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## Adolescent and Caregiver Perspectives on Receiving Gender-Affirming Care in Primary Care

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### Abstract

**BACKGROUND:** Transgender and gender-diverse (TGD) adolescents experience barriers to receiving gender-affirming care. Delivering services in the pediatric primary care setting may help facilitate improved access. With this study, we aimed to explore TGD adolescents' and caregivers' experiences receiving primary care services and their perspectives regarding gender-affirming care delivery in pediatric primary care.

**METHODS:** TGD adolescents aged 14 to 17 and caregivers of TGD adolescents currently receiving gender-affirming medical care participated in 1-hour-long, semi-structured, individual, virtual interviews. Each interview was recorded and transcribed. Transcripts were then individually coded, and themes were generated iteratively by using a reflexive thematic analysis framework. Recruitment of each group continued until thematic saturation was reached.

**RESULTS:** A total of 33 participants (15 adolescents and 18 caregivers) completed interviews. Adolescent participants (mean age of 15.7 years) predominantly identified as transmasculine or trans male (73%), and caregiver participants were predominantly mothers (83.3%). Four themes were identified, which included (1) barriers, such as microaggressions and poor psychosocial support, (2) benefits, such as existing trusted relationships with primary care providers (PCPs) and convenience, (3) improvement strategies, such as training and interdisciplinary collaboration, and (4) opportunities for integrating primary care and specialty gender-affirming care.

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Drs Sequeira and Kahn, and Mx Bocek designed the data collection instruments, collected data, conducted the initial analyses, and drafted the initial manuscript; Mx Reyes, Ms Anan, and Ms Guler designed conducted the initial analyses and drafted the initial manuscript; Drs Asante and Kidd conceptualized and designed the study and drafted the initial manuscript; Drs Christakis, Richardson, and Pratt conceptualized and designed the study and coordinated and supervised data collection; and all authors critically reviewed and revised the manuscript, approved the final manuscript as submitted, and agree to be accountable for all aspects of the work.

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**CONCLUSIONS:** TGD adolescents and their caregivers reported previous negative interactions with PCPs; however, some desired to receive gender-affirming care in this setting, citing increased convenience, efficiency, and availability. Participants highlighted an ongoing need for further work to provide resources, education, and training to PCPs and their staff and improve PCP-to-specialist communication and collaboration.

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Gender-affirming care is recommended as standard-of-care by major medical organizations, including the American Academy of Pediatrics.<sup>1</sup> Transgender and gender diverse (TGD) adolescents encounter numerous barriers that limit equitable access to gender-affirming care and exacerbate health inequities.<sup>2,3</sup> There is a critical need to expand access to gender-affirming care to address the health needs of TGD youth. Despite this need, there continue to be significant logistical, social, and political barriers that limit access to care for this population.

One barrier is the limited number of specialty centers providing gender-affirming care<sup>4</sup> and the fact that most are located in large urban areas. Another barrier relates to challenges associated with political and legislative efforts seeking to ban evidence-based gender-affirming care for minors.<sup>5,6</sup> These obstacles are further compounded by additional barriers TGD youth report facing in accessing care,<sup>7</sup> including limitations in insurance coverage for gender-affirming medications,<sup>8</sup> long waitlists for specialty care,<sup>9-12</sup> and lack of support from family and caregivers.<sup>10,13</sup> A limited body of previous research suggests that TGD youth and their caregivers feel their primary care providers (PCPs) may be ill-equipped in discussing gender-related concerns and, at times, provide biased or inaccurate medical information.<sup>7</sup> This is consistent with findings from studies of PCPs who acknowledge significant training gaps in this area in addition to bureaucratic challenges and political interference limiting their ability to provide comprehensive care for this population.<sup>14</sup>

Despite these challenges, previous qualitative studies with TGD adolescents reveal that many have had positive experiences in primary care.<sup>15</sup> PCPs are often more geographically accessible and may have cared for adolescents for many years, making this a space that could feel safe for exploring concerns about gender identity and gender-specific care needs. However, there remains a significant gap in our knowledge regarding TGD adolescents and their caregivers' perspectives on receiving gender-affirming medical care in the primary care setting. Our aim with this study was to qualitatively explore TGD adolescents' and caregivers' experiences receiving primary care services, and their perspectives regarding gender-affirming care delivery in the pediatric primary care setting. More specifically, we sought to ascertain youth and caregiver-preferred health care environments for receiving gender-affirming medical care and examine their thoughts on strategies to improve care provision.

## METHODS

This was a qualitative interview study with 2 main foci: (1) to understand the experiences of adolescents and caregivers in accessing gender-affirming care services via telemedicine and (2) to explore adolescent and caregiver perspectives regarding the provision of gender-affirming care in the primary care setting. The data presented here are limited to the second

portion of the interview. Data from the portion of the adolescent interviews focused on receiving care via telemedicine has been published elsewhere.<sup>16</sup>

### **Experience of the Research Team**

Our study team approached this study informed by both our personal and professional experiences, which influence our interpretations of the themes outlined in our study findings. Our authorship team includes individuals with clinical expertise as both primary care providers and pediatric subspecialists caring for TGD youth. This team also contributes varied lived experiences to this work and includes individuals of queer and trans experience, individuals who are parents of gender-diverse youth, as well as authors who identify with various racial/ethnic communities.

