Ethical Issues Considered When Establishing a Pediatrics Gender Surgery Center

As part of establishing a gender surgery center at a pediatric academic hospital, we undertook a process of identifying key ethical, legal, and contextual issues through collaboration among clinical providers, review by hospital leadership, discussions with key staff and hospital support services, consultation with the hospital’s ethics committee, outreach to other institutions providing transgender health care, and meetings with hospital legal counsel. This process allowed the center to identify key issues, formulate approaches to resolving those issues, and develop policies and procedures addressing stakeholder concerns. Key issues identified during the process included the appropriateness of providing gender-affirming surgeries to adolescents and adults, given the hospital’s mission and emphasis on pediatric services; the need for education on the clinical basis for offered procedures; methods for obtaining adequate informed consent and assent; the lower and upper acceptable age limits for various procedures; the role of psychological assessments in determining surgical eligibility; the need for coordinated, multidisciplinary patient care; and the importance of addressing historical access inequities affecting transgender patients. The process also facilitated the development of policies addressing the identified issues, articulation of a guiding mission statement, institution of ongoing educational opportunities for hospital staff, beginning outreach to the community, and guidance as to future avenues of research and policy development. Given the sensitive nature of the center’s services and the significant clinical, ethical, and legal issues involved, we recommend such a process when establishing a program for gender surgery in a pediatric institution.

abstract

As part of the development of the Center for Gender Surgery at Boston Children’s Hospital (BCH), the surgical team decided to initiate a process of ethical and legal consultation. As the first gender surgical center to be housed in a pediatric facility in the United States, it was expected that there would be ethical and legal concerns that were unique to the setting, in addition to the broader concerns around gender surgery raised by other authors.\(^1,2\) In the fall of 2017, these concerns were raised over a series of discussions with the hospital’s administration, ethics committee, legal team, community members, and other stakeholders, and several concerns were identified that might be relevant to both this center and other centers working with younger transgender patients.

Dr Boskey copresented to the ethics committee, provided topic-specific documentation to the committee for review, drafted the manuscript, and oversaw all revisions. Ms Johnson led the drafting of the ethics committee response to the initial committee consultation, which was used in the drafting of the manuscript, and contributed significantly to revisions; Dr Harrison, Dr Marron, Ms Abecassis, Ms Scobie-Carroll, and Dr Willard contributed to the ethics committee consultation and contributed significantly to revisions; and Drs Diamond, Taghinia, and Ganor initiated the ethics consultation process, copresented to the ethics committee, worked on all consultations, and contributed significantly to revisions, and all authors approved the final manuscript as submitted. The authors have indicated they have no financial relationships relevant to this article to disclose. No external funding.

STARTING POINT: THE WORLD PROFESSIONAL ASSOCIATION OF TRANSGENDER HEALTH STANDARDS OF CARE

The World Professional Association of Transgender Health (WPATH) has laid out standards of care (SOC)\(^3\) for the treatment of gender-nonconforming people. Although these SOC are in the process of being reviewed and revised,\(^4\) and are not without controversy,\(^2,5–8\) the center team decided to use them as a starting point for policy development. As a starting point, the center decided to follow recommendations in the SOC that state that patients are not eligible for genital surgery until they have reached the age of majority and have lived for at least a year in their affirmed gender. Twelve months of hormone therapy is also required, unless hormone therapy is not clinically indicated.\(^3\) With respect to chest surgeries, the SOC state that “Chest surgery in [female-to-male] patients could be conducted earlier, preferably after ample time of living in the desired gender role and after one year of testosterone treatment.”\(^3\) Other requirements for chest surgery in both men and women are persistent, well-documented gender dysphoria; capacity to make an informed decision; and evidence that any significant medical and mental health conditions are well controlled. (Note, the requirements for living in the affirmed gender do not require living in a binary gender.) Another important aspect of the SOC guidelines is the requirement for screening by a behavioral health professional, which is designed to provide the surgeon with relevant information about the patient’s gender identity and overall mental health. That screening is provided to the surgeon in the form of a letter, required for most insurance authorizations, that establishes the patient’s suitability for gender-affirming surgery. This requirement is somewhat controversial and has occasionally been referred to as “gatekeeping.”

