at greater risk of poor mental health outcomes. A number of studies across Europe and North America reveal that TGNC youth are more likely to have comorbid mental health issues along with gender dysphoria that contribute to psychological suffering, including anxiety, depression, and suicidal tendencies.²⁰⁻²³ These comorbidities often are associated with delays in accessing treatment.^{16,24,25}

In a sample of >500 transgender youth, nearly one-third had attempted suicide.⁶ Another survey of 55 transgender youth revealed that 26% had attempted suicide,

and ~45% reported having thought seriously about ending their lives.²⁶ A third study revealed that approximately two-thirds (61.3%) of TGNC youth reported suicidal ideation, which is >3 times the rate of their cisgender counterparts (20%).²⁷

Self-treatment

Given the desperation TGNC youth experiencing gender dysphoria often feel, many who do not have ready access to gender-affirming care resort to self-treatment. Both estrogens and androgens can be purchased illicitly, through the Internet, and/or over the counter in some settings and countries.²⁸ Risks related to self-administration involve potential interactions with existing health conditions, poor-quality or toxic hormones, inappropriate dosages, and a lack of medical monitoring throughout one's treatment.^{16,28,29} Additional risks related to injection include the development of abscesses and the transmission of hepatitis C or HIV through needle sharing.¹⁷ TGNC youth may also self-administer silicone injections with the attendant risk of infection and other complications.³⁰ There are no published data on the outcomes of those who self-treat, although this is a widely reported practice in the TGNC community.³¹

ETHICAL CONSIDERATIONS REGARDING GENDER-AFFIRMING TREATMENT OF TGNC YOUTH

Benevolence and Nonmaleficence: Risks and Benefits of Gender-Affirming Treatment Options

Many of the above-mentioned risks of harm to TGNC children and adolescents may be mitigated to a great extent by the provision of health care that is designed to support and affirm an individual's gender. Yet, gender-affirming treatment options carry their

own risks, many of which are at best tenuously understood, with important implications for medical decision-making among providers, patients, and families. Moreover, some treatment options are reversible (social transition and puberty suppressing hormone treatment), whereas others are semipermanent or fully permanent (gender-affirming hormone treatment and surgical interventions), a morally relevant distinction that must be factored into decision-making. More data are needed in several arenas to assess long-term outcomes and support ethically sound decision-making. Presently, clinicians, patients, and families must weigh the risks and benefits of gender-affirming medical treatment options, including those that are irreversible, with only limited available evidence.

Social Transition

In prepubertal youth with gender dysphoria, social transition is often the first step taken to affirm gender identity and alleviate gender dysphoria. Social transition may occur several years before any medical intervention. However, the long-term consequences of social transition for prepubertal children raise potential concerns. Although there are major limitations to and criticisms of the body of data examining the natural history of gender identity in prepubertal children with gender dysphoria,³² current evidence reveals that the majority of children who have gender dysphoria before the onset of puberty will not seek medical transition once puberty has commenced.^{3,33,34} Although it has been suggested that the intensity of gender dysphoric feelings above a certain threshold may indicate that a child will be more likely to seek permanent gender transition, further studies are needed to understand the etiology of childhood gender dysphoria. There is also a potential concern

that prepubertal children who have socially transitioned may feel "boxed in" to their affirmed gender identities if parents reinforce a gender binary and imply that their children's gender identities are irreversible.³⁵ Moreover, there is little research on adolescent-onset gender dysphoria, and the rate of persistence within this community of patients is not known.³⁶

A recent landmark study compared the mental health of prepubertal children with gender dysphoria who received support from their families in regard to their social transition to those of cisgender age-matched controls; the authors found that rates of depression were similar between the 2 groups with minimal elevations in anxiety in the socially transitioned group.³⁷ Although the findings of this study may be due in part to the particular or unique characteristics of the participants and their families, thus limiting the generalizability of the findings, the affirmative approach to care exemplified in this study is in contrast to those who encourage prepubertal children to accept their natal gender.³⁸ Long-term outcomes data are needed to better predict which children would benefit from social transition and examine the repercussions for children who have transitioned socially and who ultimately do not identify as transgender.