### **Participant Recruitment: Adolescents**

Potential adolescent participants were identified by reviewing the electronic health record (EHR) for patients who had completed an encounter in 1 academic medical center-based gender clinic in the previous month that met the following criteria: (1) current age between 14 and 17 years and (2) had completed an encounter with a medical provider in the gender clinic via telemedicine in the last 6 months. We chose to recruit only adolescents in this age range given they are able to independently consent for some aspects of their medical care, like sexual health, but require parental consent to receive gender-affirming medications.

Adolescents who met the above criteria were sent a message via e-mail, text, or through the EHR portal explaining the study, and asking if they would like to complete a brief screening survey in RedCap<sup>17</sup> to see if they met the inclusion criteria. After survey completion, those who expressed interest in participating were scheduled to complete a semi-structured individual interview over Zoom<sup>18</sup> with a research team member experienced in conducting qualitative interviews.

### **Participant Recruitment: Caregivers**

Once the adolescent interviews were completed, potential caregiver participants were recruited from a monthly list of parents/caregivers of patients aged 14 to 17 who had completed a medical visit via telemedicine. Completing a recent visit via telemedicine was considered a criterion for inclusion because, similar to the interviews with adolescents, caregiver interviews consisted of 2 portions, one focused on receiving care via telemedicine and the other on receiving care in primary care. Similar to the recruitment process conducted with adolescents, caregivers who met these criteria were sent information about the study via text message, e-mail, or through the EHR portal, along with a link to a RedCap screening survey to confirm they met inclusion criteria for participation. After completing the screening survey, caregivers who met inclusion criteria and expressed interest in participating were scheduled to complete a semi-structured individual interview over Zoom. To ensure anonymity and confidentiality for adolescent participants, inclusion criteria for caregiver participants included that their adolescent had not participated in the study.

## Interview Guide Development

Interview guides consisted of 2 parts, and each was developed in partnership with an existing advisory board of TGD adolescents and caregivers of TGD adolescents. The second portion of the interview guide consisted of ~15 questions that were designed to elicit perspectives on how participants felt about receiving gender-affirming care from their PCP. Interview guides were not adapted after the interviews began. Given the variability in the definition of gender-affirming care, our youth and caregiver advisors suggested using the following language in our interview guides to describe the specific types of services participants may desire to receive: “How would you feel about accessing some of the care you get from the gender clinic from your primary care doctor instead of the gender clinic? (this could be things like follow up visits, mental health check in’s, labs, or refills for hormones).”

## Data Collection

Participant demographic information was collected as part of the screening survey. Adolescent participants were asked to self-report their age, gender identity, ethnicity, race, travel time to the gender clinic, and their perception of how supportive their most supportive caregiver was of their gender identity. Caregiver participants were asked to report their race, ethnicity, and travel time to the gender clinic, their relationship to their TGD adolescent, and their adolescent’s gender identity. A total of 47 adolescents and 90 caregivers completed a screening survey to determine eligibility. Of these, 70 caregivers and 31 youths met the inclusion criteria to participate in an interview, and all were sent a request to schedule an interview. Participants who met inclusion criteria but had not responded to the request to schedule an interview were sent a follow-up message 1 week after their initial request was sent. Thirty-three participants (15 adolescents and 18 caregivers) responded to either the first or second attempt to schedule an interview. All participants who responded to the request completed a 1-hour, semi-structured, individual interview over Zoom between April 2021 and October 2022. All adolescents provided informed assent to participate themselves, and caregiver participants provided informed consent to participate before their interview. Interviews were conducted by 2 members of the research team (YA and KB) with experience conducting qualitative research, and recruitment continued until thematic saturation was reached. All participants received a \$20 gift card for participating. This study was approved by the Seattle Children’s Institutional Review Board (STUDY00002873).

## Data Analysis

Interview transcripts were generated by using transcription software embedded in Zoom and were then manually cleaned by members of the research team to remove identifiers. Analysis was conducted by developing a codebook generated in partnership with members of the same adolescent and caregiver advisory boards who oversaw the development of the interview guides to ensure data were interpreted within the context of community members’ lived experiences. Each transcript was then independently coded in Dedoose<sup>19</sup> qualitative analysis software by 3 research team members (JG, YA, and VR), with coding conflicts adjudicated to consensus by a separate research team member (KB). Themes were then

generated iteratively by using a reflexive thematic analysis framework<sup>20</sup> for both adolescent and caregiver participants by research team members (JG and VR).

## RESULTS

### Sample Characteristics

Interviews were completed with 33 participants (15 adolescents, 18 caregivers) whose demographic characteristics are described in Table 1.

### Experiences in Pediatric Primary Care

Four themes and 12 subthemes were identified from our qualitative interview data (Table 2).

