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“It’s kind of hard to go to the doctor’s office if you’re hated there.” A call for gender-affirming care from transgender and gender diverse adolescents in the U.S.

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Abstract

Research has identified discrimination and a lack of knowledgeable providers as major barriers for transgender and gender diverse (TGD) individuals seeking care, which contributes to greater stress and significant health disparities affecting this population. However, research involving TGD youth is limited. The aim of this study, therefore, was to describe TGD adolescents’ experiences, concerns, and needs in health care settings, including their feedback on themes previously identified by health care providers (i.e., discomfort with gender-related topics, reasons for not asking patients about gender, and previous training regarding gender diversity). The authors conducted semi-structured interviews with 12 TGD-identified adolescents aged 14–17, living in Minnesota, in 2017–2018. Inductive thematic analysis was used to summarize participant comments into themes and subthemes. Two main themes were directly relevant to concerns and needs of TGD youth in health care settings and their views on health care providers’ concerns: 1) Asking about Gender and Pronouns, and 2) Training for Health Care Providers. Findings suggest the need for revisions to clinic materials, infrastructure, and protocols. Adding training to all general medical and nursing education to increase knowledge, comfort, and competence around gender identity would further improve care and ultimately reduce health care disparities affecting TGD youth.

Keywords

adolescence; gender identity; health care; medical education; qualitative research

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Introduction

Health Care and Transgender and Gender Diverse Youth

Transgender and gender diverse (TGD) people, that is, those whose experience of their gender does not match the sex they were assigned at birth, face substantial health disparities in contrast to their cisgender counterparts. Studies have shown that TGD youth in particular have elevated risk of emotional distress, substance use, and bullying victimization compared to cisgender adolescents (Clark et al., 2014; Eisenberg et al., 2017; Perez-Brumer, Day, Russell, & Hatzenbuehler, 2017; Veale, Watson, Peter, & Saewyc, 2017). Disparities extend to access to and utilization of health care (Clark, Veale, Greyson, & Saewyc, 2017; Day, Fish, Perez-Brumer, Hatzenbuehler, & Russell, 2018; Eisenberg et al., 2017; Rider, McMorris, Gower, Coleman, & Eisenberg, 2018a; Veale, Watson, Peter, & Saewyc, 2017). As adolescence is a time of rapid physical growth, identity development, and establishment of lasting health behaviors (Sawyer et al., 2012; Shlafer et al., 2013), going without health care during this period can result in unchecked health behaviors that contribute to chronic disease (e.g., poor nutrition, smoking); unidentified mental health concerns; unnecessary suffering due to illness or injury; and missed days of school or work, leading to poorer educational and career outcomes.

Minority Stress Theory posits that those who identify with marginalized groups (including TGD populations) face chronic stressors, including experiences of discrimination, stigma, and harassment (Hendricks & Testa, 2012; Meyer, 1995, 2003). These individuals may internalize negative messages, have greater awareness of stigma, and develop hypervigilance about concealing their identities, which contribute to stress and negatively impact health. Health care providers may be a source of this minority stress for TGD people whether they do so intentionally or not.

Research has identified discrimination and a lack of knowledgeable health care providers as major barriers for TGD individuals seeking care (Corliss, Belzer, Forbes, & Wilson, 2007; Lerner & Robles, 2017; Roberts & Fantz, 2014; Safer et al., 2016; Snyder, Burack, & Petrova, 2016; Stoddard, Leibowitz, Ton, & Snowden, 2011). Ignorance of gender issues may lead to unintentional but nonetheless stigmatizing slights; examples of discriminatory mistreatment range from misuse of names and pronouns to outright denial of care for transgender patients (Grant et al., 2011). The American Academy of Pediatrics (AAP) recently issued a policy statement detailing the need for formal training, standardized treatment, and research with TGD youth. The AAP's statement further recommended health care providers focus on promoting the health and positive development of this population; for example, providing comprehensive, gender-affirming, and developmentally appropriate health care that is provided in a safe and inclusive clinical space (Rafferty, AAP Committee on Psychosocial Aspects of Child and Family Health, AAP Committee on Adolescence, & AAP Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness, 2018).

