Medically assisted gender affirmation: when children and parents disagree

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ABSTRACT

Institutional guidelines for transgender children and adolescent minors fail to adequately address a critical juncture of care of this population: how to proceed if a minor and their parents have disagreements concerning their gender-affirming medical care. Through arguments based on ethical, paediatric, adolescent and transgender health research, we illustrate ethical dilemmas that may arise in treating transgender and gender diverse youth. We discuss three potential avenues for providing gender-affirming care over parental disagreement: legal carve-outs to parental consent, the mature minor doctrine and state intervention for neglect. Our discussion approaches this parent-child disagreement in a manner that prioritises the developing autonomy of transgender youth in the decision-making process surrounding medically assisted gender affirmation. We base our arguments in the literature surrounding the risks and benefits of gender-affirming therapy in transgender children and the existing legal basis for recognising minors’ decision-making authority in certain medical situations.

INTRODUCTION

An estimated 0.7% of children and adolescents under the age of 18 years identify as transgender or gender diverse, with more recent estimates identifying up to 1.8% of high school students identifying as transgender.3 4 The use of ‘transgender’ throughout this paper refers to individuals who have a gender that does not align with their sex assigned at birth and includes individuals who do not identify with the gender binary of male/female. National trends in transgender youth visibility in the medical community remain unclear.3 4 In a single-centre study and in the experiences of the authors’ institutions, there is a significant increase in youth presenting for gender-related care.5 An increasing number of publications surrounding the care of transgender youth suggest an increase in clinical services.6-9 However, despite recent reviews of ethical issues in transgender paediatric populations10 and a comprehensive overview from the American Academy of Paediatrics (AAP),11 leading institutional guidelines for transgender paediatric patients fail to adequately address a critical juncture of care of this population: how to proceed if a child, who is still legally a minor, and their parents have disagreements concerning initiation of gender-affirming medical care.11-13

Family and guardians play an important part in gender affirmation, including social support and access to medical resources. The involvement of parents and family in the care of transgender youth is considered the standard practice.4 12 13 However, a parent’s reaction to a transgender child may not be that of acceptance. This can create conflict not only in the child or teen’s home life but also with decisions around medically assisted gender affirmation.

We discuss possible means of navigating the parent-child disagreement that prioritises the developing autonomy of transgender youth who are legal minors in the decision-making process surrounding medically assisted gender affirmation (figure 1). We will briefly discuss the literature surrounding the risks and benefits of gender-affirming therapy in transgender children and the existing legal basis for recognising minors’ decision-making authority in certain medical situations. We conclude that situations where a parent prevents a minor from receiving treatments related to gender dysphoria violate the Harm Principle and justify state intervention.

MEDICAL GENDER AFFIRMATION: RISKS AND BENEFITS IN MINORS

In accordance with the World Professional Association for Transgender Health (WPATH) guidelines, the current gender-affirming medical practice includes hormonal and surgical therapy, along with individual or family counselling and supportive social transition.12 The major benefit of all gender-affirming therapies is resolving dysphoria caused by secondary sex characteristics discordant with the patient’s self-perceived gender identity.5 9 The guidelines stratify medical intervention into those considered relatively reversible (eg, hormone blockers) versus irreversible (eg, surgery or permanent changes secondary to hormones).12

Minors who are beginning puberty may benefit from gonadotropin-releasing hormone (GnRH) analogues (puberty blockers), which prevent the development of secondary sex characteristics that exacerbate gender dysphoria. Emerging data on the effects of puberty blockers reveal decreased rates of depression and overall improved psychosocial functioning in gender dysphoric children with minimal long-term side effects.14 15 The use of GnRH analogues may decrease or prevent the need for gender-affirming surgical procedures such as gender mastectomy or facial feminisation due to the physical changes that occur during puberty. Young adults who begin gender-affirming hormones following puberty blockade also report improved quality of life.16 17 Following puberty, many patients choose to take gender-affirming hormone therapy in the form of testosterone or oestrogen, which have well-documented positive psychosocial outcomes.11 16 17 Despite the lack of long-term data on specific clinical interventions, a recent ethical
Discussion concludes that ‘the risks of not treating transgender and gender non-conforming youth with gender dysphoria are evident’.10

Although social transition and hormonal-suppression are considered reversible interventions, gender-affirming surgery is permanent. Gender-affirming surgery is currently recommended for individuals aged at least 16 years of age but often ≥18 years.12 Recent insurance database analysis and patient-reported outcome studies identified patients as young as 14 years old undergoing a gender-affirming mastectomy.18 19 Some research works suggest there are psychosocial benefits to individuals receiving gender-mastery in their teens.18 20-22 For both surgical and hormonal gender-affirming care, there are psychosocial and physical benefits for transgender minors.