#### Theme 1: Barriers to Receiving Services in Primary Care

##### **Subtheme 1: Difficulties Accessing Gender-Affirming Care Services in the Primary**

**Care Setting:** Both adolescent and caregiver participants described experiencing difficulties accessing and receiving care in the primary care setting. Some participants also described challenges in finding a gender-affirming PCP.

They don't give you very good search options for gender affirming providers with adolescent primary care. And so that is something that I would really like more help with is figuring out how to find just a general doctor ... cause I wind up having to try to personally vet each person.

[Mother of a trans female, nonbinary, gender nonconforming adolescent]

At the same time, others expressed hesitation about disclosing their gender identity to their PCP out of fear they would not be supportive of them receiving gender-affirming care.

I'm scared that I'm going to go to a doctor, and they're gonna be like, "Oh, you don't need to do this," or, "I'm not going to sign off on that because you don't need that, that's not necessary."

[17-year-old trans male adolescent]

Additionally, adolescent and caregiver participants expressed concerns that their PCP may not be knowledgeable about aspects of caring for TGD adolescents that they felt were important. Participants highlighted the degree to which this impacted their comfort in accessing primary care.

My primary care doctor is a guy, and the vibes I get from him just don't give me "I know a lot about LGBT" ... he's a cool guy, but he might just ask a bunch of questions about what I'm even talking about.

[16-year-old trans male adolescent]

There's also always that fear that I'm going to ... have to explain everything about me being trans when I'm asking for something.

[17-year-old trans male adolescent]

**Subtheme 2: Inadequate Psychosocial Support From PCPs:** Some participants shared their experiences receiving un-affirming responses from their PCP after disclosing their gender identity.

I think the guy practically fell over. You could tell there was a noticeable discomfort level there.

[Mother of a trans female adolescent]

Others reported having had experiences in which their PCP provided recommendations regarding certain aspects of gender-affirming care that were inaccurate, contributing to ongoing concerns about receiving aspects of this care in the primary care setting.

[My son's PCP] hasn't made the time to really educate themselves ... When my son was trying to learn about binding ... The first advice was something with an ace bandage which is a big no-no, and we quickly figured that out and corrected [our PCP] so that she doesn't tell others.

[Mother of a nonbinary adolescent]

**Subtheme 3: Discrimination and Microaggressions in PCP Environments—**

Both adolescent and caregiver participants described interactions with members of the care team and the physical environment of the PCP office as unwelcoming and uncomfortable.

Those appointments, especially in the beginning, are just; there's landmines everywhere. I still remember that feeling of my kid [refusing] to go check themselves in because they didn't want to be called the wrong name ... It's the little subtle details like that, that don't feel subtle to my kid.

[Mother of a trans female, nonbinary, gender nonconforming adolescent]

I'm misgendered pretty much every time I go.

[16-year-old trans male adolescent]

**Theme 2: Benefits of Gender-Affirming Care Provision in the Primary Care Setting**

**Subtheme 1: Established Ongoing Relationships With PCPs Facilitate Trust:** Multiple participants felt that there were benefits to receiving certain aspects of gender-affirming care in the pediatric primary care setting. In particular, some participants cited that their long-standing relationships with their PCPs helped them trust that they could discuss their gender identity with them.

For me, I think [seeing my PCP] would be better because I already have a relationship with them, and I'm already comfortable talking to them about pretty much anything.

[14-year-old trans male adolescent]

**Subtheme 2: PCP Has a More Comprehensive View of Health:** Additionally, participants noted that, compared with specialists, their PCP had a more comprehensive view of their

overall health and wellbeing, which made them uniquely positioned to discuss gender-affirming care in the context of other underlying health concerns.

[Our PCP] is also involved in all the other aspects of my child ... so she sees the whole picture; I'm not always sure specialists are keeping the whole picture in mind.

[Mother of a trans male adolescent]

Some participants felt that viewing gender-affirming care as a component of primary care could destigmatize its provision and make it more accessible. Additionally, adolescent participants felt that normalizing this care to consider it a routine primary care service may be particularly helpful for caregivers.

I think it'd be easier for parents to understand going to a primary care doctor for something versus [figuring] out this whole other place and all these other people ... it would be viewed more as a health thing rather than a whole separate thing.

[14-year-old trans male, nonbinary, genderqueer, genderfluid, gender nonconforming, demi-gender adolescent]

**Subtheme 3: PCP Accessibility and Convenience:** Participants noted it was much easier to schedule appointments with their PCPs compared with gender specialists.

[Getting care from our PCP] could be really convenient, and it could be immediate as opposed to having to be put on [the gender clinic] waitlist. It can be life or death care like we literally went from feeling suicidal to getting an appointment and having a complete emotional change just because that appointment was on the books.

[Mother of a trans female, nonbinary, gender nonconforming adolescent]

Participants also noted that this often meant they could receive this care from a provider that is physically closer to their home.

My primary care doctor is a lot closer by. [I] wouldn't have to schedule separate appointments and wait.