Despite their awareness of this controversy, the center staff believed it was appropriate for the care paradigm to include a surgery-specific behavioral health assessment. The implemented protocol covers general readiness for surgery, case management issues that may occur around the time of surgery, assessment of whether the patient’s expectations for surgery are realistic, awareness of postsurgical care requirements and likelihood of compliance, gender history, and fertility assessment.

INITIAL ETHICS DISCUSSIONS

The center staff consists of a multidisciplinary team of surgeons (2 plastic surgeons, 1 urologist), midlevel providers, nurses, a social worker and researcher, an administrator, and a designated research specialist. The idea for the center originated with the 3 surgeons, who serve as codirectors. After a year of planning and seeking out professional development options in transgender care, the codirectors brought the social worker and researcher onto the team because of her extensive experience working with the gender-diverse patient population. Together, those 4 team members drafted an evidence-based proposal for how the center would be structured and how care would be delivered. They also prepared a presentation in which they highlighted the needs of young people for gender-affirming surgery, key criteria and conceptual underpinnings for offering the surgery (including the SOC), and specific surgical solutions. This material was then presented to the hospital ethics committee for discussion. The ethics committee includes members from a range of medical and surgical services, nursing, patient care services, social services, pastoral care, and other clinical services as well as community representatives and ex-officio participants from administration and legal counsel.\(^9\)

The ethics committee meeting lasted ∼2 hours, and there was a vigorous discussion of concerns across a broad range of domains. A smaller team of ethics committee members and ethics staff then distilled the discussion points into an outline of ethical issues and general recommendations for approaches the center might follow in determining how to address them. This document was brought back to center staff and used to inform policy development and help formulate the center’s mission and values statements (Fig 1). As additional issues, particularly those around the intersection of hospital policy, state law, and fertility preservation, arose for center staff, less-formal discussions were held with ethics and/or legal teams to explore relevant factors to be considered by the center in developing its policies.

Key questions that arose from the ethics discussions are addressed below.

Is There a Sound Medical Rationale for the Treatment or Surgery to Be Provided Through the Center? Is Such Treatment or Surgery Consistent With the Practice of Evidence-Based Medicine?

Gender dysphoria is defined in the American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* as the distress that occurs when there is a marked incongruence between the gender a person was assigned at birth and the gender that they experience or express.\(^10\) The experience of gender dysphoria, and/or identifying as transgender, has been associated with a number of serious physical and mental health disparities, including elevated risks of depression,
anxiety, suicidality, substance abuse, and HIV. Some of these disparities can be reduced with access to transgender-affirming health care and gender affirmation procedures.

The center planned to offer gender affirmation chest reconstruction, phalloplasty, and metoidioplasty for transmasculine individuals (those assigned female at birth with a more male gender identity) and breast augmentation and vaginoplasty for transfeminine individuals (those assigned male at birth with a more female gender identity). Although the quality of the evidence base is low and relies mostly on short-term follow-up, the limited existing reports suggest that these treatments can be an effective way to improve gender congruence and body satisfaction for transgender individuals who are interested in such surgeries, and they have also been shown to improve depression, anxiety, and overall quality of life. Reports of regret do occur, but they are rare, affecting <1% of patients in 1 large study.

This rate is substantially lower than for breast reconstruction after mastectomy, a contextually similar surgical procedure (reconstructive but optional, often involving body image and sexuality) for which decision regret has been studied. On the basis of research in the field, the clinicians were able to present solid evidence that the treatments to be provided at the center were medically sound and necessary to improve the health and well-being of the patients to whom they would be provided, including reduction or alleviation of symptoms of gender dysphoria.

Is Establishment of the Center Consistent With the Hospital’s Mission?

