Gender self-determination as a medical right: Extended version

Florence Ashley[*]

Transgender people face many formal barriers to gender-affirming care, sometimes known as 'gatekeeping'. Gender-affirming care refers to a wide range of medical interventions that patients pursue to affirm, actualize, and/or embody their sense of gender. Common forms of gender-affirming care include transition-related surgeries, hormone therapy, puberty blockers, and hair removal. Healthcare providers often refuse to offer gender-affirming care to trans patients without an assessment of the person's gender identity or dysphoria. Adolescents may moreover need to show that they have experienced gender dysphoria for several years before receiving care and may be denied care until they satisfy a strict age requirement. In this paper, I sketch out the basic form of my argument that patients have a presumptive right to gender-affirming care based on the principle of gender self-determination. By presumptive, I mean that there is a presumption that patients have such a right but that the presumption can be rebutted by showing that encroachments are adequately justified under the standards described later in this article. Presumptive rights can be contrasted with absolute rights, which cannot be rebutted or derogated from.

Being transgender is a matter of diversity, not pathology.[1] When providers create barriers to gender-affirming care, they are impairing their patients' ability to live out their sense of gender. People should be able to determine their lived gender without the interference of doctors. Given the psychological and social importance of gender, it may be suggested that healthcare providers recognize a presumptive right to

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gender-affirming care and strive to remove barriers to care that cannot be justified.

A presumptive right to gender-affirming care is an important part of redressing gaps in access. Not every trans person wishes to pursue gender-affirming interventions—it is a deeply personal choice—but many do. In Canada, 73% of trans people want to or have pursued some form of gender-affirming care and another 16% is unsure.[2] Yet, only 26% of trans people have received all desired gender-affirming care.[2] Barriers to care erected by clinicians are one of the reasons for the large gap between desire for gender-affirming care and access to gender-affirming care.

The aim of this paper is not to present a definitive argument for gender self-determination as a medical right—it would be impossible given the available space—but to foster reflection among healthcare providers on how they may be knowingly or unknowingly creating barriers to gender-affirming care. For interested readers, I have addressed some common concerns with a right to gender-affirming care in a previous article.[3] My hope is that, by reflecting on their attitudes and practices, healthcare providers will help reduce the stark gap in access to gender-affirming care.

Medical Autonomy and Everyday Autonomy

At the heart of medical ethics lies the principle of autonomy, according to which patients must be free to act "in accordance with a self-chosen plan."[4] Autonomy is the reason why patients have a right to refuse care, and it underpins healthcare providers' duty to properly inform patients so that they can decide whether to accept a proposed treatment or not. Medical autonomy is, however, asymmetrical. While patients have the right to refuse an intervention, medical autonomy does not typically afford them the right to demand a specific intervention from their doctor.[4] Nor does medical autonomy generally prevent providers from imposing discretionary restrictions and conditions on access to care. Gender-affirming care can be considered along similar lines as abortion, which is also desired for its own sake and often framed as a right.[3]

Gender-affirming care, however, does not only implicate medical autonomy. It implicates autonomy over everyday life—thereby engaging the principle of gender self-determination. A person's gender is one of the most powerful determinants of the shape of their life. Gender influences how others refer to you, what facilities you use, who you date, which peers you have, how others treat you, and which social norms are applied to you. It is also implicated in the body, with primary and secondary sexual characteristics playing a central role in social and sexual intercourse. Bodily features influence whether others perceive you as male, female, or non-binary, as trans or cis. Having certain body parts also shapes your ability to do many things such as use urinals or have penetrative sex—the latter of which is recognized as significant in the treatment of erectile dysfunction. If you do not feel like your body reflects your sense of gender, you may experience persistent discomfort in everyday life and struggle to flourish in your social or romantic life. Feeling misperceived may also cause you to withdraw from meaningful relationships and can be a source of significant distress.

Gatekeeping gender-affirming care curtails everyday liberty, dictating critical aspects of trans individuals' social, interpersonal, and embodied life. The impact of gatekeeping gender-affirming care extends far beyond the medical realm, permeating the deepest reaches and crevices of trans people's lives. Access to gender-affirming care determines whether and how you get to live as yourself, every day of your life. For most, a life in another gender would be a radically different existence.