[15-year-old, nonbinary adolescent]

### **Theme 3: Strategies to Improve Access to Gender-Affirming Primary Care**

**Subtheme 1: Training and Education Specific to Serving TGD Adolescents for PCPs and Their Staff:** Multiple participants specifically mentioned that PCPs and members of their staff needed additional education and training for them to feel comfortable receiving gender-affirming care in the primary care setting.

Honestly, I think everyone should be doing training [in] how to care for trans people.

[16-year-old trans male, nonbinary, genderqueer, gender nonconforming, agender, demi-gender, gender variant, bigender adolescent]

Moving to a point where the [PCP] is caught up is also ideal ... I would love it if we didn't even have to go to the gender clinic at all.

[Father of a trans male adolescent]

**Subtheme 2: Interdisciplinary Collaboration and Care Coordination Between PCPs and Gender Care Specialists:** Participants also highlighted a need for increased communication and collaboration between PCPs and gender specialists to improve care provision in the primary care setting.

The communication between the gender clinic and our PCP hasn't been great. And it's not that they're not talking (to each other); it's that the gender clinic is so overloaded.

[Father of a trans male adolescent]

It would be my primary care provider and my doctor at the gender clinic that would be communicating and talking about my health? That would be great!

[16-year-old trans female adolescent]

**Subtheme 3: Removing Logistical Barriers for PCPs to Provide Gender-Affirming Services:** Both adolescent and caregiver participants reported needing to develop ways to overcome logistical barriers, such as short primary care appointment times, to help facilitate improved gender-affirming care provision in the primary care setting.

A gender appointment is at least half an hour, right? And our physical appointments [at the PCP] are 15 minutes max ... they would have to double the amount of time they would be available.

[Mother of a trans male adolescent]

Other participants noted how increasing gender-affirming care provision in the primary care setting had the potential to improve access to care.

Having a primary care provider team under the supervision of the gender clinic would be awesome, and it would allow the gender clinic to have a much wider reach.

[Mother of a trans female, nonbinary, gender nonconforming adolescent]

#### **Theme 4: Opportunities and Options for Integrating Primary and Specialty Care to Support TGD Adolescents**

**Subtheme 1: Services That Can Be Provided in the Primary Care Setting:** Some participants reported wanting to receive certain routine aspects of their gender-affirming medical care, such as laboratory monitoring, injection teaching education, and refills for hormones from their PCPs.



I think it does for me depend on... how big something is... I would be fine with talking to my primary care doctor about testosterone... I think it would be easier to go to [my PCP] for that.

[14-year-old trans male adolescent]

**Subtheme 2: Services That Should Continue to Be Provided by a Gender**

**Clinic:** Alternatively, there were other aspects, particularly regarding more complex aspects of care related to insurance approval for gender-affirming medications and decision-making around gender-affirming top surgery, that many participants felt should remain within a specialty gender clinic.

I'm just more comfortable talking about surgery aspect with people at [the gender clinic], because, at the end of the day, they do specialize, and even if the primary care doctors are trained, it's just nice to talk to specialized people... about super big stuff like that.

[14-year-old trans male adolescent]

I want to go someone that really knows the nitty gritty ins and outs, [like] dealing with insurance for gender care.

[Mother of a trans male, agender adolescent]

**Subtheme 3: Positive Impact of Receiving Services From a Gender Clinic:** Multiple participants indicated that, if it remained an option to do so, they would prefer to continue receiving their gender-affirming care services from the gender clinic, in part because they perceive the environment and gender clinic staff to be more knowledgeable and inclusive.

Having a place where you see the progress pride flag, you see the use of pronouns, you see the trans pride flag... it's all these visual things... the whole thing is like walking into a big warm hug.

[Father of a trans male adolescent]

For me [getting care from my PCP] wouldn't be impossible. I'd be willing to do it hypothetically, but it's definitely not preferable because I think the gender clinic is a lot more comfortable and a lot easier to talk about stuff regarding gender... and it's a more understanding environment.

[14-year-old trans male, nonbinary, genderqueer, genderfluid, gender nonconforming, demi-gender adolescent]

**DISCUSSION**

Participants' perspectives were mixed regarding the optimal setting for receiving gender-affirming medical care services. Some expressed interest in receiving aspects of gender-affirming medical care in the primary care setting, whereas for others, this raised significant concern. We noted that factors such as participants' previous experiences in health care settings, their PCPs' ability to receive education and consultation from a gender specialist,

and participants' view of gender-affirming care as primary versus specialty care might influence the preferred setting for receiving their gender-affirming medical services.

The findings from our study align with recent studies suggesting that many TGD adolescents experience recurring un-affirming interactions with health care providers in primary care settings.<sup>21</sup> They are also consistent with previous research suggesting that previous un-affirming experiences influence TGD adolescents' comfort in disclosing their identity to their PCPs and may lead them to avoid seeking medical care altogether.<sup>22,23</sup> Our study adds to the current body of literature in that it suggests these previous un-affirming experiences may also contribute to TGD adolescents' and their caregivers' willingness to receive gender-affirming care services in the primary care setting, both now and in the future.