Genital affirmation surgeries, such as vaginoplasty and phalloplasty, are generally offered to adult patients rather than pediatric patients. Therefore, one of the questions that received substantial discussion at the ethics meeting was whether and how these surgeries fit into the mission of a pediatric hospital, including its primary commitment to the health and well-being of pediatric patients. The hospital’s patient care policy defines pediatric patients as those who are under the age of 21.

The conclusion that the program was consistent with the hospital’s mission was based on several factors. First, the hospital’s mission statement addresses the importance of serving unmet need. Because of this mission, the hospital had previously established that it is appropriate to follow pediatric conditions into adulthood when other specialty care for these conditions is not available. In fact, a number of hospital departments, including surgical specialties, already provided care for patients into or through adulthood, and the hospital also had standard criteria for patients being treated through age 35. Because gender dysphoria is often a condition that originates in childhood, it meets the basis of that criteria to the extent that equivalent care is not available. Evidence was presented that there was currently a significant unmet need for gender affirmation procedures in New England. Although several surgeons offered chest surgeries in the Boston area, there was limited access to care for adolescents. There was one other surgical team in the area offering genital affirmation surgeries for transgender women, but genital affirmation surgeries for transgender men were completely unavailable in the area before the opening of the center. As such, one of the motivations for forming the center was the community reaching out to local hospitals looking for providers to address this gap in care. While it might, on the surface, make more sense to offer genital surgeries for transgender men at an adult hospital, at the time the center was formed, there were no surgeons in local adult facilities interested in providing that care. In contrast, the center surgeons had both appropriate expertise and interest in addressing the unmet need.
In addition to the unmet need in the area as a whole, clinical leaders at BCH also recognized an unmet need affecting current patients and appealed to the hospital for support. The hospital houses the Gender Management Service30,31 (GeMS), a leader in medical gender affirmation for transgender youth that was founded in 2007 and currently works with hundreds of patients a year. However, when GeMS patients were ready to surgically transition, their care had to be referred outside of the hospital system. There was agreement by center staff and hospital leaders that a dedicated gender surgery center would best serve the hospital’s mission by providing comprehensive care options and continuity of care for those transgender adolescents and young adults who had been treated in GeMS and were interested in surgical affirmation. Although the 2 programs run entirely separately, the location of the center in a pediatric hospital, with access to the expertise of GeMS providers, meant that it was also well placed to address the particular psychological and medical challenges experienced by transgender youth, including an elevated risk of bullying, violence, and other forms of school-based harassment.32–34

The hospital’s mission also includes research and education. Given its academic nature, and the presence of the GeMS program, the center is well situated to contribute to research in the field of transgender care (especially continuity of care from prepuberty to adult transitioning). The center can also support the hospital’s commitment to education, as is more fully described below.

**Does the Establishment of the Center, and the Delivery of Its Services, Demonstrate Respect for Human Dignity and Worth?**

Respect for human dignity and worth, including support for individual self-determination, are fundamental elements of medical ethics.35 The hospital has a stated commitment to serving a diverse population, representing many nationalities, cultures, faiths, and value systems as well as those with diverse gender identities and sexual preferences. The ethics discussion process addressed this question by examining research in which it was shown that identifying with a gender that is inconsistent with one’s physical characteristics can lead to psychosocial difficulties and a decreased sense of self-worth.36–41

Although not all transgender individuals want surgery, treatment to help reduce the dissonance between physical body and gender identity has the potential to restore individuals’ sense of dignity and worth. In support of this goal, the ethics team recommended that the center provide services designed to meet patients’ psychosocial, emotional, and spiritual needs. This recommendation was addressed by the integration of a social worker with transgender health experience and training in the core team, who would explore patients’ motivations for surgery as part of the assessment (Fig 2), and by the availability of transgender-affirming chaplaincy staff within the hospital. Center staff also determined that discussions of any surgical procedure should be instituted by the patient rather than offered by the team, to avoid giving the impression that providers felt any particular surgery was a necessary component of transition. The ethics team also recommended that center staff identify avenues for increasing understanding of the population.

