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

IMPLICATIONS AND CONTRIBUTION

This study gives a voice to both contemporary transgender youth and their caregivers on the topic of barriers to gender-affirming health care. Their perspectives and recommendations emphasize the need for multidisciplinary gender clinics, which currently exist in only a handful of U.S. cities.

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multidisciplinary gender clinics; (5) providing cross-sex hormones at an age that permits peer-congruent development; and (6) designating a navigator for transgender patients in clinics.

“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

![Figure 1. Study recruitment and participants.](image)
including transgender male, transgender female, or a gender identity outside the traditional male/female gender binary. Overall, 15 youth and 50 caregivers participated between April and November 2015; see Table 1 for demographic information.

Focus groups were conducted in person and lasted 1.5–2 hours; interviews were conducted in person or by phone and lasted 20–45 minutes. Scripts were semi-structured, with prompts developed based on prior research and clinical experiences with transgender patients. All interviews and focus groups were audio recorded and transcribed. The survey contained free response and multiple-choice components; in this analysis, we assessed free response answers only. See Table 2 for topics and example prompts included in each modality.

We used thematic analysis technique and Atlas.ti software (ATLAS.ti, Berlin, Germany) to analyze data [25]. We initially used a deductive approach, developing the preliminary codebook based on prior research and clinical experience. As the analysis progressed, we used an inductive approach to identify new themes and collapse similar themes. Analysis began while data collection was still underway; recruitment closed after new themes ceased to emerge (thematic saturation). This study was approved by Seattle Children’s Hospital institutional review board, with written caregiver and youth consent/assent, as applicable by age.

### Results

Six themes emerged as common or important barriers to gender-affirming health care. In this section, we describe these barriers and participants recommendations to improve care using illustrative quotes. See Table 3 for summary of key themes.

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### Table 1
Demographics of study participants

<table>
<thead>
<tr>
<th></th>
<th>Caregiver participants, n = 50</th>
<th>Youth participants, n = 15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, average (range)</td>
<td>47 (29–71 years)</td>
<td>18 (14–22 years)</td>
</tr>
<tr>
<td>Gender identity, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female: 40 (83)</td>
<td>Transfeminine: 3 (20)</td>
<td></td>
</tr>
<tr>
<td>Male: 7 (15)</td>
<td>Transmasculine: 7 (47)</td>
<td></td>
</tr>
<tr>
<td>Transmasculine: 1 (2)</td>
<td>Other*: 5 (33)</td>
<td></td>
</tr>
<tr>
<td>Did not answer: 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex assigned at birth, n (%)</td>
<td>[Data not collected]</td>
<td>Female: 10 (67)</td>
</tr>
<tr>
<td>Race/ethnicity, n (%)</td>
<td></td>
<td>Male: 5 (33)</td>
</tr>
<tr>
<td>White: 39 (78)</td>
<td>Black/African-American: 2 (4)</td>
<td></td>
</tr>
<tr>
<td>Black/African-American: 2 (4)</td>
<td>Native American/American Indian or Alaska Native: 2 (4)</td>
<td></td>
</tr>
<tr>
<td>Native American/American Indian or Alaska Native: 2 (4)</td>
<td>Hispanic/Latino(a): 1 (2)</td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino(a): 1 (2)</td>
<td>Asian/Pacific Islander: 2 (4)</td>
<td></td>
</tr>
<tr>
<td>More than one ethnicity: 4 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advanced degree: 14 (29)</td>
<td>Some college/vocational school: 4 (27)</td>
<td></td>
</tr>
<tr>
<td>Bachelor’s degree: 19 (39)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some college/vocational school: 13 (27)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma/GED: 3 (6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not answer: 1</td>
<td>Currently in high school: 6 (40)</td>
<td></td>
</tr>
<tr>
<td>Marital status, n (%)</td>
<td></td>
<td>[Not applicable]</td>
</tr>
<tr>
<td>Married: 35 (71)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced: 8 (16)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separated: 1 (2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single: 4 (8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domestic partnership: 1 (2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not answer: 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State of residency, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WA: 33 (67)</td>
<td>WA: 15 (100)</td>
<td></td>
</tr>
<tr>
<td>Other state (not WA)</td>
<td>Other state</td>
<td></td>
</tr>
<tr>
<td>Age at which realized gender identity was different from sex assigned at birth, n (%)</td>
<td>[Not applicable]</td>
<td></td>
</tr>
<tr>
<td>Age &lt; 7: 2 (18)</td>
<td>Age 8–13: 6 (55)</td>
<td></td>
</tr>
<tr>
<td>Age 14–17: 3 (27)</td>
<td>Age ≥18: 1 (9)</td>
<td></td>
</tr>
<tr>
<td>Did not answer: 3</td>
<td>Received: 2 (20)</td>
<td></td>
</tr>
<tr>
<td>Pubertal blockers, n (%)</td>
<td>Want or might want: 0 (0)</td>
<td></td>
</tr>
<tr>
<td>Received: 2 (20)</td>
<td>Did not want (was eligible): 0 (0)</td>
<td></td>
</tr>
<tr>
<td>Want or might want: 0 (0)</td>
<td>Too old for blockers (was not eligible): 8 (80)</td>
<td></td>
</tr>
<tr>
<td>Did not answer: 4</td>
<td>Received: 0 (0)</td>
<td></td>
</tr>
<tr>
<td>Cross-sex hormones, n (%)</td>
<td>Want or might want: 7 (100)</td>
<td></td>
</tr>
<tr>
<td>Received: 9 (64)</td>
<td>Do not want: 1 (7)</td>
<td></td>
</tr>
<tr>
<td>Want or might want: 4 (28)</td>
<td>Did not answer: 1</td>
<td></td>
</tr>
<tr>
<td>Gender-affirming surgery, n (%)</td>
<td>Received: 0 (0)</td>
<td></td>
</tr>
<tr>
<td>Received: 0 (0)</td>
<td>Want or might want: 7 (100)</td>
<td></td>
</tr>
<tr>
<td>Did not answer: 8</td>
<td>Do not want: 0 (0)</td>
<td></td>
</tr>
</tbody>
</table>