However, health care providers typically express a lack of comfort working with TGD patients and a desire for information, materials, and treatment guidelines (Lurie, 2005; Rider, McMorris, Gower, Coleman, & Eisenberg, 2018b; Vance, Halpern-Felsher, & Rosenthal, 2015). Indeed, health care professionals' training for working with lesbian, gay,

bisexual, transgender, and queer/questioning (LGBTQ) youth is notably lacking (Barrett et al., 2012; Carabez et al., 2015; Davidge-Pitts, Nippoldt, Danoff, Radziejewski, & Natt, 2017; Obedin-Maliver et al., 2015; Vance et al., 2015; White et al., 2015). In one study of 150 medical schools in the U.S. and Canada, the median reported time dedicated to teaching LGBTQ-related content was 5 hours during the entire curriculum (presumably much less for issues specific to TGD youth; Obedin-Maliver et al., 2015). Seven out of 10 medical school deans self-rated the quality of their schools' LGBTQ-related training as "fair," "poor," or "very poor" (Obedin-Maliver et al., 2015). In studies of family medicine and OB/GYN residents, adolescent health care providers and pediatric endocrinologists, only 14–18% felt they had received adequate training in transgender medical care (Barrett et al., 2012; Vance et al., 2015), while 86% desired such training (Vance et al., 2015).

The Present Study

Although existing research highlights the need for additional training, studies are limited in that they do not include youth input on core issues patients want their health care providers to know in order to provide optimal care. This may be particularly relevant for TGD youth, given the substantial disparities and disenfranchisement described above. Health care providers who receive training that is informed by insights from TGD youth should have greater capacity to reduce minority stress and disparities in health care through their increased comfort and competence in working with this population of young people.

In conjunction with the present study, we previously conducted interviews with 14 nurses and physicians serving adolescents to learn about their experiences and attitudes with regard to working with TGD youth to identify specific training needs (Rider et al., 2019). That work identified five themes, three of which were included in the present study with youth: 1) providers' discomfort with gender-related topics, 2) reasons for not asking about gender in clinical interactions, and 3) their previous training regarding gender diversity. The present study builds on that work by obtaining qualitative input from TGD adolescents about their experiences, concerns, and needs in health care settings, including feedback on the providers' themes noted above.

Methods

For this qualitative study, we conducted semi-structured interviews with 12 TGD-identified adolescents ages 14–17, living in Minnesota, USA, in 2017–2018. Recruitment for this convenience sample involved flyers in clinics and LGBTQ youth-serving organizations, tabling at LGBTQ youth-focused events, posting on social media of partnering community-based organizations, direct invitation by professionals working with TGD youth, and referrals by participants (i.e., snowball sampling). All adolescents in the state who were aged 14–18, identified as transgender, genderqueer, gender-fluid or a similar label, and were able to complete the interview in English were eligible to participate. Written parental consent was obtained in person or via electronic communication (email or text) for all but one participant who was living apart from family and self-consented. All participants completed a brief demographic form as part of study intake. The sample included 11 TGD young people assigned female at birth and one assigned male at birth.

We conducted interviews in person (42%) or via phone or video conferencing (58%) at the discretion of the participant; interviews took 40 minutes on average (range: 27 to 50 minutes). The semi-structured interview guide included questions about experiences with health care (general and gender-related), recommendations for health care providers, and a brief description of themes noted by health care providers in our previous work (Rider et al., 2019) with a request for feedback. Examples of interview questions are shown in Box 1, and include how previous qualitative themes from health care provider interviews were framed to elicit responses from the young people. The University of Minnesota's Institutional Review Board approved all study protocols.