**FIGURE 2**
Patient care flow sheet. MD, medical doctor; NP, nurse practitioner; PA, physician’s assistant; SW, social worker.
served by the center, both within and outside the walls of BCH; fostering sensitivity and support throughout the center and the hospital for this population; and including input of this community into the development and operations of the center. In agreement with this goal, center staff have sought out opportunities to train providers and community members both inside and outside of the hospital and continue to seek out opportunities to provide professional and community education whenever possible. This includes participation in the Care for Patients with Diverse Sexual Orientations and Gender Identities elective at Harvard Medical School and offering medical students opportunities to engage in additional research and practice with this population. The center has also sought input from community members and actively recruited transgender staff.

Does the Establishment of the Center, and Delivery of Its Services, Demonstrate Respect for Patient Autonomy?

Respect for patient autonomy is the ethical principle that generated the most controversy when developing the center’s policies and practices for patient care. Questions of respect for patient autonomy are at the core of much of the debate around the current WPATH SOC and screening guidelines, specifically care structures that require behavioral health professionals to provide approval to access care rather than prioritizing access through a process of informed consent, a model that is being adopted more and more often for hormone treatment. This is true not just in the adult setting, but in the pediatric setting, as well. Although the GeMS model requires extensive psychological screening, other models are also in place for pediatric hormone access, and the center sees patients who have taken various routes to medical transition.

Debate on this topic is not restricted to medical transition care. There is also substantial disagreement among providers and others as to whether the current guidelines requiring one or more mental health assessments for patients to move forward with gender affirmation surgeries are critical to providing quality care, are problematic gatekeeping, or are something in between. Because a clear answer to the appropriateness of these guidelines is not supported in the current evidence base, the center decided that the most-appropriate way to address the controversy would be to follow the SOC while researching the burdens and benefits of the behavioral health requirements, particularly with respect to providing services to adolescents. To date, the center has enrolled over 70 patients into a longitudinal study in which researchers are assessing quality of life, mental health, and issues and costs of health care access in the context of gender-affirming surgery.

A related issue was whether minors were able to provide informed assent to the kinds of procedures being offered. Addressing this issue is a required component of the outside letters of support needed to access surgery. In addition, it has been previously established that minors legally and ethically can provide informed consent, without parent permission, for many medical therapies related to sexual and mental health. Another issue raised around informed consent was specific to the pediatric population, namely the role of parents and guardians in providing informed consent (sometimes referred to as informed permission), because minors generally can provide assent but not consent for care.

There was substantial discussion among the ethics team, hospital counsel, and center providers as to whether the consent of both parents must be required for minor patients to undergo gender-affirming surgery. Although consent from both parents, alongside assent from the minor, is the standard for care in the hospital’s GeMS program, many transgender youth have complicated family situations. This may make acquiring 2-parent consent to perform surgery on an adolescent unfeasible or impossible, particularly when 1 parent is no longer involved in the minor’s life. Eventually, the center decided on a policy incorporating the standard of 2-parent consent but with the intention to develop formal procedures allowing for appeal in cases in which such a requirement appears to interfere unduly with the informed choices of minors and raises the possibility of significant harm.

Although for some people the requirements for parental consent and behavioral health assessment raised questions about the autonomy of adolescent patients, for others it was reassuring. There is substantial debate around adolescents’ capacity for decision-making and ability to conceptualize long-term outcomes. The involvement of both parents and multiple behavioral health providers in the process of determining eligibility for surgery, as well as the patients’ discussion with the interdisciplinary team of the benefits and risks (including possible regrets), serves as a check on the possibility of impulsivity and reduces the likelihood that age-related cognitive factors would lead to decision regret.

As such, the role of parents is not simply to provide informed consent. They are also important sources of insight and support throughout the gender affirmation process. Parental
concerns can give important insights into adolescent maturity, gender stability, mental health, and well-being and provide a window into additional areas that the behavioral health provider might need to explore before surgical approval. Because of this, parent and guardian education is an important part of the consult process for minors seeking surgery, as is assessment of those adults’ interest in and willingness to support the patient through surgery. Situations in which parents disagree with each other are particularly challenging and addressed on a case-by-case basis.

