HHS Public Access

Author manuscript

Sex Res Social Policy. Author manuscript; available in PMC 2019 March 01.

Published in final edited form as:

Sex Res Social Policy. 2018 March ; 15(1): 48–59. doi:10.1007/s13178-017-0295-8.

Barriers to Gender-Affirming Care for Transgender and Gender Nonconforming Individuals

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Abstract

Gender-affirming care, including hormone therapy, "top" (e.g., chest reconstruction surgery) and "bottom" (e.g., vaginoplasty, phalloplasty, metoidioplasty, etc.) surgeries, and puberty blockers, is an efficacious treatment of gender dysphoria for transgender and gender nonconforming (TGNC) individuals. However, many TGNC people encounter significant barriers in accessing gender-affirming care, which we detail via results from on online study. Participants included 256 TGNC individuals (78.9% White, ages 16–73, M_{age}=28.4). Among participants, 61.3% were receiving hormone therapy, 22.7% had undergone top surgery, and 5.5% had undergone bottom surgery. Open-ended responses (n=201) were thematically analyzed and common barriers included finances and insurance issues, a lack of service availability, and fears or worries. Participants reported various systemic issues and incidents of bias within medical and mental health fields, as well as a lack of medical provider awareness and education. Other themes were interpersonal barriers (e.g., fears of rejection); age and need of parental consent for minors; other medical issues; and a lack of information about how to acquire care. These findings can be utilized to educate professionals in medical and mental health fields about barriers their TGNC patients may encounter in receiving affirming care, and suggest a number of ways to improve access to these services.

Keywords

transgender; gender nonconforming; genderqueer; gender-affirming care; barriers to transition; healthcare stigma

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Conflicts of Interest: The authors declare that they have no conflict of interest.

Statement of ethical approval: All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Transgender (or “trans,” also known as gender minorities) is an umbrella term that refers to individuals who do not identify with the gender that is typically associated with someone of their sex assigned at birth. Although research with transgender populations has typically focused on individuals who are transgender women (i.e., individuals who were male assigned at birth and who identify as women) and transgender men (i.e., individuals who were female assigned at birth and who identify as men), there is a diversity of other identities under the transgender umbrella. Transgender individuals may not identify with any gender or feel that they exist between or outside binary notions of gender. These transgender individuals may use terms like agender, genderqueer, and non-binary to describe their identities. Given the diversity that exists in the transgender community, we will use the terminology of trans/gender nonconforming (TGNC).

TGNC individuals may experience difficulties such as gender dysphoria (i.e., discomfort with one’s physical gender characteristics that do not align with their identity; Bailey, Ellis, & McNeil, 2014) and non-affirmation of their gender identity by others, which can have significant implications for well-being (Sevelius, 2013). Gender-affirming healthcare can help to address these concerns and it is imperative that barriers to receiving care are addressed. As defined in this study, gender-affirming healthcare refers to procedures that help align one’s body with their gender identity. This includes a variety of medical interventions such as hormone therapy (e.g., administration of testosterone for individuals seeking to masculinize their body), as well as chest reconstruction surgery (“top surgery”), or “bottom” surgeries, such as vaginoplasty, phalloplasty, metoidioplasty, and other specific procedures. Even though these procedures may help some TGNC people with gender dysphoria, it should be noted that not all TGNC people desire or pursue these medical interventions.

The World Professional Association for Transgender Health (WPATH) provides suggestions, via the Standards of Care, for medical and mental health providers working with TGNC people pursuing gender-affirming procedures (Coleman et al., 2012). These standards include such guidelines as obtaining one referral from a mental health professional for hormone therapy and top surgery, and two letters for bottom surgery. Overall, these types of services can be helpful in decreasing gender dysphoria and have been associated with better mental health (e.g., Davis & Meier, 2014; Meier, Fitzgerald, Pardo, & Babcock, 2011). In addition, transgender children who are allowed to socially transition may not differ from their cisgender siblings in terms of mental health (Olson, Durwood, DeMeules, & McLaughlin, 2016), showing that even the social aspects of transition may indeed help to counter the mental health costs of concealment and being forced to align with one’s sex assigned at birth. Even with growing awareness of these benefits, many TGNC individuals may encounter significant challenges imposed on them if they choose to pursue gender-affirming care.

