"I just want to be treated like a normal person"

Oral health care experiences of transgender adolescents and young adults

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ABSTRACT

Background. Transgender and gender nonconforming (TGNC) people continue to experience health care disparities despite increasing visibility and acceptance. As far as is known, no information exists regarding their experiences with oral health care providers. In this study, the authors intended to understand how TGNC adolescents and young adults interface with their oral health care providers.

Methods. A total of 36 participants, including patients 14 through 24 years of age and their caregivers, were recruited from the Transgender Health Clinic at the Cincinnati Children's Hospital, Cincinnati, Ohio. Interviews were conducted using a semistructured interview guide. All interviews were transcribed verbatim, coded, and analyzed for major themes using grounded theory methodology.

Results. Overall, participants reported positive experiences with their oral health care providers. Those with negative experiences reported that the problems were corrected rapidly. Some participants reported issues processing insurance. Several indicated that stress and anxiety related to gender identity could be reduced via use of certain strategies.

Conclusions. TGNC adolescents and young adults have minimal difficulty receiving oral health care. Oral health care providers can make minor modifications to intake forms and office design to improve patient experience and reduce stress and anxiety related to gender identity in the health care setting.

Practical Implications. Although TGNC adolescents and young adults may not need oral health care specific to their identity, taking steps to provide a safe and comfortable treatment setting can improve patient experience for this vulnerable population.

Key Words. Transgender; adolescents; oral health; health disparities.

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Transgender and gender nonconforming (TGNC) people collectively refers to a small but diverse population within the lesbian, gay, bisexual, and transgender (LGBT) community. TGNC is not an expression of sexuality but of the condition of having a gender identity differing from the biological sex assigned at birth.[1] People with concordant gender identity and biological sex are referred to more specifically as cis-gender. In a clinical setting, TGNC people may receive a diagnosis of gender dysphoria, defined as a "marked incongruence between their experienced or expressed gender and the one they were assigned at birth."[2] TGNC people may view gender as a spectrum, identifying as male, female, or somewhere in between. Like their cis-gender counterparts, TGNC people may identify sexually as lesbian, gay, or bisexual relative to their gender identity. Fear of coming out or identifying as transgender and the potential negative consequences make it difficult to assess the prevalence of this population, but the best estimates suggest that roughly 0.6% of adults identify as TGNC in the United States.[3] As TGNC people gain visibility and acceptance, children and young adults

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are identifying at younger ages and go to medical providers with their families for care and education.[4]

Discrimination and violence toward this population is commonplace and stems from multiple sources, including societal bias and familial rejection. These hardships are experienced regularly by LGBT youth. Although difficult to quantify accurately, estimates indicate that between 320,000 to 400,000 LGBT youth experience homelessness annually.[5] Evidence published in 2018 suggests that discrimination experienced by TGNC youth is often more intense owing to tensions between the social expectations and norms about how gender is expressed and by whom.[4] Such biases can lead to increased suicidality, substance use, harmful weight-control behavior, and sexually transmitted infections.[4,6]

Even when there is not blatant discrimination or violence, the perceived threat of bias can have an effect. The Minority Stress Model framework, initially developed by Ilan Meyer for applications related to mental health, is now used to describe how stigma-induced social stress may affect broader LGBT health disparities. Briefly, the model explains that chronic exposure to, or even the perception of, social stigma toward sexual and gender identity may cause people to conceal their identity and internalize this homophobia with the expectation that they will encounter rejection and physical or emotional violence.[7] This expectation of discrimination can create substantial stress for a person, affecting multiple facets of life.