If the Procedures Performed by the Center Elicit Some Public Criticism on the Basis of Religious or Moral Views, How Should the Hospital Respond?

Members of the ethics committee brought up a concern that some members of the public may have moral or religious objections to transgender surgery. Objections had been raised when the GeMS program was first started, including some death threats to staff, and it was thought that it would be important to prepare for any similar backlash in response to the start of the center. The possibility of moral or religious objections to surgery was not seen as a barrier to providing these services, and the ethics team recommended that appropriate hospital staff, including public relations staff, familiarize themselves with the nature of possible objections to the establishment of the center and with the underlying medical and ethical reasons for establishing the center to be able to engage in informed communication with the public. To accomplish this goal, center staff worked with marketing and communications staff at the hospital to develop evidenced-based messaging and responses to expected objections and to increase staff confidence with transgender issues. Center staff have also offered, and continue to provide in an ongoing manner, training to health care and support professionals throughout the hospital on both how to support patients and the importance of gender-affirming care for individual well-being.

How Will the Center Show Respect for, and Accommodate, Religious or Moral Objections by Staff to Participating in the Procedures Offered by the Center?

The hospital has some existing policies related to religious and moral objections by staff. The personnel policy on “Requests to be excused from Patient Care Responsibilities,” for example, states that the hospital “will consider a request by a staff member not to participate in aspects of a patient’s care or treatment when such care or treatment conflicts with a staff member’s bona fide ethical or religious beliefs.” However, the policy is also clear that such a request cannot be accommodated if it will negatively affect care for the patient.

All participants involved in the discussions recognized the importance of education in addressing staff moral and religious concerns. To help accomplish this goal, center staff involved in education attempt to provide a safe space for questioning and discussion of care practices. In addition, center staff are currently in the process of deploying a validated survey to examine provider attitudes about and self-assessed competence in lesbian, gay, bisexual, and transgender health care across the hospital. It is suggested in the preliminary results that provider attitudes are primarily positive, although there were some responses expressing moral concerns about working with lesbian, gay, bisexual, and transgender patients and families. Results also suggest that providers were consistently less comfortable, and felt less competent, about working with transgender patients and families than lesbian, gay, and bisexual patients and families. This is being addressed through offering increased opportunities for professional education on gender surgery and gender-affirming care throughout the hospital. Center staff offered more than 20 trainings to BCH staff between December 2017 and December 2018, and trainings continue to be requested across a variety of units and departments.

How Should the Center Allocate Resources in the Event That the Need for Services Exceeds Capacity?

There is a documented unmet need for gender-affirming services, including surgical procedures. This was clearly visible in the fact that, within a few months of Boston Medical Center starting to offer insurance-covered vaginoplasty, their waitlist quickly grew to over 200 patients. Because of the possibility of waitlists for the center’s services, the ethics team recommended that the center have a clear and consistent method of prioritizing patients for care. The center decided to take a first-come, first-served approach to initial consultation with patients. However, the center recognized there would be a need to undertake further exploration of methods for allocating resources in the event that limits were reached. From the beginning, center staff anticipated that hair removal would likely provide the primary scheduling barrier for patients seeking genital affirmation, and that has proven to be the case. (Hair removal is a requirement for genital surgery because of concerns about the presence of hair in the neourethra or neovagina.) Chest surgery scheduling is more straightforward and primarily limited by the availability of operating room time. While continuing to use the first come, first served principle, the center is working on ways to shorten waiting times whenever feasible.
THE DILEMMA OF PATIENT AGE

After the initial ethical discussions were conducted, there remained several questions that the center wished to explore further. One such question was determining an appropriate age range for patients to be able to access each type of gender-affirming surgical procedure. Because the hospital is a pediatric institution, with policies about the age ranges for which it is appropriate to provide care, this discussion needed to address both the lower and upper bounds of care.