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*Percentages for some variables do not add up to 100 due to rounding.

*Other* gender identities included: genderqueer, gender fluid, nonbinary, transmasculine/genderqueer, and androgenous.

Participants’ states of residency outside WA (1 each): AZ, CA, CO, GA, FL, MD, NC, OR, PA, TN, TX.
Few accessible providers trained in gender-affirming health care for youth

Participants described three sought-after provider features: (1) accessible—not prohibitively far, within their insurance network, accepting new patients; (2) trained in gender-affirming health care—able to provide transition-related treatments, up-to-date on the literature, interacts with transgender patients nonjudgmentally; and (3) for youth—serves adolescents and preadolescents. Most participants expressed difficulty finding a provider in whom these features aligned.

…it was hard enough to find [providers] who were accepting new patients, worked with adolescents, and took my insurance… on top of it, finding somebody who was trans-friendly made it all but impossible. —Youth, 19

Lack of training in gender-affirming health care elicited frustration from many participants, especially caregivers who were new to gender-affirming health care themselves.

That’s ridiculous that I am some[one]… who doesn’t know anything and I had no idea there was even such a thing as a trans-man… so I’m trying to get up to speed, and I’m supposed to be educating the physicians? That’s a joke.” —Caregiver

Youth and caregivers described many specific factors that detracted from providers’ ability to deliver gender-affirming care, including not asking about gender identity, use of outdated/offensive language, inadequate knowledge, and judgmental or hostile clinical interactions.

…[the physician’s] calling [my child] ‘she’ and ‘Julie,’ and I keep saying ‘he,’ ‘Jack,’ and she starts getting angry with me and flipping her head at me, like I was causing her to be annoyed… she gave me a look to kill. —Caregiver (pseudonyms applied)

Some participants also described providers who emphasized rigid gender roles within a gender binary and/or who conflated sexual orientation and gender identity.

[My therapist] flat out told me that [my gender identification] was a phase I was going through because I still liked men and

N/A — not applicable.