When examining experiences within general healthcare settings (including medical and mental health settings), research has shown that TGNC people are often met with a system that does not adequately meet their needs (James et al., 2016). As previous studies report, TGNC patients often encounter discrimination and barriers to accessing healthcare (Bradford, Reisner, Honnold, & Xavier, 2013; Grant et al., 2011; Snelgrove et al 2012;

Sanchez et al., 2009). A limited body of research has begun documenting the specific types of challenges that TGNC individuals encounter. Mistreatment within medical settings can take many forms, such as misgendering or being referred to as an inappropriate gender (e.g., being referred to as a man/male when a person is female identified) in providers' offices, unnecessarily invasive scrutiny into patients' personal lives, and outright denial of care to TGNC patients (Ansara, 2013; Sperber, Landers, & Lawrence, 2008). Other issues include contact with uninformed and/or intolerant medical providers and staff (Bauer et al., 2009; Sperber, Landers, & Lawrence, 2008), as well as being shamed by providers (Poteat, German, & Kerrigan, 2013).

The majority of research on gender-affirming care has thus far focused on the experiences of transgender men and transgender women, but these issues may be particularly salient for TGNC individuals outside of these more commonly known identities, such as individuals who identify as genderqueer or non-binary. These groups may encounter many of the same barriers to care that transgender men and transgender women do, but lack of mainstream knowledge as well as lack of education within medical and mental health fields related to genderqueer or non-binary identities can limit patients' access to quality care (Ansara, 2013; Gehi & Arkles, 2007).

Given the benefits of gender-affirming healthcare to the well-being of TGNC individuals (e.g., Meier, Fitzgerald, Pardo, & Babcock, 2011), we sought to explore the barriers that are experienced in pursuing these procedures. We were particularly interested in exploring these barriers in a gender diverse sample given the range of identities that exist within the trans community but that are often not included within this line of research. In this study, we examined the following: 1) rates of pursuing or desiring to pursue different forms of gender-affirming healthcare (i.e., hormone therapy, top surgery, bottom surgery, puberty blockers); and 2) qualitative responses regarding barriers participants encountered in each of these areas.

Method

Participants and Procedures

Data for this analysis came from an ongoing research study evaluating the impact of stigma on a syndemic of psychosocial issues effecting TGNC individuals, including substance use, mental health issues, and HIV risk behaviors. Initially, we conducted a daily diary study of the stigma experiences of transgender men and women. As such, TGNC individuals with other identities (e.g., those who are genderqueer, non-binary, etc.) were not eligible for the daily diary study. For these individuals, as well as any transgender men and women who did not meet criteria for inclusion in the daily diary study, we offered them the opportunity to complete a one-time survey. Data for the current analysis comes from a combined dataset: the baseline survey of the daily diary study and the one-time survey. The inclusion criteria common across these surveys were that participants were aged 16 years and older, lived in the United States, and identified as TGNC.

To determine eligibility, participants first completed a brief screener. Those that were eligible for the daily diary study were sent information about how to enroll and those that

were not eligible for the daily diary study were sent an invitation to participate in the one-time survey. Only participants in the daily diary study were paid for their participation, receiving $50 for completing at least 85% of the daily surveys and receiving $20 if they completed less than this but at least 50% of the daily surveys. Participants in both sections completed questions related to barriers to accessing gender-affirming care (for daily diary participants, this was included in their baseline questionnaire) and therefore are included together in this analysis.

