Improving Our Understanding of Medical Decision-Making Competence in Puberty Suppression

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In this issue of *Pediatrics,* Vrouenraets et al present findings on an important study assessing transgender adolescents’ medical decision-making competence (MDC) to give informed consent for starting puberty suppression (PS) among a sample of youth receiving care at 2 specialized gender identity clinics in the Netherlands. This study has significance for 2 important reasons: (1) PS has gained increased use in care for transgender adolescents; and (2) recent legislation in several US states, as well as a recent court decision in the United Kingdom, seek to severely limit access to all gender-affirming care.

PS using Gonadotropin Release Hormone analogs (GnRHAs) has been shown to be reversible, when treatment is suspended, and has been a long-standing standard of care for children with precocious puberty. The benefits of PS include reducing the psychological distress of developing secondary sexual and other physical characteristics that may be incongruent with one’s gender identity. PS may also diminish the need for future surgical gender-affirming interventions, although a retrospective study in *Pediatrics* by van de Grift et al noted the possibility of limiting successful vaginoplasty for transfemale patients. The impact of long-term use of GnRHAs on an adolescent’s future fertility and on bone development and growth is less clear. As described by Vrouenraets et al, PS allows transgender adolescents to “mature and accrue life experiences” before deciding about gender-affirming treatments, which have irreversible changes.

Although the data collection for this study by Vrouenraets et al was initiated in 2016, the authors point to a 2020 decision handed down by the High Court of Justice in London, United Kingdom that youth 15 years and younger are “highly unlikely to understand puberty suppression (using GnRHAs), and therefore cannot give (their own) consent,” as a significant trend in localities creating barriers to care for transgender youth and their caregivers. In an article published in *Pediatrics* in 2021, Kremen et al described the intent and potential negative impact of pending legislation in 14 state legislatures in the United States. These lawmakers, despite impassioned and thoughtful input from transgender youth, their parents and other caregivers, and experienced clinicians and researchers in several disciplines, seek to limit or prevent, and, in some cases, criminalize, access to all gender-affirming care.

In all contexts of health care for adolescents when a parent or caregiver formally provides consent for care, providers should also confirm the assent of the minor. This is because, as supported by American...
Academy of Pediatrics policy, as well as by the United Nations Committee on the Rights of the Child, minors have the ability to consider health information and participate in decision-making about various treatments, including acute and chronic conditions, as early as the age of 12 years old. In many jurisdictions in the United States, when local governments do not specify a lower age limit, clinicians are able to apply the mature minor principle to determine if a minor can give consent for sensitive services like reproductive health. Much has also been written about adolescents being able to make complex medical decisions when not living in the context of an emotionally stable and consistent household, relying on the support and guidance from other trusted adults.

In terms of the specific context of PS, the authors aptly point out that high-quality programs use multidisciplinary teams with longitudinal follow-up to assure that youth and their parents are well-informed and supported as they make decisions about care options including PS. In fact, studies have noted the small number of youth who discontinue GnRHAs to resume puberty and the small number who regret their decision to have started puberty and the small number who discontinue GnRHAs to resume puberty. Vrouenraets et al make the point that MDC is largely assessed in an unstructured way, and clinicians’ assessments “may be personal and subjective.” As such, the major innovation of this study is to use the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) to assess MDC, a tool with well-supported reliability in many contexts, including for psychiatry care as well as clinical research. The researchers asked 3 questions for their study: (1) are transgender adolescents competent to give informed consent for starting PS, by standard and MacCAT-T assessment; (2) what is the intermethod agreement between standard and MacCAT-T assessments; and (3) how are age, intelligence, psychological functioning, duration of diagnostic trajectory, sex, and family situation associated with MDC for PS? To this purpose, the researchers conduct one-time semistructured interviews with 74 transgender adolescents, aged 10 to 18 years old, already receiving care at 2 Dutch specialized gender identity clinics. The MacCAT-T assesses the 4 domains considered necessary for MDC: (1) understand the information relevant to one’s condition and the proposed treatment; (2) appreciate the nature of one’s circumstances, including one’s current medical situation and the underlying values; (3) reason about benefits and potential risks of the options; and (4) be able to express a choice.

In this study, >93% of the participants were assessed as competent to consent to PS. Notably, there was high interrater agreement for both the standard approach to MDC assessment and the MacCAT-T assessment; there was also high intermethod agreement between assessment determinations. Interestingly, age, level of emotional and behavioral challenges, and duration of the diagnosis were not related to the MacCAT-T score. However, higher intelligence score was independently associated with a higher MacCAT-T. This supports the notion that cognitive and psychosocial development are more important than age for decision-making capacity.

The authors conclude that the MacCAT-T is both feasible and valid as a measure of MDC of transgender adolescents in the context of PS. Moreover, most, but not all, of the subjects were assessed as competent, evidence that supports the ability of minors who are seeking pubertal suppression or gender-affirming care to participate in decisions about their own health care, with the support and guidance of trusted caregivers and clinicians.

Together, as the authors state, these findings suggest an important role for the MacCAT-T as an adjunct, in some cases, to determine MDC for the purposes of treatment decisions around PS. It also suggests the need to further assess its role in the context of gender-affirming medical and surgical interventions. Importantly, the authors point out that the standard assessments of MDC using a multidisciplinary team, taking place over multiple time points, remains essential, and is especially crucial for youth with lower intelligence and with behavioral challenges, whose vulnerability requires additional support. Management decisions in these situations and other challenging cases often benefit from the participation of bioethicists. Of note, the authors acknowledge that such youth were not subjects in this study. The authors mention that another limitation of their study is that the subjects, along with their
parents, had already received several sessions helping them understand the range of consequences of PS. We see this more as a strength to the study than a limitation because it reflects the current real-world approach to providing high-quality care for transgender youth and their families. Nevertheless, understanding how the MDC assessment, using both standard provider assessment and MacCAT-T determinations, might change over time would provide clinicians with important information. Also, although the researchers assessed the duration of diagnosis, we do not have information on pubertal status, a point acknowledged by the researchers when considering an explanation for the differences between subjects’ sex assigned at birth. Another consideration for future research is understanding the role that the MacCAT-T can play in situations in which the adolescent and the parent may disagree about treatment options and how the determinations can assist multidisciplinary teams to better support families through this process.

In conclusion, Vrouenraets et al have provided important evidence that transgender adolescents can participate competently in decision-making regarding using GnRHas for PS and have shown us the utility of including the MacCAT-T to further supplement the current processes in place to protect and support young people and their families in this aspect of gender-affirming care. This is consistent with supporting the adolescent’s emerging autonomy and development as a health care consumer. Moreover, the literature has demonstrated the importance of adolescents participating in decisions about their medical care. As the authors mention, there is a need to perform future studies because there are limited data on transgender adolescents’ MDC.

However, this study provides scientific basis supporting continued advocacy against judicial and legislative actions that would interfere with access to this developmentally appropriate process of medical decision-making and this necessary area of care. As in so many areas of health care for adolescents, this is one in which policies need to support and respect the decision-making capacity and autonomy of the transgender adolescent, their caregivers, and the dedicated professionals who support them.

**ABBREVIATIONS**

GnRHAs: Gonadotropin Release Hormone analogs
MacCAT-T: MacArthur Competence Assessment Tool for Treatment
MDC: medical decision-making competence

**REFERENCES**


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