Table 2
Topics and example prompts from interviews/focus groups and online survey

<table>
<thead>
<tr>
<th>Topic</th>
<th>Interview/focus group prompt</th>
<th>Online survey prompt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender journey</td>
<td>Can you share a little about your/your child’s gender journey?</td>
<td>How many years old was your child when you first realized/learned their gender identity is different from the sex they were assigned at birth?</td>
</tr>
<tr>
<td>General experiences</td>
<td>Tell me about your experiences, good or bad, accessing health care related to your gender identity.</td>
<td>Think about any experiences you’ve had seeking health care for your child related to their gender identity.</td>
</tr>
<tr>
<td>General barriers</td>
<td>What barriers have you faced when seeking health care related to your/your child’s gender identity?</td>
<td>Please tell us about those experiences, especially the ones that really stand out.</td>
</tr>
<tr>
<td>Provider experiences</td>
<td>Can you think of a health care provider who did a great job providing care for you/your child related to gender identity?</td>
<td>Which type of provider did you initially seek out to inquire about care related to your child’s gender identity?</td>
</tr>
<tr>
<td>Social/legal transition</td>
<td>Did you/your child seek help navigating a social and/or legal transition? If so, can you tell me about that experience?</td>
<td>N/A</td>
</tr>
<tr>
<td>Pubertal blockers</td>
<td>Did you/your child seek pubertal blockers? If so, can you tell me about that experience?</td>
<td>Have you and your child discussed puberty suppressing hormones (also known as puberty blockers)?</td>
</tr>
<tr>
<td>Cross-sex hormones</td>
<td>Did you/your child seek pubertal blockers? If so, can you tell me about that experience?</td>
<td>Have you and your child discussed cross-gender hormones?</td>
</tr>
<tr>
<td>Mental health</td>
<td>Did you/your child seek mental health care related to gender identity? If so, can you tell me about that experience?</td>
<td>N/A</td>
</tr>
<tr>
<td>Recommendations</td>
<td>Take a minute to picture an ideal health care experience related to your/your child’s gender identity. In other words, picture a scenario where you/you and your child are treated exactly how you’d like to be treated; and you receive exactly the care you’d like to receive. Can you walk me through this ideal experience?</td>
<td>In your opinion, what can Seattle Children’s Hospital do to improve the care it provides for transgender youth and their families? In your opinion, what changes need to be made in the community more broadly to improve the lives of transgender youth and their families?</td>
</tr>
</tbody>
</table>

Table 3
Participants’ cited barriers and recommendations

<table>
<thead>
<tr>
<th>Barrier theme</th>
<th>Associated recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Few accessible providers trained in gender-affirming health care for youth</td>
<td>Mandatory training, for pediatric providers and staff, on gender-affirming health care and cultural awareness</td>
</tr>
<tr>
<td>Lack of consistently applied protocols</td>
<td>Development of protocols for the care of young transgender patients, as well as a roadmap for their families</td>
</tr>
<tr>
<td>Inconsistent use of patients’ chosen name/pronoun</td>
<td>Asking and recording of chosen name/pronoun in electronic medical record</td>
</tr>
<tr>
<td>Uncoordinated care and gatekeeping</td>
<td>Increased number of multidisciplinary gender clinics</td>
</tr>
<tr>
<td>Limited/delayed access to pubertal blockers and cross-sex hormones</td>
<td>Providing cross-sex hormones at an age that permits peer-congruent development</td>
</tr>
<tr>
<td>Insurance exclusions</td>
<td>Designating a transgender patient navigator position in clinics to guide patients through different insurance policy options if needed</td>
</tr>
</tbody>
</table>
still liked...to paint my nails. I wanted to pierce my ears. I’m not the ‘masculine,’ buff man that she felt you had to be to be trans[gender male], and I couldn’t get the care I needed because all she was telling me is, ‘This isn’t true.’ —Youth, 22

Participants also cited providers’ lack of interest and/or underlying moral opposition to gender-affirming health care as reasons for the pervasive lack of adequate care.

“It was made very clear to us at the first appointment that this doctor’s expertise was not in this area, nor her interest.” —Caregiver

“...They’re not down with it and they don’t like it...they don’t want to treat it, and you better just figure it out on your own.” —Caregiver

Other barriers to accessing gender-affirming health care included clinic distance, patient age requirements, and providers being out-of-network or not accepting insurance. Participants recommended universal provider education on gender-affirming issues to improve cultural awareness and increase the number of pediatric providers who are competent in providing gender-affirming health care. One caregiver noted the impact that provider education would have not only on health care interactions but also on family dynamics:

“Having more docs...who focus on transgender issues would be the single biggest improvement...and [provider reassurance] that being transgender is not an ailment [but] rather another variation of being human would go a long way in helping parents [like me] accept their transgenders [sic] children early on.”