Despite data showing benefits of medical gender affirmation for minors, risks remain. Minors must be informed of the potential for medical gender affirmation to foreclose on future fertility options. Hormone therapy with oestrogen or testosterone can prevent spermatogenesis and ovulation, respectively. Sperm and oocyte cryopreservation can be costly and includes procedures that can induce emotionally distressing side effects, and currently, there are no definite practice guidelines for fertility preservation for transgender patients.23 24 Surgical gender affirmation can also alter fertility, whether through the removal of gonadal tissue or for natal females, the removal of the uterus. Additionally, hormone therapy can complicate surgical therapies for minors who use GnRH analogues followed directly by hormones. The prevention of secondary sex characteristics by hormone therapy may result in the requirement of additional tissues used in vaginoplasties, for example.25 Thus, infertility due to surgical alterations in anatomy or hormone therapy as well as the potential for more challenging surgical procedures following some hormone therapy regimens should all be weighed against the potential benefits of medical gender-affirming treatment in minors.

The risks and benefits of medical gender affirmation should also be considered in a social context. Recent data showed that transgender youth who were able to use their chosen name (rather than name assigned at birth) reported fewer depressive symptoms and less suicidal ideation and behaviour, suggesting that psychosocial burdens may also unsurprisingly be alleviated by social, non-medical interventions.26 Alternatively, for example, the persistence of a prepubescent body habitus due to puberty suppression has been linked to decreased social inclusion for transgender youth whose physical development is asynchronous to their cisgender peers.19

**WHEN PARENTS AND TRANSGENDER MINORS DISAGREE**

Regardless of which gender-affirming therapy is sought, parents may disagree with their minor’s decision to proceed with gender-affirming care. The heterogeneous nature of minors’ capacity to understand their medical concerns as well as assent to treatment requires a nuanced approach to each decision-making process. Clinical reality and the current landscape of guidelines defy the possibility of making neat ethical and decision-making category distinctions among minors.

There are varying perspectives on the role of the paediatric patient in medical decision-making. The 2016 AAP’s statement on informed consent reaffirms and stresses that developmentally appropriate consent should be obtained before any medical treatment in addition to consent provided by a legal guardian.27 This statement respects the varying legal ages of consent requirements that may be legally established (often at a State level), and the individual patient’s developmental status in making a particular medical decision. In clinical practice, there is a wide variance in an individual minor’s capacity to understand the risks, benefits and consequences of a particular medical treatment or procedure. The 2016 AAP Informed Consent Guidelines suggest that children begin involvement in their medical decisions in a developmentally appropriate manner beginning at age 7, with a graduating involvement based on age and disease experience.27 Recently, the AAP has reaffirmed this position specifically in the transgender population.11 Children ‘reverting’ to their gender assigned at birth is a controversial concern that some parents may have in pre-pubertal children that has recently been denounced by the AAP and a systemic review.11 28

In the case of adolescent transgender medical care, WPATH and the Endocrine Society suggest that transgender children can make their own medical decisions at the age of 16 years.12 13 It should be noted that the age of consent to medical treatments without parental consent varies across the European Union, with roughly 35% of members requiring age of majority (18 years old), 40% ranging from 14 to 16 years old, and the remaining considering maturity rather than a strict age cut-off.29 Notably, according to current Australian treatment guidelines for transgender minors, Australian law allows an adolescent’s clinician to determine their capacity to provide informed consent for treatment.30 Additionally, it should be noted that the Endocrine Guidelines recommend initiation of puberty blockers at Tanner stage II–III, which almost always precedes the age of consent.31 In clinical practice, there is a wide variance in an individual child’s or adolescent's capacity to understand the risks, benefits and consequences of a particular medical treatment or procedure. WPATH and AAP guidelines suggest that an adolescent’s decision-making capacity should be honoured unless there are concerns surrounding the ability to do so.12 13 These include the adolescent’s lack of ability to understand the ramifications of medically assisted gender transition such as potential side effects.
and irreversible effects of treatment, or having unrealistic expectations surrounding the medication’s effect. Importantly, a diagnosis of gender dysphoria is not considered a legitimate reason to doubt an adolescent’s decision-making capacity.