Although some participants reported having un-affirming experiences in primary care, multiple participants saw value in shifting the future model of care delivery for adolescent gender-affirming care, which is currently predominantly housed in specialty care settings, to one that more actively involves pediatric PCPs. Participants felt primary-care-based service provision offered notable benefits, including increased convenience, efficiency, and availability compared with care in the specialty setting. They also saw value in receiving care from a provider with whom they had an established ongoing and trusting relationship, and who has a more comprehensive view of their overall health. These findings align with another recent qualitative study of TGD adolescents,<sup>15</sup> which revealed that many have a positive overall view of their PCP experiences. Our findings add to this by suggesting that with adequate improvement of PCP resources and support, some TGD adolescents and their caregivers would desire to receive gender-affirming care in the primary care setting. It is critical to note that, although some were open to receiving a majority of their gender-affirming care in primary care, others participants wanted to receive only certain aspects of this care, such as laboratory monitoring and medication refills from their PCPs while continuing to receive other services, like discussions about gender-affirming top surgery, in the specialty setting.

Similar to findings from another qualitative study with TGD adolescents about their primary care experiences,<sup>15</sup> adolescents and caregivers in our study felt there were specific ways the care they receive in the primary care setting could be improved. They highlighted a clear need for opportunities for PCPs and their staff to receive education and training in caring for TGD youth. Additionally, both adolescent and caregiver participants noted the importance of a TGD-inclusive clinic environment and the degree to which this would help them feel more comfortable receiving care. Adding to the findings of Guss et al,<sup>15</sup> participants in our study reported it was important for their PCPs to have opportunities to consult with gender specialists regarding their care. Interestingly, these findings align with data from a recent qualitative study of pediatric PCPs that highlighted a need to develop a more robust infrastructure to systematically provide education and consultative support to primary care providers to improve care for TGD adolescents.<sup>14</sup> This is particularly important given a recent study involving Black TGD adolescents found gender affirmation in health care settings may mitigate the relationship between anticipated stigma and health care nonuse.<sup>24</sup> Thus, creating more welcoming environments, and increasing the number of

affirming interactions with providers in pediatric primary care, could mitigate existing health disparities.

Emerging data suggest that, even before the increasing number of legislative and political attempts to further limit access to pediatric gender-affirming care in many US states, the number of specialty clinics providing gender-affirming services was largely insufficient to care for the number of adolescents who desire to receive it.<sup>4</sup> Therefore, primary care-based gender-affirming care provision, similar to the model of care provision for TGD adults, has the potential to make care more accessible for adolescents. Recent findings from a national survey of 13- to 17-year-old adolescents revealed that <10% of those interested in receiving gender-affirming hormones were receiving them.<sup>25</sup> Limited access to gender-affirming care is particularly concerning given the growing body of literature suggesting this care is associated with lower rates of depression and attempted suicide.<sup>26,27</sup> Therefore, improving PCPs' comfort with and ability to provide these services has the potential to increase access to care, and improve mental health outcomes among adolescents, particularly those who experience barriers to receiving care in the specialty setting.

Our study findings must be interpreted with an acknowledgment that study participants were recruited from a clinic-based sample of adolescents and caregivers who had begun accessing gender-affirming care in a specialty care setting in the Pacific Northwest. Therefore, their perspectives and experiences regarding primary care-based care provision may differ from adolescents who have not yet received care, are already receiving care in the primary care setting, or live in a different geographic region of the United States. Additionally, although the demographic characteristics of participants in our study are similar to those of adolescents receiving care in the specialty clinic from which they were recruited,<sup>28</sup> they exhibit limited diversity with respect to multiple social constructs, including race, ethnicity, rurality, and gender identity, highlighting ongoing disparities in access to gender-affirming care services among TGD youth of color, transfeminine and nonbinary youth, and youth living in rural communities. Therefore, it is critical that future research be done to understand the perspectives of TGD adolescents and their caregivers who desire but are not currently able to access care, or those receiving care in pediatric primary care. Additionally, the authors of future studies must work to explicitly ensure that the voices of TGD youth of color and rural youth are more adequately represented.

Despite these limitations, our study substantially adds to the existing literature by describing both TGD adolescent and caregiver perspectives regarding ongoing challenges related to the current infrastructure of gender-affirming care delivery in the United States and factors that may influence adolescent and caregiver comfort receiving services in primary care settings.

## CONCLUSIONS

Although TGD adolescents and their caregivers reported experiencing previous negative interactions with PCPs, some desired to receive aspects of gender-affirming care in this setting, citing benefits related to convenience, increased efficiency, and availability. However, to increase access to care in primary care settings, participants indicated further

work is needed to provide resources, education, and training to PCPs and their staff and improve PCP-to-specialist communication and collaboration.