The Principle of Gender Self-Determination

Recognizing the impact of gender-affirming care on everyday autonomy brings us to the principle of gender self-determination. Gender self-determination means that individuals have a right to define, express, and embody their gender identity as they see fit. Gender self-determination is one of the cornerstones of the *Yogyakarta Principles*. The *Principles* are an international legal document that sets out human rights recommendations regarding sexual orientation and gender identity.[5] They were developed in 2006 by leading human rights experts at an meeting held in Yogyakarta, Indonesia. While the *Principles* do

not use the term "gender self-determination," it is the golden thread that binds the document. According to the document:

> Each person's self-defined … gender identity is integral to their personality and is one of the most basic aspects of self-determination, dignity and freedom. … No one shall be subjected to pressure to conceal, suppress or deny their … gender identity.[5]

I would suggest that the principle of gender self-determination can be derived from many long-recognized rights. Given the expressive facets of gender, the right to free speech offers a compelling foundation for gender self-determination.[6] The principle could also be justified based on equality rights since cisgender or non-trans people typically have a body that aligns with their sense of gender and since lack of access to gender-affirming care facilitates social discrimination.[3] The right to privacy, the right to identity, the right to dignity, and the right to live and act with integrity may also offer support the principle of gender self-determination.[7,8] As explained by Loukēs G. Loukaidēs, later of the European Court of Human Rights: "For [someone] to be able to function freely, in the full sense of the term, [they] must have the possibility of self-definition and self-determination: the right to be [oneself]."[9] Gender self-determination is implicitly and explicitly recognized by multiple international actors, including the European Court of Human Rights, the Inter-American Court of Human Rights, and the United Nations Independent Expert on Sexual Orientation and Gender Identity.[10–12]

Gender Self-Determination as a Medical Right

The principle of gender self-determination alters the ethical obligations of healthcare providers. Given the impact of gender-affirming care on people's ability to express, embody, and live out their gender in everyday life, trans people have a presumptive right to gender-affirming care. Trans patients are, in this sense, in a special situation that expands the traditional scope of medical autonomy. This reasoning is perhaps best expressed in the decision of the European Court of Human Rights in *Van Kück v Germany*, which explained that "the burden placed on a person to prove the medical necessity of treatment, including irreversible

surgery, in the field of one of the most intimate private-life matters, appears disproportionate."[10]

Medical care often constrains everyday liberty; that is not the sole province of gender-affirming care. But there are differences of kind and degree where gender-affirming care is concerned. Conventional approaches of diagnosis and treatment have little place in gender-affirming care, as being trans is a matter of diversity rather than pathology.[1,8,13] Gender-affirming care is a way for the person to shape themselves from a gendered perspective, not a means of treating an underlying pathology. Once we understand trans existence in terms of diversity rather than pathology, we can begin to rethink gender self-determination as a medical right.

Justifying Barriers to Gender-Affirming Healthcare

Given the presumptive right to gender-affirming care, healthcare providers should avoid creating unjustified and unnecessary barriers to accessing transition-related medical interventions.[14] The presumption in favour of access to gender-affirming care can be outweighed by other considerations. Barriers to gender-affirming care are, however, infringements that must be retrieved from the jaws of immorality by greater goods. Because trans people have a presumptive right to gender-affirming care, the burden of justifying barriers to care lies on the healthcare providers who erect them. Whether a barrier is sufficiently justified cannot be reduced to an algorithm. It requires the careful exercise of personal judgment and collaborative discussion. These discussions must include trans scholars, communities, and patients.

A barrier to gender-affirming care would be justified if there was clear and compelling evidence that it prevents harms of sufficiently great magnitude and quantity that they unambiguously outweigh the barriers' negative impacts on gender self-determination and wellbeing. Clear evidence reports ethically relevant outcomes (e.g., quality of life), can be generalized to the relevant clinical population, and cannot reasonably be interpreted differently.

Compelling evidence is derived by robust scientific methodologies that are suited to the research question and, considered as a whole, establish

the existence of disproportionate harm. The harm that barriers seek to prevent must be sufficiently serious to outweigh individuals' autonomy in defining the most fundamental aspects of their personal identity. From the perspective of non-maleficence, impairing one's ability to live out their sense of gender is itself harmful. Unfortunately, healthcare providers have historically failed to recognize the psychological and social harm of denying gender self-determination. When evaluating whether a barrier is justified, providers should give considerable weight to its impact on autonomy, with the understanding that autonomy includes the right to make bad decisions for oneself. The freedom to make only good decisions would be meaningless.

The threshold I propose for justifying barriers to gender-affirming care—clear and compelling evidence that the barrier's benefits outweigh its negative impacts—does not seem to be satisfied for at least three common barriers to gender-affirming care. These questionable barriers involve (1) the requirement of gender assessments, (2) the requirement of several years of gender incongruence for adolescents, and (3) rigid age requirements.