All interviews were professionally transcribed and reviewed by the interviewer (G.N.R.) to confirm accuracy of transcription and reliability of the data. Data were managed and analyzed in Microsoft Word and Excel, providing an audit trail and thus, dependability and confirmability. Inductive thematic analysis was used to summarize participant comments into themes and subthemes (Braun & Clarke, 2006; Thomas, 2006). This process allowed new themes to emerge from youth responses to any of the interview questions; responses were not categorized according to health care provider themes a priori. Two coders (M.E.E. and B.J.M.) independently reviewed all transcripts, grouped responses by topic, and assigned a heading or code to sections of text that illustrated common themes (e.g. "asking about gender and pronouns"). Subheadings were used to identify subthemes within broader areas, as needed (e.g. "reasons to ask," "how to ask"). Coders met to review codes and discuss and resolve discrepancies. Before arriving at a final organization for all themes and subthemes, coders met with the entire research team to discuss themes and exemplar quotes. Member checking with members of the TGD and/or LGBQ communities, as well as those who treat young people in therapeutic settings was conducted. This investigator triangulation incorporates different perspectives, expertise, and lived experience and increases the validity of the analysis (Carter, Bryant-Lukosius, Dicenso, Blythe, & Neville, 2014).

Findings

Characteristics of the Sample

Study participants provided self-descriptors of their gender identity, sexual orientation, and race (Table 1). Participants' mean age was 16.2 years, and youth were diverse on all characteristics assessed here, providing a range of terms to describe their gender and sexual identities.

Interview findings

Two main themes were directly relevant to concerns and needs of TGD youth in health care settings, and offered suggestions for content and skills important for training providers, outlined below with sample quotes.

Theme 1: Asking about Gender and Pronouns—Youth consistently commented on the importance of health care providers, as well as clinic and office staff, asking about gender and pronouns. They also provided explanations about reasons to ask and many suggestions about when and whom to ask, and ways in which to ask respectfully.

Reasons to ask

Participants felt that asking about gender and pronouns demonstrated caring and respect on the part of the health care provider, and increased the patient's comfort in the clinical interaction. Participant 1 commented, "One of the first things was literally just ask people's pronouns. It's way more polite than misgendering them." Another described their experience:

I am like relieved when people ask me, or I'm like happy that they cared to ask, because then it actually shows that they're interested in respecting you. And so even if they say something that isn't right or just kind of makes me feel uncomfortable, it's still good for them to ask, because I can always just correct them, and, if they really care, then they'll listen to me (Participant 2).

Participants also acknowledged that having a provider ask about gender was important because it was less comfortable and could be unsafe for a patient to initiate a conversation about gender identity, not knowing how it would be received by an adult authority figure. For example, one young person noted, "There's a lot bigger safety risk for a trans person coming out to you than there is for you to ask them" (Participant 1).

Finally, young people commented that routinely asking about gender and pronouns normalized gender diversity and reduced stigma for this population. Participant 3 stated:

I think part of the reason why people are so afraid to ask is that they think it's going to be a bad thing, but if we erase that idea that it's a bad thing, then the question being asked wouldn't be such a big deal. So, I think if we asked more people about it, then it wouldn't be such a bad thing.

When and whom to ask

A dominant subtheme was that young people thought questions about gender and pronouns should be part of routine intake and/or introductions, and should be part of all health care visits. Participant 4 commented, "I think it could be asked to any patient, because you never know who identifies [as transgender, non-binary, or a similar label]...". However, some participants also commented that the focus of the visit should be on the presenting health concern, and gender should only be brought up when relevant to the presenting complaint. For example, Participant 5 stated, "if you're coming in for like a specific thing like, oh, I have ear pain, I don't think it should really be brought up because it's not really the focus." However, even in cases where participants thought issues of gender identity should not be raised, they wanted to be asked about names and pronouns.