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## ABBREVIATIONS

<b>EHR</b>	electronic health record
<b>PCP</b>	primary care provider
<b>TGD</b>	transgender and gender-diverse

## REFERENCES

1. Rafferty J; Committee on Psychosocial Aspects of Child and Family Health; Committee on Adolescence; Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness. Ensuring comprehensive care and support for transgender and gender-diverse children and adolescents. *Pediatrics*. 2018;142(4):e20182162 [PubMed: 30224363]
2. Call DC, Challa M, Telingator CJ. Providing affirmative care to transgender and gender diverse youth: disparities, interventions, and outcomes. *Curr Psychiatry Rep*. 2021;23(6):33 [PubMed: 33851310]
3. Hafeez H, Zeshan M, Tahir MA, et al. Health care disparities among lesbian, gay, bisexual, and transgender youth: a literature review. *Cureus*. 2017;9(4):e1184 [PubMed: 28638747]
4. Weixel T, Wildman B. Geographic distribution of clinical care for transgender and gender-diverse youth. *Pediatrics*. 2022;150(6):e2022057054 [PubMed: 36443242]
5. Kidd KM, Sequeira GM, Paglisotti T, et al. "This could mean death for my child": parent perspectives on laws banning gender-affirming care for transgender adolescents. *J Adolesc Health*. 2021;68(6):1082–1088 [PubMed: 33067153]
6. Hughes LD, Dowshen N, Kidd KM, et al. Pediatric provider perspectives on laws and policies impacting sports participation for transgender youth. *LGBT Health*. 2022;9(4):247–253 [PubMed: 35363079]
7. Kearns S, Kroll T, O'Shea D, Neff K. Experiences of transgender and non-binary youth accessing gender-affirming care: a systematic review and meta-ethnography. *PLoS One*. 2021;16(9):e0257194 [PubMed: 34506559]
8. Gridley SJ, Crouch JM, Evans Y, et al. Youth and caregiver perspectives on barriers to gender-affirming health care for transgender youth. *J Adolesc Health*. 2016;59(3):254–261 [PubMed: 27235374]
9. Clark BA, Marshall SK, Saewyc EM. Hormone therapy decision-making processes: transgender youth and parents. *J Adolesc*. 2020;79:136–147 [PubMed: 31972534]
10. Inwards-Breland DJ, DiVall S, Salehi P, et al. Youth and parent experiences in a multidisciplinary gender clinic. *Transgend Health*. 2019;4(1):100–106 [PubMed: 30949585]
11. Pullen Sansfaçon A, Temple-Newhook J, Suerich-Gulick F, et al. ; Stories of Gender-Affirming Care Team. The experiences of gender diverse and trans children and youth considering and initiating medical interventions in Canadian gender-affirming speciality clinics. *Int J Transgenderism*. 2019;20(4):371–387
12. Sperber J, Landers S, Lawrence S. Access to health care for transgendered persons: results of a needs assessment in Boston. *Int J Transgenderism*. 2005;8:2–3, 75–91
13. Carlile A The experiences of transgender and non-binary children and young people and their parents in healthcare settings in England, UK: interviews with members of a family support group. *Int J Transgend Health*. 2019;21(1):16–32 [PubMed: 33015656]

14. Ricklefs C, Kahn NF, Asante PG, et al. Resources pediatric primary care providers need to provide gender-affirming care to transgender and gender diverse youth. *J Adolesc Health*. 2023;72(3): S61–S62 [PubMed: 36376148]
15. Guss CE, Woolverton GA, Borus J, et al. Transgender adolescents' experiences in primary care: A qualitative study. *J Adolesc Health*. 2019;65(3):344–349 [PubMed: 31227384]
16. Kahn NF, Anan YH, Bocek KM, et al. Understanding transgender and gender-diverse youth's experiences receiving care via telemedicine: qualitative interview study. *JMIR Pediatr Parent*. 2023; 6:e42378 [PubMed: 36745775]
17. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377–381 [PubMed: 18929686]
18. Zoom [computer program]. San Jose, CA: Zoom Video Communications; 2021
19. Dedoose [computer program]. Los Angeles, CA: Dedoose; 2018.
20. Braun V, Clarke V. Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Couns Psychother Res*. 2021;21(1):37–47
21. Sequeira GM, Boyer T, Coulter RWS, et al. Healthcare experiences of gender diverse youth across clinical settings. *J Pediatr*. 2022;240:251–255 [PubMed: 34536494]
22. Sequeira GM, Ray KN, Miller E, Coulter RWS. Transgender youth's disclosure of gender identity to providers outside of specialized gender centers. *J Adolesc Health*. 2020;66(6):691–698 [PubMed: 32089449]
23. Boyer TL, Sequeira GM, Egan JE, et al. Binary and nonbinary transgender adolescents' healthcare experiences, avoidance, and well visits. *J Adolesc Health*. 2022;71(4):438–445 [PubMed: 35725539]
24. Goldenberg T, Jadwin-Cakmak L, Popoff E, et al. Stigma, gender affirmation, and primary healthcare use among black transgender youth. *J Adolesc Health*. 2019;65(4):483–490 [PubMed: 31303554]
25. Green AE, DeChants JP, Price MN, Davis CK. Association of gender-affirming hormone therapy with depression, thoughts of suicide, and attempted suicide among transgender and nonbinary youth. *J Adolesc Health*. 2022;70(4):643–649 [PubMed: 34920935]
26. Chen D, Berona J, Chan YM, et al. Psychosocial functioning in transgender youth after 2 years of hormones. *N Engl J Med*. 2023;388(3):240–250 [PubMed: 36652355]
27. Tordoff DM, Wanta JW, Collin A, et al. Mental health outcomes in transgender and nonbinary youths receiving gender-affirming care. *JAMA Netw Open*. 2022;5(2):e220978–e220978 [PubMed: 35212746]
28. Lucas R, Kahn N, Bocek K, et al. Telemedicine utilization among transgender and gender-diverse adolescents before and after the COVID-19 pandemic. [published online ahead of print February 15, 2023] *Telemed J E Health*. doi:10.1089/tmj.2022.0382