EXISTING LEGAL CARVE-OUTS FOR MINOR’S CONSENT TO MEDICAL TREATMENT

Ideally, the discussion to initiate gender-affirming treatment would include both parent and minor (figure 2). A child’s participation in their medical decision making is considered a dynamic process based on age and an individual child’s experience with capacity to understand a medical condition, aimed at ultimately honouring the child’s assumed best interest. Beyond medical guidelines, the conflict between child autonomy and parental consent in decision making has been explored within the law, particularly in the field of reproductive health, where a precedent of privacy ensures access to specific services. All states and the District of Columbia allow young people to consent to Sexually Transmitted Infection (STI) services without parental consent, of which 39 states have no lower age limit. Parental disclosure may lead to a subset of minors not receiving medically necessary care. The initial basis for these varied state laws pertaining to reproductive health also stems from Casey vs Population Services International, in which the Supreme Court ruled that the state cannot prevent minors from buying non-prescription contraceptives under the 1st and 14th amendment on the basis of privacy.

Legal carve-outs for specific areas of healthcare for minors are also applicable to the issues of abortion, mental health and substance abuse in which potential harm to the minor by denial of medical services trumps parental disclosure and are recognised as exceptions for obtaining parental consent by the AAP. Although the legal reasoning and jurisprudence behind each carve-out is beyond the scope of this paper, the ethical exceptions given to minors regarding consent to these services are well established.

Treatment for transgender children can be viewed in the same light, as the current literature suggests improvements in psychosocial outcomes. Access to healthcare is particularly important for the overall health of transgender minors, who are at increased risk of suicide, anxiety and depression. Seeking parental consent for transgender minors may also result in further harm such as domestic violence, homelessness and worsening mental health. The combination of (1) pre-existing legal carve-outs around sexual/reproductive health and (2) data supporting the benefit of gender-affirming care in minors support including gender-affirming care in the existing exceptions to minors’ capacity to consent.

The distinction between gender-affirming medical interventions and interventions that currently carry exceptions to consent for minors, for example, reproductive healthcare, are at times artificial. In situations where parents wish to withhold gender-affirming care, it is necessary to consider categories of gender-affirming care that could be accessed by a minor’s consent alone through pre-existing legal carve-outs. For example, menstrual manipulation (ie, menstrual cessation through "birth control") could be considered gender-affirming care but could be accessible to a minor without parental consent.

This is conditional on provider liability tolerance; however, we urge providers to consider how some gender-affirming interventions have very strong ethical support in a landscape with robust legal and ethical precedents for a minor’s ability to pursue sexual and reproductive interventions. Gender-affirming care implicates privacy and adolescent well-being concerns in similar ways as contraceptive access, STI testing, mental healthcare and substance abuse care. The existence of legal carve-outs to parental consent for these latter forms of care supports the need for legislatures to adopt similar legislation creating carve-outs for gender-affirming care.

MATURE MINOR DOCTRINE AND TRANSGENDER YOUTH

Another area of ethical exception to minors’ inability to consent is the mature minor doctrine. The doctrine states that adolescents deemed mature have the capacity to consent. Holder summarises the doctrine as follows: ‘If a young person understands the nature of proposed treatment and its risks, if the physician believes that the patient can give the same degree of informed consent as an adult patient, and if the treatment does not involve very serious risks, the young person may validly consent to receiving it’. Importantly, the mature minor doctrine is an ethical principle, and its applicability does not necessarily grant legality to a decision-making process. The law’s recognition is both limited and patchwork. Within the USA, 34 states have no legal exceptions in place for mature minors and only 14 states permit mature minors to consent to general medical treatment. Despite the highly varied nature of legal support for the mature minor doctrine across state jurisdictions, as an ethical concept, it is highly relevant to gender-affirming therapy. In situations where gender-affirming treatment is deemed low risk and aligns with current guidelines, we believe the mature minor doctrine can be applied to adolescents.

The unique ethical consequences of applying the mature minor doctrine to gender-affirming treatment should be noted in considering the doctrine’s blanket applicability. The precedent for the treatment types often applied under the mature minor doctrine has outcomes that are not readily apparent to family members who may have withheld consent to such services (eg, STI testing and treatment). Notably, the pursuit of gender-affirming care and its results on patient presentation are likely to be apparent to family members. Specifically, the mature minors’ reliance on ‘small degrees of risk’ is compromised by the likely discernable outcomes of gender-affirming treatment and potential negative impact on the parent–child relationship (which sought to bypass parental consent in the first place). Thus, the utility of the mature minor doctrine as an avenue to gender-affirming care contains salient exceptions to existing precedents for its use.