How to ask

Participants generally favored a simple and respectful approach to asking about gender and pronouns. One participant commented, "As long as you're doing it in a respectful way, I don't think anybody, or at least I don't get offended when somebody is like, 'hey, is this how you identify?' Or, 'what's your pronouns?' ... I don't think any of us get offended if somebody just asks" (Participant 6). A second subtheme focused on use of forms as an appropriate mechanism to begin a conversation about gender identity, as many clinics used

intake forms, and this was a familiar tool for gathering patient information. For example, Participant 7 stated, “But I guess having some place that it’s written down before you start a conversation, that people can express if they need support for their gender identity; I think that would be a good way to get a conversation going.” Participants interested in using forms stressed the importance of having appropriate face-to-face follow-up conversations about gender-related topics during the clinical visit.

Theme 2: Training for Health Care Providers—Participants offered numerous suggestions of gender-related content they felt health care professionals should know in order to provide high quality, sensitive care. Comments are grouped around content that should be incorporated into every health care practice (basic gender information, diversity of gender identity and experiences, need for respectful care), knowledge of external resources (options for medical transition, additional resources), and methods of training (inclusion of TGD people).

Health care providers obtaining a basic understanding of information related to gender identity was a priority for participants, including definitions of key terms and appropriate use of pronouns: “Queer 101. It’s like you tell them.... ‘These are what the pronouns are. There are many of them. People sometimes make up their own, and that’s okay’” (Participant 8). Young people felt it was important to explicitly include non-binary identities as part of training, since these terms were generally less well known to the general public: “I want people to know that non-binary people exist, and that we might have like different, like more unique healthcare circumstances” (Participant 7). Participants also wanted providers to distinguish between sex (i.e. physiological characteristics) and gender identity, and felt this discussion should be part of health care provider training. Participant 9 stated, “I think getting it out of your head that it’s what’s in your pants, just the idea of like your genitals determine your gender.”

Young people also pointed out that there are numerous ways to experience gender identity, and the needs of TGD patients are diverse. Participant 10 commented:

I think just like learning how to listen to people and ask them what they need is basically the most important thing, because there’s no one-size-fits-all what to do when you have a trans patient. It’s just not the same for everybody, and I’m sure what I want is definitely not the same as what a lot of other people want.

Similarly, providing quality care to all patients regardless of gender identity was of paramount importance, and training on how to receive all patients respectfully was essential. Participant 1 summed up this point as follows: “It’s your place to provide care, to provide safety and to make sure that this kid is okay. So, whatever you believe about trans people, listen to them and respect them. I feel like I keep coming back to that because it’s really, really important.” Participant 6 commented:

We need to be able to go to the doctor and not have anxiety of I’m deathly sick, but I don’t want to have to go try to deal with all the hate at the doctor’s office or all the discrimination against me at the doctor’s office. I guess that’s what I would say. Just try to be more open-minded, and if you’re not open-minded then still respect

us and just kind of keep your mouth shut about it. I know it sounds harsh, but it's kind of hard to go to the doctor's office if you're hated there.

Participants also felt it was important for all health care providers to have some awareness of gender-related treatment or resources even if they did not provide those services themselves. Medical transition was seen as a key component of gender-related care that young people did not expect all providers to offer, but where information and referrals to other competent providers would be helpful. Participant 7 stated:

I guess just to kind of know the basics of what some common forms of medical transition are for, I guess, like either assigned sex at birth to either binary gender, or kind of like the basics of knowing about top surgery; hormones; hormone replacement therapy with testosterone or estrogen or testosterone blockers; knowing about bottom surgery, at least to some extent; and maybe even knowing about just like different things that people do for more like cosmetic things, like people get laser hair removal or body alterations, all kinds of stuff that is kind of common for people to do as part of their transition. That's just useful at least for medical providers to know that those types of procedures or things exist.