Gender Assessments

The traditional requirement of assessing gender identity and/or gender dysphoria is based on expert consensus and there is "no scientific evidence of the benefit of these requirements."[15] No clear and compelling evidence shows that assessments are effective in predicting and preventing regret, or that they are necessary and proportionate.[16] Diagnostic requirements were developed to legitimate gender-affirming care in the eyes of the public, avoid legal liability, and restrict access as much as possible.[17] These requirements reflected providers' pathologizing understanding of trans communities as well as suspicion towards them, with the original standards of care—published in 1979—encouraging providers to assess gender identity and gender dysphoria "independent of the patient's verbal claim" and referring to patients as "possibly unreliable or invalid sources of information."[18] Assessments are viewed negatively by many trans individuals, and can cause distress due to increased delays and mistrust in patients' fundamental self-understanding.[19] Standardized questionnaires and freeform evaluations

often reflect stereotyped, narrow, and inaccurate understandings of trans communities.[20] No reliable predictor of regret has been identified in the literature.[16] There is no test for being trans. On the contrary, some studies have suggested that assessments do not improve outcomes.[21,22] Clinics that de-emphasize or renounce assessments do not report higher rates of regret or lawsuits.[21] De-emphasizing or renouncing assessments has become prevalent in North America and no evidence of negative outcomes has yet to emerge.

Duration of Gender Incongruence for Adolescents

The requirement that adolescents experience "several years of persistent gender diversity/incongruence" prior to initiating hormone therapy or surgery is also on uncertain footing. The requirement is not grounded in evidence that immediate access to gender-affirming interventions, without waiting several years, is associated with regret or negative mental health outcomes.[23] Nor is it backed by evidence that being older correlates with better mental health outcomes. Instead, its proponents justify it based on precautionary reasoning, pointing to the fact that some youths elect not to pursue transition-related interventions and claiming that low regret rates are only applicable to youths who "demonstrated sustained gender incongruence and gender-related needs over time."[23] The empirical claim is misleading given that studies demonstrating positive outcomes often do not specify the length of identification prior to the intervention and come from a wide range of clinical context, including some that deliberately aim to reduce delays and barriers to care.[24,25] Critically, there is no clear and compelling evidence that the requirement is necessary. No available data suggests that faster access to gender-affirming care would lead to worse outcomes. Given this dearth of supporting evidence, providers may instead prefer to focus on supporting adolescents' decision-making process.

Age Requirements for Physical Interventions

Another barrier to gender-affirming care takes the form of rigid age requirements for puberty blockers, hormone therapy, and surgeries. Age requirements vary across providers and guidelines but are typically 12 or Tanner II for puberty blockers, 14 or 16 for hormone therapy, 15, 16

or 18 for chest surgeries, and 17 or 18 for genital surgeries. These age thresholds are not based on empirical evidence, but are rather linked to assumptions about youths' cognitive and emotional maturation.[26] Concerns over maturity and capacity to consent are legitimate, but are not adequately captured by strict age requirements. Rigid age requirements act as barriers for youths who are younger but equally as mature, disciplined, and supported as some older patients. Moreover, these types age requirements betray an all-or-nothing understanding of autonomy that belies its gradual development and heterogeneity across the population.[27] The developing autonomy of youth is recognized in Canadian law under the mature minor doctrine. In the words of the *Convention on the Rights of the Child*, youths' views must be "given due weight in accordance with the age and maturity of the child." No clear evidence suggests that acceding to youths' reasoned requests for gender-affirming care would be harmful, especially in contexts where the intervention is hormonal or where the patient has sufficient discipline and support to follow post-operative care. From the foregoing, it is unclear whether rigid age requirements can meet their burden of justification.

Conclusion

Gender is an immensely impactful facet of who we are, one that should not be determined by healthcare providers. In this paper, I have suggested that providers of gender-affirming care may have an ethical duty to respect the gender self-determination of patients, and accordingly bear the burden of justifying the barriers they erect on access to gender-affirming care. Being trans is a matter of diversity, not pathology. By avoiding unnecessary and unjustifiable barriers to care, providers can acknowledge the role of gender-affirming care in one's ability to live out their sense of gender and demonstrate respect for the dignity of trans patients. My aim is not to chastise providers but invite greater reflection. Ours is a painful history, one that we must take care not to reproduce. Going forward, I hope that providers working with trans communities will carefully examine their practices to ascertain whether they are justified by clear and compelling evidence. Practices that fail to meet this threshold of justification should be abandoned.

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