Unfortunately, the evidence suggests that this bias, real or perceived, is not limited to just the social and familial arenas but also has been reported in the health care context. Evidence exists that LGBT patients have been denied access to medical treatment and have received substandard care. They often are blamed for their health status and have even endured physical abuse.[8] A 2015 national survey consisting of over 27,000 TGNC participants revealed that one-third reported at least 1 negative health care experience, including being refused treatment by practitioners, verbal harassment, physical or sexual assault, or having to teach the provider about TGNC people.[9] This increased stress, prejudice, and fear can lead patients to delay routine medical care.[10,11] To date, there is scant evidence to describe the experiences of TGNC people in obtaining oral health care. Evidence reported in 2017 suggests that TGNC people are less likely than their cis-gender counterparts to have visited a dentist in the past year.[12] It stands to reason, however, that TGNC people are at elevated risk of incurring similar discriminatory behavior in the dental operatory, which may lead to avoidance of care.

This evasive behavior can be accompanied by substantial detriment to oral health, given the increased risk among TGNC people for disordered eating, sexually transmitted infections, and substance use. It is well accepted that acid erosion may result in loss of sound tooth structure. In addition, it is understood that sexually transmitted infections may lead to painful or unsightly pathology with high risk of transition to malignancy, especially in the presence of increased steroid hormones. Alcohol, tobacco, and illicit drug use exposes the oral tissues to harmful substances, which can lead to xerostomia, periodontal concerns, and other distal pathologies like tooth loss and malignancy. Having an oral health care team that is attuned to these risk factors can minimize morbidities for this highly vulnerable population.

Dentists serve as health care providers who strive to see their patients at least semiannually from age 1 into young adulthood. As a result, they are witness to child development in all facets, be it dental, physical, social, or sexual. This frequency of care places the dentist and auxiliary staff in a unique position to see TGNC youth through each stage of the transition. It is incumbent on the oral health care team to be well-informed and provide safe, culturally competent care at each of those stages. Moreover, we are obligated to understand existing disparities in oral health care and the real risk of experiencing certain oral conditions and use this knowledge to educate patients and their families on effective ways to minimize this risk. Therefore, the purpose of this study was to understand the experiences, knowledge, and perceptions of oral health care among TGNC youth and their families throughout the transition process.

ABBREVIATION KEY

FTM: Female to male.
LGBT: Lesbian, gay, bisexual, and transgender.
MTF: Male to female.
TGNC: Transgender and gender nonconforming.

METHODS

Participants

This study was conducted in the Transgender Health Clinic at the Cincinnati Children's Hospital in Cincinnati, Ohio, and was approved by the institution's institutional review board. The review

board waived documentation of consent, allowing a verbal willingness to participate in an interview to serve as consent. Recruitment began at a clinic-sponsored Transgender Research Day and continued in the transgender clinic. Eligible participants were English-speaking clinic patients 14 through 24 years of age and their caregivers. Patients were invited to participate in a semistructured interview covering oral health care knowledge, perceptions, and practices.

Procedures

The initial semistructured interview was conducted in person at Transgender Research Day. Subsequent interviews were conducted via phone. The same 2 investigators (D.W.M., S.B.S.) conducted all interviews. A commercial medical transcription firm transcribed the interview recordings verbatim, and the study staff verified the transcriptions for accuracy. The investigators interviewed the participants and their caregivers individually or together, depending on their availability. Some participants 18 years or older who attend the clinic without a caregiver completed the study alone. We developed a semistructured interview guide on the basis of a review of relevant literature, previous clinical experience, and the study's specific aims.

Analysis

We analyzed qualitative data using grounded theory methodology.[13] Grounded theory is a hypothesis-generating method that is used when there are no existing theories to be tested. To counteract any potential bias, at least 3 of the authors depending on who was present coded the transcripts, with any conflicting interpretations resolved through consensus. Data analysis was concurrent with data collection, allowing for an iterative interview guide based on emerging insights. For the initial coding, we analyzed 1 sentence or segment of a sentence related to the research question at a time. We did this by means of naming the concept in the interviewee's own words, using the constant-comparative method.[14] Focused coding followed, in which we grouped similar data segments together in emergent thematic categories. We ended recruitment once the data analysis indicated that thematic saturation had been reached.[15] Thematic saturation is the point in qualitative research in which the data reflect the breadth of the themes and the model's originality, usefulness, and credibility.[16] We used NVivo Version 11.0 software (QSR International) for analysis.