Data were collected from February to June of 2015. Participants were recruited from social media sites (e.g., Facebook, Twitter, Tumblr) and through community organizations that served the transgender community. The study was approved by the Institutional Review Board of the primary investigator's institution with a waiver of parental permission under 45 CFR 46.408(c). All participants provided their consent/assent to participate in the study, which was completed via an online survey. In addition, a community advisory board (CAB) was formed with local transgender individuals who met weekly for a month prior to data collection and periodically after the initiation of data collection. The CAB provided feedback regarding study questions, design, and recruitment materials/methods, as well as engaged in discussions concerning the findings of the study and relevance to their lived experiences.

The analytic sample consisted of 256 participants who provided information about whether they had obtained/desired to obtain gender-affirming care. Of these, 201 participants also provided written responses to open-ended questions regarding barriers to care. For the total analytic sample of 256 participants, the mean age was 28.4 years old (SD = 11.5; range 16–73). The majority of the sample was White (78.9%) and a large number of participants had an income below $10,000 a year (45.3%). Participants had a variety of gender identities, with the majority identifying as transgender men (30.1%) or transgender women (23.4%), but nearly a quarter identified as genderqueer (13.7%) or non-binary (10.9%). In addition, the most commonly endorsed sexual orientations in the sample were queer (31.3%) and pansexual (21.1%). For a full description of the sample demographics, see Table 1.

Measures

Demographics—Participants reported their age, gender identity, sex assigned at birth, whether they had a difference of sex development/intersex condition, sexual orientation, and racial/ethnic identification. Participants also reported their income, employment, and level of education. Age was reported with a text box; all other questions were asked in a single item each (e.g., gender identity was assessed with the question "Which of the following best describes your gender?"). The response options for all demographic questions are listed in Table 1.

Gender-affirming care—Participants completed four questions about whether they had undergone different forms of gender-affirming care: hormone therapy, top surgery (removal, creation, or enhancement of breast tissue), bottom surgery (removal, creation, or enhancement of genital tissue), and puberty blockers (medications to stop or delay puberty). Response options for these questions are provided in Table 2. To ensure accuracy and

inclusivity of these questions, we collaborated with the CAB to finalize the wording of these items.

Open Ended Responses

For each type of gender-affirming care, participants were asked: “If applicable, what are some of the barriers you’ve experienced to…” with each type of care specified in the question, followed by a free response text box.

Analysis

Descriptive statistics were calculated for demographics and for the questions regarding pursuit of gender-affirming care. Demographic differences between participants who did and did not provide written responses about barriers to gender-affirming care were analyzed using SPSS. Participants’ responses to the open-ended items about barriers to care were thematically analyzed (Miles & Huberman, 1994). The coding team consisted of the first, second, and third author.

For the thematic analysis, the first and second author began by familiarizing themselves with the data and reading all participant responses, taking notes about prominent themes present in the data. Following this, the second author developed an initial list of codes that exemplified the themes that were emerging from the data and created definitions of each code. The first author reviewed this initial list of themes, compared them to the participant responses, and discussed the definitions with the second author, and through a process of consensus, they decided on a final list of codes. These were then applied by the second author to the data and the first author reviewed all coding. Where discrepancies existed, the first and second author worked together to further detail the definitions of the codes for clarity. After the first and second author agreed on all coding, the third author conducted reliability coding with a random subset of 20% of participants, which yielded a Kappa of 0.81, indicating “almost perfect agreement” (Viera & Garrett, 2005).

Results

Analyses were conducted to examine whether participants who did and did not provide qualitative responses differed on demographic variables. A t test revealed that participants who provided written responses regarding barriers to gender-affirming care were older (M = 29.5, SD = 11.59) than participants who did not provide responses (M = 24.42, SD = 10.36), $t(254) = 2.94$, $p < .01$. A chi-square test indicated that there was an association between sex assigned at birth and providing written responses to the questions about barriers to gender-affirming care, with people who were male assigned at birth being more likely to provide written responses (87.7%) than people who were female assigned at birth (75%), $X^2(1, n = 253) = 4.97$, $p < .05$. Due to the small cell sizes of participants within the various racial/ethnic minority groups, a dichotomous variable was created to compare White participants and participants of color. A chi-square test revealed that there was not a significant association between race/ethnicity and providing a written response regarding barriers to care, $X^2(1, n = 254) = 1.07$, $p = .30$.