Puberty Suppression

According to current clinical practice guidelines, appropriately screened TGNC youth are eligible for pubertal suppression with gonadotropin-releasing hormone (GnRH) agonists on initiation of puberty.^{39,40} The purpose of suspending puberty is twofold: First, blocking puberty buys more time for individuals to explore their gender identities with the support of their families and mental health providers without the development of unwanted secondary sex characteristics (such

as voice deepening and breast development). Second, blocking the development of such characteristics means that TGNC youth who persist in their transgender identities will require fewer medical and surgical interventions in the future. Evidence reveals that pubertal suppression is associated with a reduction in depression and anxiety.⁴¹ There are potential risks, however, with using GnRH agonists in this patient population. Although they have been used for >30 years in children with precocious puberty, and the efficacy and side effect profile has been studied in this patient population, there is a paucity of data with which the long-term outcomes of use in TGNC youth are examined. Specific areas of uncertainty include the effect of pubertal suppression during this critical window of time in which the adolescent brain is developing and bone density is accruing.^{39,42} Delaying puberty also may place youth at risk for additional psychosocial challenges because they will remain physically prepubescent while their peers undergo puberty.³⁹ Moreover, they may feel trapped on a certain trajectory once puberty suppression begins because even well-intentioned parents and providers may inadvertently reinforce a particular gender identity.^{3,43}

Gender-Affirming Hormone Treatment

For those who have entered puberty, hormone treatment can help TGNC youth develop secondary sex characteristics that are in line with their gender identities. Similar to puberty suppression, there is a lack of data with which long-term outcomes of gender-affirming hormones in TGNC youth are examined. Specifically, there is uncertainty surrounding the long-term cardiovascular and metabolic effects of estrogen and testosterone therapy in addition to mental health outcomes.⁴⁰ In its most recent guidelines, the Endocrine Society now recommends flexibility in the

minimum age for the initiation of gender-affirming hormones; thus, hormones may sometimes be used in youth <16 years of age.³⁹ A recent study in which researchers managed 55 transgender adolescents who underwent a rigorous psychological and/or gender assessment process before a clinical protocol of pubertal suppression, gender-affirming hormones, and gender-affirming surgery revealed a complete resolution of gender dysphoria. There were no cases of regret for making the decision to transition, and psychological outcomes were similar to or better than those of cisgender, age-matched young adults.⁴¹

Gender-Affirming Surgery

Surgery is often the final and generally irreversible step in gender affirmation. The Endocrine Society recommends delaying surgery in adolescents until the age of 18, although there is only limited, low-quality evidence to support this recommendation.³⁹ The World Professional Association for Transgender Health proposes limiting surgery to the age of majority with the exception of chest surgery in trans men, which may be performed at a younger age as long as there is satisfaction with testosterone treatment.⁴⁰ In practice, despite attachments to such organizations, at least 11 surgical specialists in the United States report having performed vaginoplasties on minors between the ages of 15 and 17 years, with implications for informed consent.⁴⁴ No additional published data regarding the prevalence of gender-affirming bottom surgery performed in TGNC youth were found.

Autonomy and Informed Consent and/or Assent

Informed Consent and/or Assent

For practitioners working with pediatric and/or adolescent populations, determining how and to

what extent young patients are able to participate in decision-making regarding their care continues to present ethical dilemmas. In both clinical and research contexts, the informed consent process serves to protect individual autonomy by ensuring that patients have a clear understanding of the risks and benefits associated with a specific medical decision and are able to make decisions freely. Given their developmental status, children are commonly regarded as being capable of providing assent rather than fully informed consent, and criteria for obtaining informed consent from parents and/or surrogate decision makers vary.⁴⁵

The age at which a pediatric or adolescent patient can provide consent or assent for medical treatment is still in question,^{46,47} particularly for novel or innovative therapies in which risks and benefits are not well documented or understood. From a legal standpoint, competence to make medical decisions is typically recognized as a multifactorial and fluid construct; in the absence of a reliable approach to applying the construct in practice, many countries still default to age-based thresholds.⁴⁸ The World Health Organization defines adolescents as individuals between the ages of 10 and 19 years⁴⁹; although most countries recognize the age of 18 years as the threshold for full decision-making rights, thresholds for involvement in decision-making for younger adolescents and children vary greatly.⁴⁷ Groups such as the international Convention on the Rights of the Child have sought to focus instead on the capacity for understanding as a condition of consent, referring to evolving capacities for self-determination to describe one's ability to participate in medical decision-making during adolescence.⁵⁰ In the United States, minors are able to consent to medical care for sexual health and for most

reproductive health issues, and in many states, they also may consent to care for psychiatric health and substance use.⁴⁵

Ambiguity regarding the appropriate involvement of children and adolescents in decision-making about their medical treatment has particular implications for those seeking gender-affirming care. Patients are increasingly presenting for gender-affirming care at younger ages. There is a range of possible treatment trajectories, including social transition for prepubertal children before the initiation of medical intervention⁵¹; according to the most recent Endocrine Society and World Professional Association for Transgender Health guidelines, medical intervention requires the onset of puberty.^{39,40} In some cases, children or adolescents may not agree with their family members about the optimal course of care, raising questions about how best to resolve differences in opinions and perspectives, which may or may not be developmentally related. For instance, children at age 10 or 11 years might have a different understanding or appreciation of the ramifications of choosing to forego fertility preservation than they would as older adolescents or adults, and ethical issues clearly arise in performing such an elective procedure on an unwilling participant. Given these difficulties, some scholars have issued a call to revisit the role and scope of consent and assent in the TGNC youth population.⁵²