**WHAT'S KNOWN ON THIS SUBJECT:**

Access to gender-affirming care is associated with improved mental health outcomes in adolescents; however, access to this care is limited. Care provision in primary care would help improve access, yet adolescent and caregiver perspectives have yet to be explored.

**WHAT THIS STUDY ADDS:**

Adolescents and their caregivers report challenges related to the existing model of gender-affirming care delivery. Some desired to receive aspects of this care in primary care; however, further work is needed to improve education and primary care provider-to-specialist collaboration.

TABLE 1

## Demographic Characteristics of Adolescent and Caregiver Interview Participants

	Adolescents (n = 15)	Caregivers (n = 18)
Mean age (y)	15.7	—
Mean caregiver support for transition (1–10) <sup>a</sup>	8.5	—
Caregiver relationship to adolescent, n (%)		
Mother	—	15 (83.3)
Father	—	3 (16.7)
Adolescent's gender identity <sup>b</sup> , n (%)		
Trans male or male	11 (73.3)	13 (72.2)
Trans female or female	3 (20.0)	3 (16.7)
Nonbinary	6 (40.0)	2 (11.1)
Genderqueer	3 (20.0)	0 (0.0)
Genderfluid	2 (13.3)	0 (0.0)
Gender nonconforming	3 (20.0)	1 (5.6)
Agender	1 (6.7)	1 (5.6)
Demigender	2 (13.3)	2 (11.1)
Gender variant	1 (6.7)	0 (0.0)
Bigender	1 (6.7)	0 (0.0)
Selected >1 gender identity, n (%)	5 (33.3)	3 (16.7)
Ethnicity/race <sup>b</sup> , n (%)		
Hispanic	2 (13.3)	1 (5.6)
American Indian/Alaska Native	0 (0.0)	2 (11.1)
Asian	2 (13.3)	0 (0.0)
Black/African American	1 (6.7)	0 (0.0)
Native Hawaiian/Pacific Islander	1 (6.7)	0 (0.0)
White/Caucasian	13 (86.7)	18 (100)
Distance to clinic, n (%)		
30 min	5 (33.3)	3 (16.7)
31 min-1 h	9 (60.0)	6 (33.3)
1–2 h	0 (0.0)	5 (27.8)
2–3 h	0 (0.0)	3 (16.7)
3–4 h	1 (6.7)	0 (0.0)
>4 h	0 (0.0)	1 (5.6)

—, n/a.

<sup>a</sup> Adolescent response to the following survey item: 'On a scale of 1 to 10 how supportive would you say your most supportive parent/legal guardian is of your transition? (1 being not supportive at all and 10 being extremely supportive)'.

<sup>b</sup> Participants could select >1 gender identity and race/ethnicity.