Rates of Gender Affirming Procedures

Table 2 contains responses to the four questions about whether participants had received or desired to receive hormone therapy, top surgery, bottom surgery, or puberty blockers. This table contains information for the total sample, in addition to information specifically for transgender men, transgender women, genderqueer participants, and non-binary participants separately. We provide information separately for genderqueer and non-binary individuals because participants self-selected into the identity group that best fit their gender and thus we did not want to assume that the individuals in these categories would homogenously experience their genders. In addition, participants who are in one category may not feel that the other aligns with their identification (e.g., some genderqueer people may not identify with the label of non-binary and vice versa). In Table 2, participants who reported identifying as transmen, trans men, and men were combined into the category of "transgender men" and participants who reported identifying as transwomen, trans women, and women were combined into the category of "transgender women." Although the other subgroups (e.g., individuals who identify as agender) are included in the total sample information, we did not include information for these other subgroups separately as the sample size within these other categories was considerably smaller.

In total, 61.3% of participants had obtained hormone therapy, most frequently from a general doctor's office. Receiving hormone therapy was more frequently endorsed by transgender men (76.8%) and transgender women (80.3%); however, over a quarter of genderqueer (28.6%) and non-binary (33.3%) participants also had received hormone therapy. Top surgery was less common overall, with 22.7% of the sample having undergone this procedure (most commonly transgender men; 39.4%). Bottom surgery was even more uncommon, with 5.5% of participants receiving this procedure (most commonly transgender women; 10.6%). Lastly, for the vast majority of participants (82.4%), they were not considering puberty blockers because of their age (i.e., they had already undergone puberty and thus this was not an option for them).

Barriers to Care

Results from the thematic analysis revealed a number of barriers to gender-affirming care. We present themes from across all open-ended questions together instead of one question at a time because themes tended to repeat across the different forms of gender-affirming care (e.g., financial barriers being an issue for hormone therapy and top surgery). In total, there were 201 participants who provided at least one response to the questions about barriers to gender-affirming care. Four participants' responses did not include any mention of barriers and were therefore not included in this analysis. When examining the individual questions, 166 participants reported barriers to pursuing hormone therapy, 134 participants reported barriers to top surgery, 85 participants reported barriers to bottom surgery, and 22 participants reported barriers to puberty blockers. As seen in Table 2, puberty blockers were not considered for many participants and therefore there were much fewer responses to this item. Each theme is described below, along with quotes to exemplify the themes that emerged and the participants' gender identities, ages, and the specific type of procedure being referenced are included in parentheses following the quotes.

Financial, insurance, and employment barriers—The most commonly reported barrier to gender-affirming care was financial issues. Many participants reported that the cost of hormones, surgery, and associated procedures were prohibitive to pursuing care. For example, to pursue hormone therapy, this includes the cost of co-pays (if this is even covered by health insurance), lab work, and doctor's visits, on top of the cost to see a therapist who can provide a letter of support for obtaining hormone therapy. One participant who spoke about the costs of seeing a therapist and the implications for access to top surgery stated:

> Due to financial issues I have not been able to keep up my therapist appointments regularly… I have not had an appointment with him in two years. I have one set up for the end of this month and I am hopeful that I will have enough money to keep it. Due to not seeing him as regularly as I should I have not been able to get a letter to state that I am ready for top surgery. I also have not been able to save enough money for top surgery. (trans man, 25, top surgery)

Obtaining the finances to pursue gender-affirming care can be difficult and individuals often reported saving for extensive periods of time, taking out loans, going into debt, or fundraising. For example, one participant stated that his barrier was:

> Financial. My insurance also doesn't cover this, so I've been saving money for nearly three years to pay for the cost of phalloplasty. If my insurance did cover the operation using their usual 80/20 split I would be able to afford it. I currently have 23% of the costs saved up. (man, 20, bottom surgery)

In addition, many people have to sacrifice important experiences or parts of their life to be able to shoulder the financial burden of gender-affirming care. As one participant stated, "[I] couldn't go to college until I was done saving for surgery" (man, 27, top surgery).