As practitioners endeavor to differentiate reliably between children whose gender dysphoria will resolve on its own with time and those whose gender dysphoria will persist into adolescence and adulthood, those involved in gender-affirming care (gender-variant children and adolescents, their parents or guardians, and their medical providers) must make

decisions about treatment in which (1) there is uncertainty about long-term risks and benefits associated with a given treatment plan and (2) the optimal or appropriate role for young patients in decisions regarding their care is still in question. As patients and their families contemplate treatment options, they must engage in a risk/benefit analysis that often includes weighing the risk of unknown long-term outcomes with the more immediate benefit of avoiding detrimental mental health outcomes associated with nontreatment, including an increased risk of suicide.^{26,27,53}

Dual Parental Consent

In the United States, anecdotal reports reveal that treating institutions sometimes require both parents to consent to gender-affirming medical procedures.⁵⁴ It is not known if this requirement is applied consistently across programs and geographic areas, but where it does exist, it is likely to serve as a potential barrier for TGNC youth seeking care to affirm their chosen gender identities.

Dual parent consent may be unnecessarily prohibitive for adolescents who come from households with only 1 parent who is actively involved in the child's life or in situations in which there may be interparental conflict. A state court of appeals in Florida has upheld the sufficiency of 1 parent's consent for nonemergent medical procedures even when the health care provider knows or should have known that 1 parent objected to the procedure.⁵⁵ There is thus a need to understand parental consent requirements for gender-affirmation services given the legal inconsistency.

Justice and Equitable Access to Care

Youth seeking gender-affirming care face countless socioeconomic and geographic barriers, raising issues of equitable access and fair

distribution of resources. Disparities in access to care exist between TGNC youth and their cisgender peers because stigma faced by TGNC youth prevents them from both seeking and receiving appropriate care; disparities also exist among TGNC youth as a result of differences in individual socioeconomic status, urban or rural status, and the country or state in which they happen to live. For example, although gender-affirming care is considered a right in European Union member states,⁵⁶ some countries in Africa and Asia have criminalized TGNC identities, thereby barring access to health care for this population.¹³

Stigma

TGNC youth face significant stigma, which can hinder or obstruct access to care at structural, interpersonal, and individual levels.⁵⁷ Stigma as a stressor has been demonstrated to have an adverse impact on physical health that exceeds the impact of other nonprejudice-related stressors.⁵⁸ Structural stigma can take a variety of forms, including but not limited to a lack of resources, a lack of insurance coverage, the medicalization of gender nonconformity, electronic health records that include only 2 options for gender identification, being denied access to one's restroom of choice, and a lack of health data available for TGNC individuals.^{57,59} Interpersonal stigma also pose a barrier to those seeking care, and many TGNC youth experience such stigma within their families, schools, and health care settings.^{60,61} Although family responses to a child's experience of gender variance differ widely, many do not respond favorably, substantially increasing a child's risk of adverse outcomes.^{62,63} Social settings can also contribute to experiences of interpersonal stigma and significant harm in transgender youth. In a survey of transgender students in the United States, 75% reported feeling unsafe at school,

25% reported being physically harassed, and 12% reported being physically assaulted.⁶⁴ Many youth are also hesitant to seek care for fear of experiencing stigma, reporting that they are wary of discrimination in health care settings or provoking negative reactions to their use of hormones obtained on the street.⁶⁵ Finally, individual stigma can also impact access to care; a reluctance to disclose one's experience of gender variance and a fear of being seen as different have both been reported by TGNC individuals as central barriers to seeking care.^{59,66}

Inequitable Geographic Distribution of Providers

In many cases, the small number of qualified medical and mental health professionals who are trained to provide gender-affirming care means that appropriate treatment is not available for all those in need. This dearth of trained and experienced professionals disproportionately affects certain areas of the world, resulting in pronounced geographically driven inequities in access to care.

In the absence of providers who are qualified or willing to provide gender-affirming care, unqualified clinicians are joining the ranks in hopes of filling these gaps, sometimes causing harm by doing so.⁶⁶ Lesbian, gay, bisexual, transgender, and queer and/or questioning-related education is not sufficiently taught to medical students in the United States and Canada.⁶⁷ Three surveys of small physician samples from the United States and Canada revealed that knowledge deficits in medically treating gender dysphoria impeded physicians' ability to clinically manage treatment plans for TGNC patients.^{68–70} A lack of qualified providers may lead to care that is medically inappropriate or even harmful to patients.