Finally, many participants noted that a supportive clinical environment could simply mean treating transgender patients like any other patient. A desire to be seen as normal—rather than an “outsider,” “sexual deviant,” “science experiment,” or “spectacle” —permeated the data set.

**Inconsistent use of patients’ chosen name/pronoun**

Misgendering incidents, in which the nonpreferred name and/or pronoun was used in a health care setting, were common and often distressing for participants. Most cited incidents were verbal and repeated events, even after correction by the patient or caregiver. A caregiver who described herself as “grieving the loss of a [male] child and embracing a new [female] one” equated a misgendering appointment reminder to “a dagger to the heart.” A 19-year old described the lasting impact of being misgendered in clinic:

Situations like that, I will never forget them ‘cause I always feel like everyone turns and looks at me right away...you’re just sitting in a room and everyone’s eyes on you and you’re hot and nervous...

Although most incidents were perceived as unintentional errors, some participants discussed incidents they perceived as intentional or even malicious.

...the doctor said, ‘her, her, her’ and [my son], who’s 10, said, ‘him, him, him!’ and the doctor got mad and started sort of being dismissive and irritated, and kept saying ‘her!’...this weird sort of oppositional like ‘I’m not calling you that.’ —Caregiver

The difference between caregivers’ and adolescents’ responses to misgendering was striking. Caregivers frequently described correcting the speaker or requesting a note in the chart, whereas adolescents in clinic without a caregiver more commonly said nothing:

“I’m not gonna take the very limited time that I have with this specialist to talk about my gender. I just need to get my throat fixed.” —Youth, 19

However, many adolescent participants described relief or elation when their chosen name and pronouns were used (“It made my whole day”). Participant recommendations to address misgendering in clinic included asking patients their chosen name and pronoun and recording/making these preferences visible in the medical record. Many participants described not wanting special treatment but rather freedom to focus on health issues when seeing a provider.

“It’s really cool to be able to go somewhere that I wasn’t immediately uncomfortable as soon as I got there.” —Youth, 19

**Lack of consistently applied protocols**

Many participants described what they perceived as lack of protocols for transition-related health care, especially for younger patients and those desiring pubertal blockers. Participants specifically lamented when physicians were unaware of professional guidelines or the potential consequences of not following them.

[Our physician] said, ‘Well it’s still considered controversial for early trans care,’ and honestly I thought, ‘What the [expletive]?’ I used to work for [a clinic] as a volunteer, and I saw what happened to a lot of these trans people, the diseases, the things they did just to get medicines, and it was really sad. I did not want that to be my kid... —Caregiver

So why would you not do blockers immediately? To me that is insane... This is an emergency. Look at the suicide rates on these kids. —Caregiver

Many participants recommended that clinics develop clear, evidence-based protocols for providers as well as age-appropriate roadmaps for transgender patients and families to help guide expectations. Participants desired concrete language—“a step-by-step list... ‘Call this person, tell them this’”—as opposed to “a whole lot of talk” without specific instructions for moving toward a transition-related goal.

**Uncoordinated care and gatekeeping**

Many participants cited uncoordinated care as a barrier. This was particularly true with respect to accessing cross-sex hormones; patients were often told by one provider they were not a candidate for hormones, whereas another provider was willing to administer them. Other participants discussed disorganized care underlying a façade of teamwork in transition-related health care.