Given the financial hardships of obtaining gender-affirming care, it was not surprising that the next most commonly endorsed barrier was insurance. This included being unemployed and therefore uninsured or unable to afford insurance, as well as being on family members' insurance plans which sometimes stopped participants from pursuing care. Even for individuals who had health insurance, the insurance companies often stood in the way of obtaining care, such as by having limited providers and having transgender specific exclusions in their policies: "Inability to access a clinic which offered hormones due to lacking insurance coverage; I was, for six months, ineligible for public health but also denied by every insurance company I applied explicitly because of my trans status." (trans man, 25, hormone therapy).

For others, this meant having insurance coverage but being denied for specific gender-affirming procedures even if they were medically necessary and recommended by medical professionals. This was the case for the following participant:

> Insurance gave me an extremely hard time with top surgery. My insurance initially had trans exclusions, so I had to fight my employer to get it covered. That took 9 months and I had to get city councilors involved. It was humiliating and horrible. Then, insurance hit me with this other bullshit and tried to make me wait a bunch more months for surgery. Even though my doctor recommended I get it

> immediately. They have outdated standards and they don't care what the medical establishment recommends for trans people. (trans man, 35, top surgery)

Participants also reflected on insurance companies creating loopholes which resulted in them being denied care, such as limiting the total amount of money that could be spent on transgender related healthcare to amounts below the cost of procedures. These policies made it appear they provided coverage but did not provide a reasonable means to obtain the care.

Employment was often mentioned as an intersecting issue with financial and insurance barriers. This was exemplified by statements about a lack of employment interfering with financial abilities to pay for care or to afford insurance coverage, as well as participants who did not have insurance because they were unemployed. In addition, some participants commented on it as a distinct barrier, which tended to reflect participants who felt that pursuing gender-affirming care would place them at risk for losing their employment or facing negative consequences at their job (e.g., “I have not notified my employer of my decision to undergo hormone replacement therapy, because I risk losing my job;” trans man, 27, hormone therapy).

Availability of care—The third most commonly reported barrier was availability, which referred to a lack of access to services. For example, many participants commented on the general lack of providers, as well as a specific lack of competent providers who were willing to provide care to TGNC patients. As one participant stated:

> It is due solely to a lack of access. Currently, I have not been assigned a primary doctor through [Health Insurance Plan] because there is a shortage of doctors here and urgent care is my only option. Urgent care won’t prescribe me hormones because I haven’t been there before and have no history with them. Before this time, I previously lived in [State Name] and every doctor’s office I called gave me the reply, 'we don’t do that here' which was direct discrimination as the doctors I called were endocrinologists that do prescribe hormones to cisgender individuals. (trans man, 34, hormone therapy)

This lack of availability also sometimes resulted in participants encountering barriers related to travel in order to find providers – these providers could be located a few hours away and other times much farther, even in other countries. For hormone therapy, it was common for participants to report traveling to nearby cities or places with gender clinics (e.g., “No doctors familiar with hormones in area, so have to take 8 hour drive to [Large City Name] 4×/year for assessment;” man, 17, hormone therapy). When discussing gender-affirming surgeries, top surgery often meant traveling longer distances or crossing states whereas bottom surgery often meant having to travel outside of the US. Even after finding individuals who can provide care, the limited availability of competent professionals meant patients often encountered long waitlists.