RESULTS

A total of 20 patients and 16 caregivers participated in the semistructured interviews. Of the 20 patients, 16 (80%) were assigned female at birth and identified as male (female to male [FTM]); 3 (15%) were male to female (MTF); and 1 identified as nonbinary. Exemplary quotations supporting our findings are found in the Table.

Many participants reported visiting the dentist twice a year, the recommended number of visits for the general population. For those who reported missing 1 or more visits, nearly all participants were aware of the recommended periodicity. Most participants described few issues in receiving oral health care, with 1 participant reporting, "I feel safe [at the dentist] … never needed care that I could not receive." Some participants reported changing providers at some point, but few related the change to their TGNC identity or coming out.

Most participants reported either neutral or positive experience when responding to questions related to disclosing their TGNC identity to the oral health care team. In several cases in which the patient was interviewed independent of the caregiver, the patient had no memory or knowledge of how that information was disclosed or its reception. Some caregivers mentioned the patient's TGNC identity to a member of the oral health care team (dentist, receptionist, and hygienist) before the appointment began without the patient's knowledge. One caregiver described that "as a parent, you walk a couple steps ahead and have private conversations before any exposure." Reports of disclosure mainly followed a pattern of ease and comfort that did not cause any additional anxiety. No patient or caregiver reported negative commentary or reaction to this disclosure.

Uncomfortable interactions, however, still did occur. One participant stated, "It wasn't as welcoming because they kept messing up pronouns." In another instance, a patient requesting to be referred to by their chosen name was told, "We can't do that, for whatever reason." Participants who reported untoward remarks or uncomfortable interactions with the dentist or staff regarding their

Table. Major themes and exemplary quotations.

DOMAIN	MAJOR THEME	EXEMPLARY QUOTATION
Knowledge	LGBT*-friendly providers	"Yeah [important to know about LGBT-friendly providers], especially if they don't feel safe or accepted where they're going to."
		"If you visit your dentist regularly, like having another place where you can feel safe and feel accepted is very, very important."
		"I'm on a trans parent list, like I am involved with this parent group. So it is something that we do like talk about."
Attitudes	Comfortable environment	"I am always thrilled when I walk into a place, and it doesn't matter if it's a school or a classroom or a dentist's office, a doctor's office or whatever, and I see an LGBTQ flag of any kind, that makes me happy because I know that that's a safe place for my child. So … I'm always looking for anything that will clue me in."
		"I'm really concerned because he's got a lot of prayers and things on the walls."
		"… you want to be respected as an individual by your health care providers and like whoever you're going to."
		"Just not making a huge fuss about my gender … treating my gender and my transition as it's something that's absolutely normal. Like, not making a huge deal about it. Like even if it's a huge deal, like a positive deal where everybody is fussing over me, I'm not a huge fan of that.… I just want to be treated like a normal person."
		"Since it's an open room … the layout of the orthodontist I go to, there's multiple chairs lined up in a row and the doctor takes turns with each patient … so like someone were to misgender me, a lot of people would hear and that was kind of embarrassing."
Perceptions	Minimal issues accessing care and being accepted at dentist	"I don't think so, no." [any dental care you were unable to receive]
		"Twice a year." [how often visits dentist]
		"I feel safe [at dentist] … never needed care that I could not receive."

* LGBT: Lesbian, gay, bisexual, and transgender.

gender indicated that these instances were addressed quickly without interruption to care. There were no reports of seeking a new dentist owing to discrimination from the dentist or dental staff.

