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Navigating Evolving Ethical Questions in Decision Making for Gender-Affirming Medical Care for Adolescents.

By Laura Kimberly, Kelly McBride Folkers, Baer Karrington, Jeremy Wernick, Samantha Busa, and Caroline Salas-Humara, 2021¹

Short summary

In this article Kimberly et al. outline the ethical challenges associated with assessing capacity for decision-making and obtain assent or consent for gender-affirming medical care (GAMC) in adolescents. Two case examples are outlined to illustrate what a family-centered collaborative process for decision making around gender affirming medical care for transgender or gender expansive (TGE) youth might look like. The ethical challenges that clinicians, minors who identify as TGE, and family of TGE youth face around decision-making are described, and recommendations for best practices for obtaining the assent or consent of the minor and parental consent for GAMC are laid out.

Introduction

Today more TGE adolescents have the opportunity to seek GAMC to reduce symptoms of gender dysphoria and/ or help with transition. There are multiple ethical considerations around obtaining assent or consent from minors who identify as TGE youth and their parents that health care providers should keep in mind when providing GAMC to minors. Two cases are included to illustrate what a multidisciplinary, patient-and family centered approach to achieving assent or consent may look like.

The first case describes a 12 year old transgender male with gender dysphoria, who wish to explore options for GAMC, and whose parents are in support of this. The case describes a multidisciplinary team approach to the informed consent process, where a social worker, psychologist, and healthcare provider are working together with the patient and family to discuss options and risks involved with the use of hormones to suppress puberty, in particular the risk of fertility loss, and options to preserve the possibility of the patient having children in the future.

The second care describes a 14 year old transgender male seeking treatment for gender dysphoria. In this case one of the parents objects to the use of puberty suppressing hormones. The case

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illustrates a multidisciplinary team approach where health care providers across specialties are working with the minor and their parents to come to an informed agreement around a treatment approach that is in the patient's best interest.

Key discussion points

Informed consent and decisional capacity:

Historically, health care providers have debated whether pediatric patients can consent to medical treatment at an early age. In most countries, individuals 18 years or older are considered to have full decisional capacity. Minors may be able to consent to specific types of medical care (such as medical care for prevention and treatment of sexually transmitted infections, vaccinations, and contraception). Previous Endocrine Society guidelines stated that youth ages 16 years or older would be able to understand the irreversible consequences of gender-affirming hormones, but newer guidelines reflect a more flexible approach to the age of consent, highlighting that decisional capacity is evolving over time. The newer guidelines also suggest that gender-affirming hormone treatment should be started earlier than the age of 16 to protect bone density and to prevent the minor from experiencing unwanted social consequences of experiencing puberty.

The mature minor doctrine that applies in some countries, including the USA, does in principle open the possibility for achieving assent or consent to GAMC among minors younger than 16. The authors argue that GAMC, including use of hormones to delay puberty, should be available to minors younger than 16, but recognize that there is a need for exploring at what age an individual is able to demonstrate capacity to understand the implications of GAMC and provide consent to use of gender-affirming hormones to delay puberty. The authors argue that health care providers working with TGE youth should respect the minor's autonomy as it evolves. They should pay special attention to the inherent power imbalances and avoid externalizing their own biases in the capacity assessment process of a minor seeking GAMC.

Other relevant ethical considerations relating to informed consent and decisional capacity include the potential risk associated with changes to laws and policies around thresholds for consent to GAMC for TGE youth under 16. The authors caution that such attempts to bar minors from accessing GAMC may lead to severe mental health outcomes and has the potential for creating a public health crisis for youth identifying as TGE.

Assent:

Getting assent is a way to obtain agreement from someone when they are not able to give legal consent. Currently there is no standard or best practices in place for assessing capacity for provision of informed assent. The MacArthur Competence Assessment Tool for treatment to assess decisional capacity (MacCAT-T) is an instrument that assesses decision-making capacity for treatment decisions by using semi-structured interviews to assess a patient's level of understanding, reasoning, appreciation and ability to express a choice. Studies have shown promising results of the application of this tool in adult populations. However, research is needed to determine if the tool is appropriate for a pediatric population, including TGE youth.

The lack of guidelines and standards for assessment of decisional capacity in TGE minors makes the capacity assessment and assent/consent process for TGE minors seeking GAMC more challenging and may result in delays in access to treatment. Lack of informational material to support the assessment and consent process contribute to complicate the process further.

Implications for Equity and Justice:

Inconsistencies in or even a lack of policies around assessment of capacity for decision making and obtaining assent and/or consent from minors identifying as TGE creates inequitable access and unjust barriers to accessing GAMC.

A lack of, or inconsistencies in, policies may also result in highly subjective assessments of the minor's decisional capacity. To alleviate this problem, the authors recommend a multidisciplinary patient- and family-centered approach, where a team consisting of health care providers across specialties, including social work, mental health, and medical care supports the minor and their family to help them identify their values and goals for treatment as well as help them better understand the implications of GAMC.

Policies or practices that call for parental consent from both parents may also contribute to inequity or injustice in access to GAMC by causing delays. This was illustrated in the second case, where the patient's parents disagreed about whether to allow their 14-year-old child to proceed with GAMC.

Recommendations and Conclusion

The paper concludes that there is room for improving approaches to obtaining assent/consent from minors identifying as TGE and their parents for GAMC. Based on the discussion, the authors put forward a set of recommendations to establish best practices for obtaining assent or consent from minors and parental consent for GAMC, which includes: facilitation of the assent/consent process by an interdisciplinary health care team to support the TGE minor and their parents; being less rigid about age restrictions for assent/consent; take into account individual lived experiences among TGE youth when assessing and determining decisional capacity; provide and develop age-appropriate information materials (including multimedia presentations and the like) to support patients and their families in the decision-making process.