Issues within medical and mental health fields—Participants reflected on a few issues that were related to the medical and mental health fields. For one, participants encountered unfamiliarity from medical professionals, such as a lack of knowledge about transition-related care (e.g., appropriate dosage of hormones) or the diversity of transgender

identities. As one participant stated: “I've mainly experienced the issue of even trans-specializing providers not understanding that you can take testosterone and not identify as male/man and/or not take T in the usual way (dose etc.)” (genderqueer, 38, hormone therapy). This resulted in participants feeling like they needed to educate their providers or in them being unable to obtain care that met their needs.

Participants frequently reported encountering bias and stigma from individuals within the medical field, including doctors, nurses, office staff, and at pharmacies. This ranged from overt acts to more subtle experiences. For example, several participants reported being denied services by medical providers (e.g., “Finding a doctor who was willing to see trans patients;” trans woman, 30, hormone therapy), and others reported experiencing verbal harassment (e.g., “My doctor was very understanding, but the general nursing staff of the clinic was somewhat difficult about it. One nurse handed me my prescription and made a snide comment about me being a pervert;” woman, 40, hormone therapy). A smaller portion of participants reported abusive experiences, such as the following participant:

> On multiple occasions he gave me repeated breast exams within the same year; since then I have asked other physicians about this and they have stated this was unnecessary. On two occasions he would ask me questions about my sex life that had nothing to do with the exam and were clearly for his own amusement. When I asked him for help finding a surgeon for a vaginoplasty he referred to the procedure as 'getting my dick cut off.' (woman, 26, hormone therapy)

Other common experiences included being asked invasive questions that perpetuated beliefs in only two genders and left participants feeling invalidated. As one participant said, “Then uncomfortable doctor questions about my childhood where I pretended I'd always hated my body and ‘always’ knew I was a boy. I didn't -- I had a fine girlhood, and now I have a fine manhood.” (trans man, 27, hormone therapy). Sometimes participants were able to navigate these questions and still obtain care; however, other times, these types of questions and assumptions/stereotypes were the basis of being denied care: “I can't find someone who is willing to discuss my body and chest when it comes to my non-binary identity.” (non-binary, 21, top surgery).

Several participants reported experiencing bias and stigma from mental health providers. This included participants feeling that their mental health was inappropriately used as a rationale to deny care, being denied mental health services (e.g., “turned away by 11 different mental health providers;” trans man, 26, hormone therapy), as well as therapists “gatekeeping” and interfering with obtaining letters that are recommended under WPATH guidelines. This was exemplified by one participant’s response which showed particular challenges for non-binary identified participants: “Many therapists only let binary trans people start Hormone Replacement Therapy, and don't believe that non-binary people should be on hormone therapy. We have to meet certain binary-gender requirements to have access to this.” (genderqueer, 20, hormone therapy).

Beyond issues with individual provider behavior, participants also reported systems level issues within medical and mental health fields. For example, participants felt that the guidelines suggesting that they obtain letters from therapists were problematic (e.g., “Also,

the requirements of speaking to and getting letters from a psychologist and psychiatrist were unreasonable and unnecessary;" woman, 26, bottom surgery). This also reflected the barrier of needing a diagnosis to acquire care: "I had to be diagnosed with GID at the time after seeing a therapist" (man, 34, hormone therapy). Other participants reflected on the general climate of these systems being difficult, such as "it requires contact with a cissexist medical system which I feel unsafe in" (genderqueer, 21, hormone therapy).