The WPATH SOC state that genital surgery should not be done until the age of majority in any given country (18 in the United States), but that it may be reasonable for chest surgeries to be done earlier.3

Unfortunately, there is extremely limited published research on the impact of chest surgeries on the pediatric and young adult population. In what research there is, it is suggested that chest surgery can make it easier for young transmasculine individuals to participate more fully in society, including making it easier to exercise and maintain their health.58 This research is supported by the clinical experience of center staff. Breast augmentation also has the potential to allow young transfeminine individuals to present more effectively as feminine, although fewer transfeminine than transmasculine individuals are interested in chest surgery.32

After weighing the guidelines and feedback from stakeholders, the center decided to deviate from the SOC and set 15 as a minimum age for undergoing a chest reconstruction or breast augmentation, with surgery at age 15 only being appropriate for those individuals who have had a strong and consistent gender identity and, in rare cases, those who are significantly limited in life activities by the presence of their breasts. Because the risk of desistence of a transgender identity declines sharply after puberty,22,65 the center thought that this allowed for a reasonable balance of recognizing the possible risk of a premature decision with respecting patients’ current needs and preferences. Determining the minimum age for genital surgeries was somewhat more complicated. Although all center staff felt comfortable with requiring phalloplasty candidates to wait until the age of majority for surgery, the same was not true for vaginoplasty candidates. Transgender women who have not undergone vaginoplasty may face a number of challenges related to the existential threat that is sometimes perceived to accrue through the presence of male genitalia in a women’s-only space.32

This concern may be particularly salient for young transgender women who are going off to college and who want to live, and be treated, like any other young women on campus. As a result, a number of American surgeons perform vaginoplasty procedures in patients under the age of 18 to allow young women to begin their adult lives feeling safe and affirmed in their gender.5 Although mental health outcomes associated with vaginoplasty have generally been shown to be quite positive, to date there have been few published studies specifically exploring the psychosocial outcomes of vaginoplasty in minors.70,71 Two studies following the same small population of girls who underwent vaginoplasty during adolescence did report improved psychological functioning and decreased gender dysphoria at 1 and 5 years follow-up.72,73

However, performing vaginoplasty in patients under the age of 18 raises several particular concerns.1 These include the ability of the patient to adequately provide assent52 and a detailed assessment of whether the young woman will be capable of the extensive postsurgical care required by the procedure.72,74 It is also critical to explicitly address the fact that the procedure will render the patient permanently sterile and attempt to determine whether the patient is capable of making an informed decision to permanently impact their fertility. Although fertility assessment is, in theory, a standard part of assessment earlier in the transition process, the center team felt it was critical to include such an assessment as part of the initial social work consult with every potential patient, regardless of age. This fertility assessment includes questions about whether the patient wants to have biological children, any history of gamete preservation, and appropriate referrals as necessary. The center team has found that doing such an assessment is critical because a sizeable minority of patients do not have a clear understanding of the fertility impacts of gender transition at the time of the initial consult.

The center staff eventually came to the conclusion that it is appropriate to offer vaginoplasties to certain individuals before the age of majority so that they can safely embark on their adult lives. However, to address legal concerns related to performing vaginoplasties in Massachusetts minors, it was necessary to institute a policy requiring such patients to either have undergone fertility preservation or to seek out a court order granting permission for surgery. To date, the only family to which this option has been offered has decided to pursue the court order.

CONCLUSIONS

Building a gender surgery center in a pediatric setting requires
institutions to address unique ethical and legal challenges. It is important for providers and administrators to have a clear understanding of the local legal environment and relevant ethical principles. Plans for navigation of ethical challenges should be discussed early in the process, and institutions should plan to respond to ethical and moral considerations brought up by staff, patients, and the public at large. Ongoing ethical and legal consultation, as well as a broad range of staff, patient, and public educational opportunities, are likely to be needed. Such processes are necessary to provide optimal care for members of the transgender community in an ethically responsible fashion.

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ABBREVIATIONS

BCH: Boston Children's Hospital
GeMS: Gender Management Service
SOC: standards of care
WPATH: World Professional Association of Transgender Health

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