So we were told that ‘This is our team,’ but they hadn’t actually all talked together, and then there’s a plan in care, but it’s all talk, it’s not organized, thought out, and planned, so no one really knows who and what everybody else is doing. —Caregiver
Many participants viewed mental health providers as gatekeepers to cross-sex hormones, and commonly described feeling frustrated that they had to wait for mental health provider approval to medically transition. Most participants wished therapy were integrated with medical care rather than a prerequisite. Some described negative experiences with mental health providers, including perceptions that therapists disliked transgender persons, feared legal consequences if transitioned patients later had regrets, or did not understand or minimized potential consequences of delayed treatment (“... it’s like, ‘Well, we’ll see you in six months, if you don’t kill yourself first’”). Others described feeling they had to prove that they are “trans enough” to be cleared for gender-affirming treatments. Participants who identified outside the gender binary also described dissatisfaction with numerical scales used by mental health providers to quantify how much one’s gender identity differs from one’s natal sex; “100 is supreme trans,” scoffed a 17-year-old youth.

To address uncoordinated care and gatekeeping, some participants recommended that transition-related care be housed under one roof (“Two words: gender clinic”). A few caregivers had heard about successful multidisciplinary clinics and wanted one in their area.

Limited/delayed access to pubertal blockers and cross-sex hormones

Participants described difficulty accessing both pubertal blockers and cross-sex hormones. For many youth who experienced the puberty of their natal sex, their gender dysphoria and lack of access to appropriate medical interventions were overwhelming, for example, “every day I was just terrified”; “they would consider ending [their life].” Most participants who had sought cross-sex hormones encountered a minimum age requirement of 16 set by their provider. Many viewed this age as too high and described the potential emotional and other consequences of prolonged waits for hormones.

“I guess that’s the thing that kills everybody is the waiting to do something... until you’re of age, especially when it’s something that you’re like ‘I’m solid and I’m not giving this up’... I’m not phasing through it.” —Youth, 17

I had been trying to find any way I could get on [testosterone], even if it wasn’t legal, which really sucks, because you can seriously get hurt by doing that... I was feeling really, really desperate. —Youth, 19

Although many youth would prefer to receive pubertal blockers than undergo a puberty incongruent to their identity, a few said that receiving pubertal blockers without access to cross-sex hormones until age 16 would have been even worse, leading to “ridicule” from sexually maturing peers, “depression,” and impaired romantic relationships.

Another barrier to treatment frequently cited by youth was lack of family approval. Many emphasized the necessity of caregiver approval to receive services that go through caregivers’ insurance. Some caregivers had difficulty accepting body alterations:

I’m still not entirely convinced that [my 17-year-old] has more male tendencies than, for instance, a relatively masculine dedicated lesbian. I certainly wouldn’t say that [my child] is as male as I am... For the time being, we’re using [insurance exclusions] as a stalling tactic for when a little bit more age, experience, and maturity come into play in a clearer knowledge of who [my child] is. —Caregiver.

Other caregivers’ hesitancy originated from concerns about long-term side effects or worries that their child would later regret not being able to have biological children.

I felt like [my child] was giving up the ability to be able to procreate someday. And at sixteen I didn’t want kids either, so that’s not something you can really decide when you’re sixteen... — Caregiver

Other barriers to accessing gender-affirming treatments included lack of provider training and provider hesitancy about unknown long-term side effects. One caregiver weighed urgent mental health problems more heavily than potential future side effects:

I don’t give a [expletive] if my child has heart disease at 50, if he kills himself at 17... I’m trying to get my child to survive. —Caregiver

Many participants recommended that blockers be offered to all prepubertal patients with gender dysphoria and that provider-set minimum age requirements for cross-sex hormones be lowered.

...it needs to be treated like the life-threatening issue that it is... a huge majority of these children commit suicide...It needs to not be ‘You need to be 16 for this. You need to be 17 for this.’ It needs to be treated early, aggressively, and respectfully. —Caregiver.

Insurance exclusions

Insurance exclusions were another barrier to gender-affirming health care. On learning that their plan excludes such services, some participants halted care, not realizing they could appeal a denial. Others endured the appeals process and won:

[We] had to fight like crazy to get [blockers] covered. Just fought and won appeal to get son’s top surgery covered at age 14. Was appealed and won the appeal. —Caregiver

Almost all participants seeking gender-affirming surgery faced exclusions or had coverage only after age 18. In addition to the financial burden and delayed care these exclusions imposed, the diction used to describe gender-affirming surgery—“optional,” “cosmetic”— invalidated the experience of gender dysphoria for some participants. Some participants’ insurance plans deemed certain gender-affirming treatments “necessary,” leaving them baffled by exclusions of other aspects of care:

They’re paying for all the medical visits... up until that point where he needs the surgery and it’s like really? Now you say he doesn’t need the medical assistance, ‘cause it’s not a medical issue anymore? —Caregiver

Some participants had difficulty understanding their insurance policies, preventing them from advocating for transition-related coverage. As one youth described:

It might as well have been another language because it’s so dense and complicated.

