Transgender and nonbinary individuals are those whose gender is incongruent with their sex assigned at birth. These individuals will often experience psychological distress and functional impairment related to gender incongruence and may meet criteria for a diagnosis of gender dysphoria, as outlined in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition Text Revision (DSM-5-TR).1 Many people with gender dysphoria will pursue gender-affirming medical and/or surgical interventions to alleviate their distress.2,3 The World Professional Association for Transgender Health and The Endocrine Society have published clinical protocols for providing gender-affirming medical and surgical care.2,3

Existing research suggests that discontinuing or regretting gender-affirming medical interventions is rare. In a large cohort study from The Netherlands, among the nearly 7000 individuals who had engaged in services at the clinic between 1972 and 2015, only 0.6% of transwomen and 0.3% of transmen who underwent gonadectomy were identified as experiencing regret about those procedures.4 Of note, regret is a complex and heterogeneous concept, which we will subsequently explore. Studies of adolescents who start pubertal suppression have found that only a few percent ultimately chose to discontinue gender-affirming medical care.4,5

Despite the fact that discontinuation of gender-affirming medical or surgical interventions is rare, clinical protocols should be in place to support patients who have dynamic needs surrounding these interventions. In this issue of JAMA Network Open, MacKinnon et al6 provide findings from qualitative interviews to better understand the diverse perspectives of patients who wished to discontinue or reverse prior gender-affirming treatments, their clinical needs, and what research should be conducted to better support these individuals.

The fact that some individuals discontinue or reverse gender-affirming medical or surgical care has been woefully politicized, often used as evidence to criminalize the provision of medical care.7 Common themes emerged from the interviews conducted by MacKinnon et al6 indicating that those with dynamic gender-affirming needs did not believe that gender-affirming medical care should be banned, nor did they necessarily regret having undergone such interventions. In fact, only 6 of the 27 (22%) who had undergone medical interventions experienced regret and felt that medical transition was the wrong pathway for them. For many, these interventions were the right decision at the time and an important aspect of their lived journey. Many participants noted that their discontinuation of gender-affirming medical interventions was not driven by personal internal factors such as a fluctuation in gender, but rather was the result of unsupportive social environments (including family members). Given the heterogeneity of explanations for discontinuation or reversal of gender-affirming care, we caution against use of a broad label such as detransition to describe this complex phenomenon, favoring more specific terms like discontinuation of gender-affirming medical care, regret regarding gender-affirming medical care, or evolution regarding conceptualization of one's gender identity.

A common theme among participants in the MacKinnon et al6 study was the concern that their decision to discontinue interventions would be stigmatized by their clinicians. MacKinnon et al6 emphasize the importance of clinicians regularly reminding patients that they will be supported regardless of how their gender identity and needs related to gender-affirming medical care evolve.
There are limited data on the physiological and psychological effects of discontinuation of exogenous hormones because it is such a rare occurrence. Owing to a paucity of published research, clinicians have little to guide them when patients wish to discontinue gender-affirming medical or surgical interventions. In lieu of professional sources of information, MacKinnon et al briefly discuss the role of information procured by participants from online “detrans” communities. For example, participants in the present study found information online suggesting discontinuation of testosterone could lead to low energy. It is difficult to know if testosterone discontinuation itself results in low energy, or if this is due to a nocebo effect. More research is needed on the effects of discontinuation so that clinicians can better educate patients.

MacKinnon et al also provide some preliminary data regarding drivers of discontinuation of gender-affirming interventions. Participants cited a range of diverse reasons including concern related to a family history of carcinoma, pressure from family to discontinue interventions, fear that presenting as transgender and nonbinary would lead to employment discrimination, evolution in one’s conceptualization of their gender, and satisfaction with the physical changes one has already experienced from the intervention to date with no desire for additional physical changes.

In the past, we have suggested that clinicians adopt a framework of internal and external factors when understanding why someone may discontinue gender-affirming medical interventions. External or distal factors include harassment, discrimination, victimization, or other conditions arising from the sociocultural context in which an individual is situated. The study by MacKinnon et al adds to the existing literature indicating that many individuals who discontinue medical interventions do so in response to distal, rather than proximal factors. This information should encourage all of us to work on improving the sociocultural context so that people can live their most authentic self. Clinicians ought to inquire about such external factors and intervene when possible (eg, family therapy or connecting patients with legal support). Internal or proximal factors are those that come from within oneself (eg, evolution of one’s understanding of their gender identity, contentment with the physical changes already obtained by interventions). It is important that clinicians consider how external factors can exacerbate internal factors. Much as the gender identity minority stress model explains the ways in which societal stigma can lead to internalized concepts (eg, internalized transphobia) and subsequent anxiety and depression, external factors such as societal stigma may lead to what seem to be internal factors driving desires to discontinue gender-affirming care. Exploring such factors can help clinicians understand how to best support patients experiencing evolution of gender-affirmation needs.

Although the field of gender medicine has historically focused on binary and static conceptualizations of gender identity and gender-affirmation needs, the time has come for clinicians to recognize that these conceptual frameworks do not align with the lived experiences and embodiment goals of every individual seeking care. Gender-affirming care should encompass the entirety of an individual’s embodiment goals, even when those goals may have pivoted over time. MacKinnon et al provide a key jumping off point to move the field forward, as we continue to study factors that drive evolving embodiment goals and the physiologic and psychological impacts of dynamic provision of gender-affirming care. What is most vital throughout this process is that patients know their clinicians will respect and support them regardless of how their trajectory evolves, and that they will continue to strive toward research and models of care that support all patients.
REFERENCES