Interpersonal barriers—Some participants reported issues in their interpersonal relationships that interfered with pursuing care. This included a general concern about societal acceptance, but to a greater extent, concern about the acceptance from individuals directly within the participants' social networks (e.g., "Primarily social. My parents tried to stop me from taking them for a significant time, and when I went behind their back to get them I was threatened with disownment (we're cool now);" trans woman, 21, hormone therapy). Some participants delayed care because they could not broach the topic because of concerns about coming out and repercussions (e.g., "I delayed getting medical treatment for my gender dysphoria for years because I was afraid of being estranged from my family. After I graduated college and my conservative grandfather had passed away, I felt ready to come out;" trans man, 25, hormone therapy). Lastly, when it came to surgeries, participants reported that a lack of social support can interfere with obtaining care: "a lack of support network (friends and/or family) to care for me during recovery" (non-binary, 25, top surgery).

Barriers related to emotions and worries—Participants reported that fear, anxiety, and worries interfered with pursuing care. This typically was characterized as emotional experiences that led to participants being unable to approach providers about transition related care: "Fear of ridicule and discrimination has prevented me from even asking a doctor for such procedures." (genderqueer, 40, hormone therapy). Participants also specified fears about post-procedural body/health related issues, such as being worried about weight gain from hormones and not knowing their long term effects. Participants also reported being worried about having scars or experiencing pain associated with surgical procedures.

Concerns about quality—Some participants expressed concerns about the quality of outcomes, which was primarily a barrier for transgender men in regard to bottom surgery. The statement by the following participant was generally shared by others: "I haven't seen any pictures or read any stories that are satisfying to me. I am concerned about the loss of sensitivity, the limited functionality in sex and urinating, and the dissatisfying appearance." (trans man, 25, bottom surgery).

Lack of information—Participants indicated feeling there was a lack of knowledge about gender-affirming care that interfered with seeking services. This included feeling unsure about the steps to obtaining care (e.g., "There was no clear path to follow. I wasn't sure who to speak with, where I needed to go, or anything like that;" trans woman, 25, hormone therapy), as well as feeling unsure about requirements that may need to be met for care or about the potential side effects of procedures. This lack of information may be exacerbated for individuals who identify with non-binary gender identities as transition related

information tends to focus on transgender men and women. This was the case for the following participant: “There is not a lot of information for people who wish to have surgery, but do not wish to necessarily change from one binary sex to another.” (genderqueer, 21, top surgery).

Other medical issues—Having medical issues also presented barriers. For most individuals, this meant having other health complications that may interfere with gender-affirming care. For example: “I'm on multiple medications to control chronic hypertension and have been told by a medical professional that estrogen may interfere with the effectiveness of these medications.” (non-binary, 39, hormone therapy). Other participants mentioned conditions that should not interfere with care being used against them, such as this participant: “The first doctor I saw refused to give them to me on the grounds that I was in a wheelchair.” (trans woman, 53, hormone therapy).

Age and timing of care—Age was a barrier for a minority of participants, mostly related to being too young to pursue care without parental permission (e.g., “I have to wait to pass the age barrier of 18 to obtain hormones, because my mom will not consent to me having them;” trans woman, 17, hormone therapy). In addition, some participants felt that they had to undergo more extensive screening prior to obtaining care because of their age. One participant also reported being told they were too young to make medical decisions for themselves, even though they were legally of age: “Being told by medical professionals that I was too young to know that I wanted surgery.” (genderqueer, 22, bottom surgery).

Another barrier was timing, including the order in which participants received different forms of gender-affirming care, as well as the timing of recovery with life events and experiences. For example, some participants discussed feeling that they needed to wait until a later stage of life to undergo certain care, such as this participant: “I'm planning to reduce my breasts after having kids.” (genderqueer, 28, top surgery). Similarly, some participants reported work or school making the timing of obtaining care difficult: “The amount of recovery time needed after certain surgeries makes it very difficult to remain a full-time student.” (man, 21, bottom surgery). Lastly, being at earlier stages of transition resulted in some participants waiting to undergo top and bottom surgery: “wanting to start [hormone therapy] before getting the surgery (else I might just look like a flat chested female…).” (non-binary, 21, top surgery).