Many participants recommended that clinics hire a patient navigator to assist with insurance issues and connect patients to
resources that will enable them to complete prerequisites for each step of a medical transition.

Discussion

Participants cited key barriers to gender-affirming health care and offered recommendations to improve access. Some barriers overlapped with those cited by transgender adults in prior studies, including cost, limited access to transgender-friendly and transgender-knowledgeable providers, limited access to cross-sex hormones, misgendering experiences, and uncoordinated care and gatekeeping [21,24,26]. Others were unique to transgender youth, including lack of gender-affirming treatment protocols for preadolescents, limited/delayed access to pubertal blockers, and prohibitive minimum age requirements for initiating cross-sex hormones.

Our data suggest that the implementation of clear, comprehensive, evidence-based best practices and policies that take into account patient age, pubertal stage, desired future treatments, and comorbid conditions and address barriers to gender-affirming care are likely to improve mental and physical health outcomes for transgender youth. Specific participant-driven recommendations largely align with guidelines put forth by American Academy of Pediatrics [9], American Academy of Child and Adolescent Psychiatry [10], the Endocrine Society [8], and World Professional Association for Transgender Health [11]; however, they are not always followed in practice. For example, Endocrine Society guidelines recommend initiating cross-sex hormones at about age 16 but also allow for earlier initiation at the discretion of the provider, who must consider the potential harm associated with waiting until age 16 [8,27]. Nearly all our study participants encountered a rigid provider-set minimum age of 16, indicating that many providers feel uncomfortable performing this risk/benefit assessment for earlier initiation. A rigid high minimum age requirement carries its own risks, as evidenced by our participants’ descriptions of psychological distress and risky behavior induced by prolonged waiting for cross-sex hormones. Given that the age 16 recommendation is largely based on two Amsterdam studies [6,28], more research is also needed to understand the relative risks and benefits of this age requirement.

Insurance coverage is another important issue [29]. Although the Affordable Care Act increases transgender patients’ access to health insurance, 40 states still allow exclusions for gender-affirming health care under state- and federal-regulated health insurance plans, in spite of evidence that coverage would be cost effective [30,31]. In addition, although recommendations for inputting gender identity data into electronic medical records have been published [32,33], they have not been universally applied.

Provider use of outdated/offensive language and intentional misgendering also need to be urgently addressed. One way to discourage these behaviors is instituting an ombudsman to whom patients can report maltreatment [34]. Cultural awareness training for providers and staff would foster more accepting clinical environments and creating more multidisciplinary gender clinics would increase the number of health care safe havens for transgender youth.

There are limitations to this study. Convenience sampling may have led families with negative health care experiences to be over-represented. The requirement of caregiver consent for minors’ participation translated into a relatively small participant pool of transgender youth, all of whom had undergone social transition and had a supportive caregiver. Transgender youth may be rejected on “coming out” to family, making transgender youth with parental support challenging to recruit. However, thematic saturation was reached with triangulation of youth and parent data, giving us confidence that we captured the main barriers to care experienced by our specific study population. In addition, 75% of study participants (including all youth) were Washington residents; regional differences in health care may exist. However, given the progressive Northwest political climate, it is likely that these barriers are present, if not more extensive, in many other regions. Finally, participants were mostly white and well educated, which may reflect a higher socioeconomic status. Barriers may be amplified or different among minorities and youth of lower socioeconomic status.

This is the first study to delineate key barriers to gender-affirming care and potential solutions from the perspectives of transgender youth and their caregivers. Further research is needed to understand the health care experiences and long-term outcomes of transgender youth in all stages of transition, those who have minimal or no family support, and those from a variety of racial, ethnic, and economic backgrounds. Additional research is also needed to refine best practices, policies, and trainings for health care professionals and determine how they could be implemented in widespread and meaningful ways.

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