Beyond other health care services, participants noted that having other types of recommendations or resources from a health care provider would be useful and demonstrate caring:

If you're a health care provider who cares about their patients and wants to help them in their transition, finding resources outside of you if they need something that you can't provide, I think that would show a lot about who you are as a person, like that you care about your patients and that you will just see whatever treatment they need. So, going out of your way to find resources for them is meaningful (Participant 9).

Examples of external resources included organizations that provide social support or aid in social transition, mental health providers, websites and books.

Participants felt it was important for health care provider training on gender-related issues to involve TGD-identified people. Key components of this interaction were sharing personal stories, exposure to "real people who have real lives" (Participant 7), and moving beyond stereotypes. One young person had served on a panel presenting LGBTQ information to the senior health classes at his school, and summarized this need as follows: "What we did at the panel is share our stories, and I think that drives home the idea that people are affected and that it's really important to know the information" (Participant 4).

Discussion

TGD adolescents suggested numerous ways in which training for health care providers can be expanded to better prepare professionals for talking about gender-related topics and working with this population. Although themes identified from youth participants were not in direct response to themes identified in health care provider interviews, overarching topics ran parallel, and several of the exemplar quotes from youth were in direct response.

Specifically, in response to health care providers' descriptions of their discomfort and reasons for not asking about gender, youth emphasized the importance of basic communication around gender-related topics, with a particular focus on asking about gender identity and pronouns in clinical interactions, regardless of the provider's discomfort. This relatively small behavior was seen as indicative of respect, caring, and a desire to provide a safe space for TGD patients. Similarly, health care providers described their minimal previous training in gender diversity, and youth made numerous recommendations about essential content to include in primary and continuing education for health professionals, as well as training methods that would increase providers' competence in working with this population.

This research employs the unique approach of having youth comment on themes from health care providers, which yields strong recommendations that are directly relevant to the work force and their training needs. In this way, the present study builds on previous research from both youth and adults (Corliss et al., 2007; Lerner & Robles, 2017; Roberts & Fantz, 2014; Safer et al., 2016; Snyder et al., 2016; Stoddard et al., 2011) regarding experiences of discrimination and other barriers to health care. Intervention and training activities based on these findings will address shortcomings in existing health care provider education (Obedin-Maliver et al., 2015) and the expressed need for more robust training on LGBTQ, and specifically TGD, health issues (Barrett et al., 2012; Vance et al., 2015).

Findings from this study are also consistent with principles and recommendations laid out in the new AAP policy statement regarding health care and support for TGD children and adolescents (Rafferty et al., 2018). In particular, young people highlighted the need for gender-affirming care, appropriate use of pronouns, and basic knowledge of gender-related medical interventions and referrals to specialists. Without integrating TGD health into training programs for all health professionals working with young people, the recommended changes set forth by the AAP cannot be achieved.

Limitations and Strengths

Several limitations must be considered in interpreting these findings. First, despite additional efforts to purposively sample youth assigned male at birth, 11 of 12 participants were assigned female at birth. Although TGD youth in Minnesota schools are more likely to have been assigned female at birth (Eisenberg et al., 2017), viewpoints of those assigned male may be different and under-represented in this work. Similarly, all participants came from a single state, which generally provides a more welcoming climate for LGBTQ individuals than some other parts of the country. Experiences and views of youth found here may therefore differ from those that would be found elsewhere. Finally, all participants were "out" about their gender identity in at least some settings, which allowed them to be reached via recruitment efforts. Young people who have not disclosed their gender identity and are not in touch with any formal services or informal social networks serving TGD adolescents are not included here and may have different experiences. Likewise, only participants who could obtain parental consent for this study were included (with one exception whose circumstances permitted self-consent).