Although attending regular dental appointments did not prove to be an issue for most TGNC participants, problems related to insurance emerged as a major issue. Several participants discussed issues relating to insurance coverage and legal versus chosen names. Many patients expressed being called by the incorrect name as a triggering emotional experience, as it forces them to recognize a person they do not consider alive. Some described the process to make changes to insurance policies as ominous and difficult to navigate, requiring legal documentation that is difficult to obtain. Many participants said it was important to find an LGBT-friendly oral health care provider. One participant reported, "If you visit your dentist regularly, like having another place where you can feel safe and feel accepted is very, very important." Some insurance providers now offer a list of LGBT-friendly dentists to aid in patient comfort, but participants were not always aware of this resource. Caregivers and patients alike felt this was a useful tool, but some stated that their decisions stemmed largely from word of mouth via their peers and fellow parents in the TGNC community. Transgender-friendly social media pages and support groups were among the resources that participants used to find their dental providers.

Although many participants in our study did not feel uncomfortable or unwelcome in their dentist offices in the past, it was still clear that some aspects of the experience could be managed to improve comfort. Many dental offices are appointed with an open-bay delivery system, which 1 participant identified as a source of anxiety, much preferring to discuss sensitive topics in a private area. An outward expression of inclusion could make patients feel entirely comfortable disclosing their identity and coming to an appointment. Some participants stated that they take comfort in a physical sign that the office is a safe space, such as a rainbow flag or posted nondiscrimination policy statement. One caregiver expressed this by saying, "I am always thrilled when I walk into a place, and it doesn't matter if it's a school or a classroom or a dentist's office, a doctor's office or whatever, and I see an LGBTQ flag of any kind, that makes me happy because I know that that's a

Box. Recommendations for improving comfort for TGNC* patients.

- Provide separate selections for "Sex at Birth" and "Gender Identity."[21]
- Provide separate selections for "Legal Name" and "Chosen Name."
- Ask for patient-specific pronouns or how patient would like to be addressed.[21-22]
- Be cautious in making assumptions about gender. For example, avoid terms like "dude" or "darling."
- Connect patients and families to local resources if possible.[22,23]
- Post a transgender pride or gay pride flag or sticker, serving as a sign of acceptance and comfort to patients and families.[22]

* TGNC: Transgender and gender nonconforming.

safe place for my child. So … I'm always looking for anything that will clue me in." Others claimed the best environment is one in which they are treated just as every other patient is, with no need to draw special attention to their identity or inclusion. Members of the oral health care team often attempt to build rapport and encourage patient comfort via using terms of endearment such as "sweetheart," "honey," or "dude." One participant pointed out how these terms, although well-intentioned, can be emotionally jarring if they do not correspond with the patient's gender identity.

DISCUSSION

The purpose of this study was to evaluate the experiences, knowledge, and perceptions of oral health care among TGNC youth and their families. Although 2009 US statistics indicate that 1 per 10,000 people transition from MTF and 1 per 30,000 FTM,[17] our study population had more FTM participants. Despite the contrast with general population estimates, the study participants were representative of the patients receiving care in the Transgender Health Clinic. For the purposes of this study, the act of transitioning was more important than the direction of transition. None of the findings were unique to those who were transitioning either MTF or FTM but were representative of those experiencing the transition process overall.

Perhaps the most salient of the findings in our study was related to feelings of comfort in the dental office. Participants in the study reported greater satisfaction and less anxiety when referred to by their chosen names and pronouns. Evidence from the medical literature supports this notion. It has been shown that the use of the legal, or birth, name in a clinical setting can lead to distress on the part of patients and ridicule, and even assault, by others.[18] Inversely, the use of a TGNC youth's chosen name affirms gender identity and reduces depression and suicidal ideation.[19] Despite the increased visibility of this population, many providers are not aware of how to provide care sensitively for TGNC people. In a 2017 survey of clinicians, the authors reported that "of 411 practicing clinician responders, almost 80% have treated a transgender patient, but 80.6% have never received training on care of transgender patients."[20] Schools in the health care professions must evolve their curriculum to prepare students to deliver culturally aware care to these patients.[18] Creating a safe and accepting environment for TGNC youth may include both verbal and nonverbal approaches. For example, posting a rainbow gay pride or a pink, blue, and white transgender pride flag in the window or on a bulletin board may indicate discreetly to TGNC patients that this office is a safe space. Other recommendations for increasing comfort for TGNC youth and their families are listed in the box.[21-23]