Ultimately, allowing transgender minors to consent to gender-affirming treatment, that is, over-riding parental consent, should be sought only when all other avenues to try to bring caretakers around have failed or if approaching them poses a clear and present risk to the minor’s well-being. The discussion of such approaches is outside the scope of this paper. The avenues

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discussed previously should be considered only after attempts to reconcile parent–child disagreement with psychosocial intervention have been thoroughly pursued.

WHEN DISPUTES BECOME DANGEROUS: REFUSAL OF TREATMENT AND NEGLECT

Healthcare professionals have a unique role as providers of gender-affirming therapies that improve quality of life, decrease depression and decrease high-risk behaviours.16 17 Neglect may be used in extreme cases, assuming psychosocial interventions have been diligently pursued, to provide paediatric patients with gender-affirming treatment. Neglect, as defined by the AAP Committee on Child Abuse and Neglect, is ‘failure to heed obvious signs of serious illness or failure to follow a physician’s instructions once medical advice has been sought’.22 Factors contributing to this definition include direct harm to the child with refusal of treatment, net benefit to the child with treatment and baseline access to healthcare and medical advice that is not being used.24 Neglect, as a medico-legal term, can be used to initiate an evaluation by Child Protective Services and remove a parent as a child’s legal guardian in the most severe instances.27 42 This action is supported by Mill’s Harm Principle, in which a physician is ethically obligated to involve the state when an individual’s actions may directly cause harm.43

Gender dysphoria should not be an exception to the evaluation of neglect when a guardian is preventing the treatment of a child with severe mental health sequelae and possible physical self-harm that gender-affirming therapy can resolve. Thus, research supports invoking parental neglect when youth who experience extreme gender dysphoria are prevented from accessing medically recommended gender-affirming interventions. This course of action as a recourse for parent–child disagreement over gender-affirming medical interventions requiring consent is consistent with the established understanding of paediatric ethics and thresholds for over-riding consent. Diekema’s foundational paper stated that ‘state intervention is justified when the parental refusal places the child at a significant risk of serious preventable harm’.43 The literature on paediatric gender-affirming medical interventions supports the applicability of Diekema’s conditions to justify state interference with parental decision-making to transgender minors. Some of these include: refusing consent places the child at a significant risk of serious harm; the refused intervention has proven efficacy; and the interventions projected benefits outweigh its projected burdens.43

Consensus supports Diekema’s conclusions that the harm threshold is more robust ethical guidance than ‘best interest’ standards.44 However, critics have noted the ‘insufficiency of the harm threshold for over-riding parental decisions’, arguing that determining harm requires complex value judgements that are no more ethically clear that ‘best interests’.45 It is outside the scope of this paper to address this debate. But as outlined previously, the current data landscape supports the conclusion that over-riding parental consent to provide gender-affirming care for transgender minors with a harmful manifestation of gender dysphoria is consistent with established ethical precedents.

The consequences of over-riding parental stakeholders are a critical aspect of determining net harm in the above-mentioned ethical framework for bypassing parental consent. We perceive two potential salient manifestations of this type of harm: (1) material harm (eg, loss of shelter, food, basic resources and so on) and (2) compromising the patient’s psychosocial bond/relationship with their family. Transgender treatment guidelines emphasise psychosocial education and counselling to mitigate such harms.11–13 30 However, persistent parent–child disagreement around gender-affirming care can generate significant harms. Family rejection and refusal of gender-affirming care can have severe consequences, such as anxiety, depression and high-risk substance use and suicide.9 37 Children with parents who reject their transgender identity are 8.4 times more likely to attempt suicide and are 5.9 times more likely to suffer from depression than peers with supportive families.36 Thus, the harm secondary to compromised parent–child relationships is an additional ethical consideration in determining at what harm threshold to over-ride parental consent.

CONCLUSIONS

Despite the absence of clear clinical guidelines for transgender minors seeking medical treatment in the absence of parental consent, there is sufficient ethical precedent and clinical data to conclude that treatment should not be withheld when a minor is at risk of undue suffering. Because there is evidence to suggest dysphoria and associated comorbidities would be relieved by treatment, this logic aligns with Diekema’s criteria for over-riding parental consent and Mill’s Harm Principle. Although guidance is not law, the capacity of a transgender minor should be strongly advocated for in a matter consistent with a provider’s general treatment of adolescents in any other medical decision-making settings such as STI services and contraception. The clinician should consider the decision to pursue hormone therapy or surgery in relation to current guidelines, risks to the individual patient and the child’s decision-making capacity.

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