This research also has several strengths. Aside from sex assigned at birth, participants were diverse with regard to several demographic factors (sexual orientation, race) and contributed a range of viewpoints and experiences. In addition, the study design that incorporated findings from our companion study, allowing youth to build on findings from health care providers, gives context provided by the population ultimately served by improvements in training and clinical practice. Finally, triangulation helped to ensure trustworthiness of study findings, (Creswell, 2012), in that study team members had relevant expertise in public health, sociology, and psychology, extensive training and experience with qualitative and mixed methods studies; community members used in member checks had regular interactions with TGD young people in therapeutic settings, and lived experience identifying as LGBTQ.

Implications for Clinical Practice and Training

Based on findings from this study, in combination with previous research with health care providers and AAP recommendations, we suggest revisions to clinic materials, infrastructure (e.g. forms, electronic records) and protocols (e.g. routine introductions that include gender and pronouns). Such changes would reduce barriers in providing high quality health care for TGD youth. Developing local referral networks and closer connections between clinics and community organizations working to advance the well-being of TGD populations can provide ongoing support to health care providers in this work. Adding training components to all general medical and nursing education, as well as continuing professional education, to increase knowledge, comfort, and competence around basic gender identity information and relevant specialized resources would further improve care and ultimately reduce health care disparities affecting this population. These efforts, along with broader efforts to reduce transphobia in society at large, and in medical education in particular, may result in better health care for all young people.

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Box 1: Examples of semi-structured interview questions

1. We're going to talk today about your experiences with health care, and I want to cover both health care related specifically to gender stuff and health care for other reasons, like if you have a cold or need a sports physical or have a rash or whatever. First I want to ask about regular health care - going to a doctor's office, talking with a doctor or nurse, going to urgent care or even going to the school nurse for a health problem (not just to use the bathroom). Think about the last time you did this. What did you go for? How did it go?
2. If you had the opportunity to tell health care providers something about gender fluid teenagers, what would it be? This can be for general health care providers or someone you see specifically for gender-related issues.
3. In the past few months we have talked with about a dozen health care providers about working with gender fluid youth. One of the main things they told us was that they're uncomfortable asking about gender because they're afraid of offending you or sounding judgmental. Some people told us they just wait for the patient to bring up gender. What do you think about this? Should doctors and nurses bring it up at all? Is there a way you would recommend that they ask about gender that wouldn't be offensive or awkward?
4. We also asked them what kind of training they had about gender stuff in medical or nursing school - or even since then - and many had none at all, so they didn't feel like they knew much about gender fluid kids or what they might need. As I mentioned, we're hoping to design some training programs for health care providers. Where do you think we should start? In your experience, what's the most important thing doctors and nurses need to know about? What else would you recommend?

Note: Language for gender identity labels (e.g. trans, gender fluid, non-binary) was adapted in each interview to match participant's word choices.

What is known about this topic

- Transgender and gender diverse (TGD) individuals face disparities in health care.
- Discrimination and a lack of knowledgeable providers are barriers for TGD individuals seeking health care.
- Health care providers desire information, materials and treatment guidelines for working effectively with TGD youth.

What this paper adds

- TGD youth felt it was important for health care providers and other staff to ask about gender and pronouns.
- TGD youth recommended content and techniques for providing high quality, sensitive care, including basic protocols, knowledge of external resources, and methods of training.

Table 1:

Characteristics of Quoted Participants

Label	Gender identity	Sexual orientation	Race	Age
Participant 1	Transman/transmasculine	Queer	White	17
Participant 2	Non-binary	Pansexual	Asian/White	14
Participant 3	Gender fluid	Questioning	White	15
Participant 4	Trans-male	Pansexual	White	17
Participant 5	Demiboy/non-binary boy	Bisexual	White	16
Participant 6	Non-binary/gender fluid	Pansexual	White	16
Participant 7	Non-binary/transgender	Queer	White	17
Participant 8	Other	Pansexual	Black	17
Participant 9	Gender fluid	Pansexual	White	17
Participant 10	Male	Straight	White	16
Participant 11	Female and boy	Stud	American Indian, Black, and White	17
Participant 12	Girl	Queer	White	15

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