Cost of Care

Cost of Procedures

The cost of gender-affirming care varies by country, and accurate estimates of the costs incurred by patients worldwide are difficult to obtain.⁷¹ Moreover, the cost of some gender-affirming procedures may be prohibitive for TGNC youth and their families, particularly if they are not covered by insurance. In the United States, annual costs of injectable or implantable GnRH agonists range from \$12 000 to >\$20 000, although there is a trend toward puberty-suppressing hormone treatments being covered by insurance.⁷² The cost of gender-affirming hormone treatment is more difficult to estimate because the costs have not been as widely reported and vary greatly depending on the route of administration (oral versus injectable).⁷³ Fertility preservation options have a wider range of costs and are usually not covered by insurance. Sperm banking has an average cost of \$350 with a yearly \$300 storage fee. Oocyte cryopreservation is substantially more expensive, costing ~\$10 000 for the collection and freezing of gametes and \$800 per year for storage.⁷⁴ Fertility drugs are not included in this estimate. In New York, average costs for mastectomy total \$49 149, and breast procedures other than mastectomy, such as breast augmentation, cost on average \$50 886.⁷⁵ Similarly in New York, genital surgeries range from \$34 218 to \$41 996 depending on the payer.⁷⁵

The costs referenced here represent some but not all procedures that a TGNC individual might undergo as part of gender-affirming care. Additional procedures with attendant costs, such as facial feminization surgery, body contouring, speech therapy, and hair removal, can be equally important in assisting TGNC individuals in affirming their desired genders; and yet, these procedures are often considered cosmetic and

as such are not covered by many insurance carriers.

Health Insurance Coverage

Health insurance mechanisms and health care systems vary widely across the world.^{2,9,56}

In the United States, several states have adopted formal policies protecting the right of TGNC people to access gender-affirming medical care through their health insurance providers.⁹ Currently, 16 states and the District of Columbia prohibit transgender exclusions in both private insurance and Medicaid, and 4 states ban such exclusions in 1 but not both forms of insurance coverage. Although many state policies protect coverage for TGNC individuals, federal protections have recently been curtailed.⁷⁶

In the current political climate, the role of state antidiscrimination laws may be crucial to ensure equitable access to gender-affirming care for TGNC youth, but considerable variation in and interpretation of state policies is still a barrier for many of those seeking accessible and affordable gender-affirming care.⁷⁷

Access to Other Forms of Health Care

TGNC youth often have difficulty accessing other forms of needed health care beyond gender-affirming care. Cultural acceptance and the extension of legal rights for TGNC people differ worldwide, which creates variations in the accessibility of health care.¹¹ In the United States, when asked about barriers to accessing health care, a sample of transgender youth in New York noted that it was difficult to find physical health care services in addition to care for their sexual and mental health needs.⁶⁵ TGNC youth participating in the Minnesota Student Survey (Minnesota is a state with both Medicaid and private insurance antidiscrimination policies) reported significantly lower rates of preventive health checkups

compared with cisgender youth participating in the survey as well as poorer overall health outcomes.⁷⁸ Thus, it is important to evaluate barriers to the overall health and wellbeing of TGNC youth that cannot be addressed by state and federal laws governing health insurance coverage alone.

CONCLUSIONS: TRACKING OUTCOMES TO SUPPORT ETHICALLY SOUND PATIENT-CENTERED CARE

Access to care for TGNC youth presents significant ethical issues, raising concerns about beneficence, nonmaleficence, autonomy, and justice. Despite the well-documented risk of suicide without treatment in this population, gender variance is still met with intense social stigma, creating extensive structural and political roadblocks to improving access to appropriate health care. Although medical institutions may not be equipped to address these broader concerns, ethical questions that arise in the clinical context are complicated by a lack of outcomes data revealing which procedures and therapies are beneficial for TGNC youth. In the United States, such data are needed to assist children, parents, and providers in making informed health-related decisions about care and to assist policy makers in ensuring that health care is provided on an equitable and well-substantiated basis.

Accordingly, the careful tracking of physical and mental health outcomes for youth undergoing gender-affirming care can help to create a transparent and sound evidence base to support the equitable provision and coverage of treatment options. This in turn will enhance informed consent by helping TGNC youth and families assess the risks and benefits of different treatment options. Tracking patient-centered outcomes will enable those in the field to demonstrate that an unmet medical

need exists for many TGNC youth, better assess which gender-affirming treatment options for youth are safe and effective, and provide grounding for a consensus on the indications for various gender-affirming procedures.

Until a comprehensive registry to track outcomes is established in the United States, educating providers about the need for treatment, available patient-centered treatment options for TGNC youth, and the extensive barriers that TGNC youth may face in accessing needed health care can help ensure that the health care needs of TGNC youth are acknowledged and addressed in an ethically sound and developmentally appropriate manner.

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ABBREVIATIONS

GnRH: gonadotropin-releasing hormone
TGNC: transgender and gender-nonconforming

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