Youth and Caregiver Perspectives on Barriers to Gender-Affirming Health Care for Transgender Youth

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ABSTRACT

Purpose: Few transgender youth eligible for gender-affirming treatments actually receive them. Multidisciplinary gender clinics improve access and care coordination but are rare. Although experts support use of pubertal blockers and cross-sex hormones for youth who meet criteria, these are uncommonly offered. This study’s aim was to understand barriers that transgender youth and their caregivers face in accessing gender-affirming health care.

Methods: Transgender youth (age 14–22 years) and caregivers of transgender youth were recruited from Seattle-based clinics, and readerships from a blog and support group listserv. Through individual interviews, focus groups, or an online survey, participants described their experiences accessing gender-affirming health care. We then used theoretical thematic analysis to analyze data.

Results: Sixty-five participants (15 youth, 50 caregivers) described barriers spanning six themes: (1) few accessible pediatric providers are trained in gender-affirming health care; (2) lack of consistently applied protocols; (3) inconsistent use of chosen name/pronoun; (4) uncoordinated care and gatekeeping; (5) limited/delayed access to pubertal blockers and cross-sex hormones; and (6) insurance exclusions.

Conclusions: This is the first study aimed at understanding perceived barriers to care among transgender youth and their caregivers. Themed barriers to care led to the following recommendations: (1) mandatory training on gender-affirming health care and cultural humility for providers/staff; (2) development of protocols for the care of young transgender patients, as well as roadmaps for families; (3) asking and recording of chosen name/pronoun; (4) increased number of

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“Transgender” describes a person whose gender identity does not match their natal sex or does not align with traditional notions of masculinity or femininity [1]. Transgender youth have higher rates of anxiety, depression, substance abuse, and suicide than their peers [2,3]. Delaying gender-affirming treatment, including pubertal blockers and subsequent cross-sex hormones, is correlated with further increased psychiatric comorbidity within this population [4]. In contrast, timely administration of these treatments correlates with improved body image and lower risk of long-term mental health problems [5–7]. However, in spite of guidelines by the Endocrine Society, American Academy of Pediatrics, American Academy of Child and Adolescent Psychiatry, and World Professional Association for Transgender Health which support gender-affirming medical management for transgender youth [8–11], few transgender youth who are eligible for these interventions actually receive them [12]. Multidisciplinary gender clinics pose a promising solution to this access problem by offering coordinated, team-based gender-affirming health care [1,13,14]. However, few medical centers house such clinics or even offer gender-affirming treatments to eligible youth [12].

Many provider- and health care system–related factors impact access to these interventions. Pediatricians rarely receive training in gender-affirming health care, which may lead to insufficient understanding of the unique health issues transgender youth face and inadequate knowledge of how to prescribe treatments [12,15–17]. Other barriers include limited insurance coverage [12] and provider concerns about limited data on long-term outcomes and the validity of gender dysphoria as a medical diagnosis rather than a social construct [17].

Prior qualitative studies assessing barriers to gender-affirming health care have focused on the perspectives of physicians [16,18–20] or adult transgender patients [21–23]. Little is known about the experiences of transgender youth and caregivers; the single study examining male-to-female transgender youths’ perspectives about health care utilization is based on data over 15 years [24]. The present study aimed to identify barriers to accessing gender-affirming health care and solicit recommendations from transgender youth and their caregivers for overcoming these barriers.

Methods

We used a mixed methods approach to increase flexibility for participants and allow for triangulation of key themes from multiple data sources. We invited transgender youth age 14–22 and caregivers who are parenting a transgender youth age ≤ 22 years to participate in qualitative interviews, focus groups, or an online survey (Figure 1). Although caregivers from other states were allowed to participate, recruitment efforts were concentrated in Washington State. Participants were specifically recruited from Seattle-area clinics serving transgender youth, a support group listserv, and a hospital-sponsored blog.

Potential participants were informed that they would be asked about their experience seeking gender-affirming health care, including barriers encountered. Youth at any stage of gender transition were eligible to participate as long as they self-identified as having a gender identity incongruent to their sex assigned at birth. Youth participants endorsed a range of gender identities...
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