**TABLE 2**

**Themes, Subthemes and Representative Quotes From Adolescent and Caregiver Interview Participants**

Caregivers	Adolescents
Theme 1: Barriers to receiving services in primary care	
Subtheme 1: Difficulties accessing gender-affirming care services in the primary care setting	
We haven't had good experiences so far, [my child] has actually not been to their primary care doctor, since they came out as trans. [Mother of a nonbinary adolescent]	I don't go to my primary care doctor super often... and I have nothing against them, but I feel a little bit uncomfortable because I don't I don't know them super well... and also because it... feels uncomfortable because... it's an environment where it's not something that's already talked about... it feels like maybe it might bring up confusion, and then you have to explain it, and then that's the whole thing, that's a big deal and not fun to talk about. [14-y-old trans male, nonbinary, genderqueer, genderfluid, gender nonconforming, demi-gender adolescent]
Subtheme 2: Inadequate psychosocial support from PCP	
I am not entirely sure that our physician, as supporting as they are, would be knowledgeable enough to answer many of the questions that we have. [Mother of trans male adolescent]	I wouldn't want any primary care doctors to say that you have to be in therapy, to make sure you're not just trans because of trauma. [14-y-old trans male adolescent]
Subtheme 3: Discrimination and microaggressions in PCP environments	
I felt like the provider kind of clicked into this ... anxious state of, "Okay don't say anything wrong, don't say anything wrong." [Mother of a trans male adolescent]	[My PCP office] is a bit of a smaller clinic though I feel a bit more subjected to people being biased or being influenced by other sources. So that's I guess a little bit of a worry about going to a primary. [16-y-old trans male adolescent]
	I don't really remember how it came up because I think they figured that [me being transgender] was a possibility, but they didn't really want to bring it up and so after a while of them typing out [the wrong pronouns], I was just like, "Hey, I'm not really comfortable with you using those pronouns". [14-y-old trans male adolescent]
Theme 2: Benefits of gender-affirming care provision in the primary care setting	
Subtheme 1: Established ongoing relationships with PCPs facilitates trust	
For us, obviously the comfort that my kid has talked to their [PCP], that is a great benefit, instead of having to go see somebody they've never met. [Mother of a demi-gender adolescent]	I had an old doctor that I was with ... for a really long time. And she was my mom's doctor and my dad's doctor... I would have felt totally comfortable talking with her [17-y-old trans male adolescent]
Subtheme 2: PCP has a more comprehensive view of health	
Ideally... I could take my child to talk to the PCP about emotional social concerns, biochemical, physical, and mental concerns. Yeah, all the whole body, the whole person. [Father of a trans male]	For me, I think it would be better, because I already have a relationship with them and I'm already comfortable talking to them about pretty much anything. [14-y-old trans male adolescent]
Well, I mean the continuity of care would be awesome to get it all in one place. Be a one-stop shop. [Father of a trans male adolescent]	It would certainly be easier to have everything in one place. [15-y-old, nonbinary adolescent]
Subtheme 3: PCP accessibility and convenience	
It's closer and I think it's easier to get in. I mean, if we make an appointment [with] his primary care physician, you can generally get an appointment that following week. I think it would be easier. [Mother of a nonbinary adolescent]	I think I might prefer [to see my PCP] because i'll be honest, [they are] literally just down the street from us, so I think it'd be easier to have in-person visits. To just, be able to just walk down there. [16-y-old trans male adolescent]
When it's closer to home, it takes less time so I can find a babysitter for the smallest kids. When it's farther away, and you have to commit four hours with travel and doctors and travel home, I can't usually go. [Mother of a nonbinary adolescent]	
Theme 3: Strategies to improve access to gender-affirming primary care	
Subtheme 1: Training and education specific to serving TGD youth for PCPs and their staff	
If you're doing advising and training with primary care providers, I would also want to make sure their entire clinic staff also has	There's been a lot of advancement in recent years, like we [are] progressing quite a bit, but that doesn't mean that everybody's been

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Caregivers	Adolescents
some kind of training. [Mother of a trans female, nonbinary, gender nonconforming adolescent]	catching up on stuff I just wish that more places would put more efforts into educating themselves and their staff [17-y-old trans male adolescent]
Subtheme 2: Interdisciplinary collaboration and care coordination between PCP and gender care specialists	
I want to reiterate how good of an idea it seems to me to have very open communication and collaboration between the gender clinic and the child's PCP [Father of a nonbinary adolescent]	It would make a difference, because at least the doctor would know what to do if they consulted the gender clinic doctor. [17-y-old trans male, nonbinary, genderfluid adolescent]
Subtheme 3: Removing logistical barriers for PCPs to provide gender-affirming services	
Our primary care doctor that we see is very, very busy It's even hard to get an appointment and it's very hard to get her to follow up with anything like prescriptions or blood work orders or anything, so I just feel like that's going to be a big problem. [Mother of a trans male adolescent]	It would probably take longer for my insurance to approve [my hormones] and send it off without my dad having to pay like \$80. [17-y-old trans male adolescent]
Theme 4: Opportunities to integrate primary and specialty care to support TGD adolescents	
Subtheme 1: Services that can be provided in the primary care setting	
It'd be nice if we could even go to the primary care doctor to administer the injections once a week. [Mother of a nonbinary adolescent]	I do have to go through the gender clinic to get refills on hormones. So, if I could do that through my primary care provider, it would probably be easier [15-y-old, nonbinary adolescent]
Subtheme 2: Services that should continue to be provided by a gender clinic	
The specialized knowledge that the gender clinic has about future questions that we may have, the directions we might go, or what we want to do next. I'm a little leery of how much the general PCP knows about those specialized questions. [Mother of a trans male adolescent]	I mean, I definitely feel more comfortable talking about trans stuff with my main doctor, but I think I still would prefer any big changes to be done through the gender clinic. [15-y-old trans male adolescent]
	I personally feel a little iffy about getting surgery recommendations in general, let alone from someone who doesn't know much about gender [17-y-old trans male, nonbinary, genderfluid adolescent]
Subtheme 3: Positive impact of receiving services from a gender clinic	
There was something in the just feeling affirmed about going to the gender clinic, that I think is important to acknowledge. [Mother of a trans male adolescent]	In the gender clinic I can trust that they already know what I'm talking about. [17-y-old trans female, nonbinary, genderqueer, gender nonconforming adolescent]