Health care is moving away from simply treating patients and their chief symptoms with an algorithmic intervention and toward treating people who have personal narratives that shape their health care preferences and desired outcomes. TGNC patients are a prime example of this movement toward person-centered care: just calling people by their desired names and pronouns improves psychological outcomes. For the oral health care provider, person-centered care for the TGNC patient may include reframing orthodontic, cosmetic, or surgical procedures via conversing about preferred outcomes on the basis of gender identity instead of assuming a 1-size-fits-all

approach. To be truly effective, a treatment cannot be only curative but must hold value and importance to the person receiving the intervention as well. In addition, concerns may be addressed more effectively if the oral health care provider is a fixture in the overall care team, so that primary care physicians and specialists can communicate about broader patient desires.

Unlike findings in the medical arena, the results from our study show that most TGNC youth had positive experiences in the dental environment and faced minimal barriers to care. The phenomenon of care avoidance and fear of medical providers among TGNC patients is robust in the medical literature.[24-26] TGNC youth report substantial fear that they will be treated differently (73% of respondents in a study) or refused treatment (52% of respondents) by medical personnel because of their gender dysphoria.[27] Although dentists are health care providers, TGNC people may view the dentists' scope as so limited that revealing their gender identity does not factor into their decision to seek care. Given that many participants in this study were adolescents and young adults, parental influences to seek oral health care may be strong enough to overcome care avoidance. Regardless, the oral health care team should be aware of the elevated risks germane to TGNC people and be prepared to link the importance of ongoing oral health care with the transition.

When asked about insurance coverage, participants indicated few issues related to obtaining dental insurance and receiving services. Those who indicated that there were problems related them to issues in processing claims owing to differences between their legal and chosen names. In medicine, however, the situation is markedly different. Researchers in 1 study reported that one-half of TGNC patients had claims for gender-affirmation surgery denied and another one-quarter were unable to have gender-affirming hormones covered.[9] Despite a clarification in 2016 to the Affordable Care Act that made discrimination in the health care marketplace based on gender identity illegal, some interpretations of the law have allowed this practice to continue.[28] The Trump administration determined that Title IX, the federal law that prohibits discrimination based on sex, does not apply to gender identity, and as the judiciary grapples with how the federal government views and protects gender identity, this is an issue likely to be settled by the US Supreme Court.[29] Although dentists may remain largely shielded from these insurance intricacies, oral surgeons who perform facial feminization surgeries or similar procedures may be subject to more serious issues related to insurance coverage.

With a dearth of available research, our study's strengths lay in providing the foundation for future studies into the relation of TGNC people and their oral health care. In addition, our findings provide important insight into how oral health care providers can interact positively with TGNC patients and improve their experiences.

Our study had several limitations. First, not all of the interviews with TGNC youth were conducted in the presence of their caregivers. Complete parental participation was unachievable because some caregivers elected to not participate and others did not know that their children are TGNC. When caregivers were present, many relayed important details about first informing oral health care providers about the patients' ongoing transition, their reaction, and obstacles related to insurance. Therefore, the positive responses or environment that patients experienced may not have been true when the caregivers first disclosed information about the patients' TGNC identity. Second, the patients who attend the Transgender Health Clinic exhibit health-seeking behaviors that may have contributed to a selection bias. Given that among TGNC people there are a substantial number of those who are homeless or not out, the results of our study may not be generalizable.

CONCLUSIONS

Despite the limitations, the results of this study indicate that TGNC people may have minimal difficulty receiving oral health care. Clinicians and their staff can use certain strategies in an effort to provide gender-affirming care to reduce anxiety and improve patient experience. ■

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