Related to the issue of timing, participants who responded to barriers to puberty blockers commonly reported that this was a missed opportunity. These participants reflected on either not identifying as transgender at an age young enough to take puberty blockers (e.g., “I didn't even know that it was possible to be FTM until I was 17, long after my puberty at 11;” trans man, 23, puberty blockers) or identifying as transgender when younger but not knowing about the possibility of taking puberty blockers (e.g., “I did not know they were a thing until I had already gone through puberty;” genderqueer, 21, puberty blockers).

Discussion

The available research indicates that affirming one's gender can improve mental health and well-being (e.g., Davis & Meier, 2014; Meier, Fitzgerald, Pardo, & Babcock, 2011), although more work is needed with diverse gender samples that include non-binary, genderqueer, and other TGNC individuals. Given the benefits of gender-affirming care, it is important to assess and overcome the barriers that prohibit TGNC individuals from pursuing services, if they choose to do so. Our findings highlight a number of concerns that face TGNC individuals in obtaining care which have implications for medical and mental health professionals.

Comparable to other studies (e.g., Bradford, Reisner, Honnold, & Xavier, 2013), in this sample, over half of the participants had received hormone therapy. Although this was most common for transgender men and transgender women, a sizable portion of genderqueer and non-binary participants had received hormone therapy. Many fewer participants had undergone top and bottom surgery, with transgender men having the highest endorsement for top surgery and transgender women the highest for bottom surgery. Even so, a large percentage of transgender men, genderqueer, and non-binary participants expressed a desire to undergo top surgery. As we have shown here, a proportion of genderqueer and non-binary individuals may desire or be in the process of questioning if they would like to receive gender affirming care.

Similar to other research (Shipherd, Green, & Abramovitz, 2010), the most common barrier to receiving care in this sample was financial concerns, with the cost of care often being prohibitive, especially for top and bottom surgery. As other researchers have shown (Conron, Scott, Stowell, & Landers, 2012; Grant et al., 2011), a large number of TGNC individuals live in poverty and that was no exception for this study in which almost half of the sample reported an income of less than $10,000 a year. The low incomes reported by TGNC individuals is not likely a product of being undereducated as almost 40% of the sample had at least a bachelor's degree. This is similar to other studies where TGNC individuals tend to be more educated but earn substantially less than cisgender individuals (Grant et al., 2011). In contrast, these income levels may be a product of the stigma that TGNC people experience when seeking and maintaining employment (Grant et al., 2011). Indeed, there were several participants in this study who reported not being able to pursue transition-related care because of the danger of losing their jobs.

Second to financial concerns, insurance was another frequently reported barrier to care. These two barriers likely intersect with one another, as some participants reported not being able to afford insurance or insurance not covering certain gender-affirming procedures (or any at all), which resulted in needing to pay out of pocket for care. Furthermore, prior research has shown that TGNC people are less likely to have health insurance or a primary care provider than cisgender people (dickey, Budge, Katz-Wise, & Garza, 2016). As we found in this study, encountering these barriers takes a significant toll on the individual, sometimes resulting in going into debt and delaying or not gaining important life experiences (e.g., not going to college or not having children). As such, providers may benefit their patients by being advocates and helping them to navigate insurance issues.

Also, as seen in participants' responses and previous research (Poteat et al., 2013), available medical providers were often viewed as uneducated about how to provide gender-affirming care, which can result in TGNC patients needing to educate their providers (Bradford et al., 2013). There may be an even greater need for education around genderqueer or non-binary individuals who seek gender-affirming care. On the surface, this may seem to be an issue that exists solely at the systemic level, but individual providers need to be responsible and take the initiative to educate themselves about the needs of TGNC patients instead of common practices such as referring to other providers or denying care, which serve to continue marginalizing TGNC individuals (Bauer et al., 2009). Improved education about the needs of TGNC individuals is imperative because current knowledge often reflects systemic, cultural, and individual level issues within medical and mental health professions often built on assumptions of cisnormativity (Bauer et al., 2009; Snelgrove, Jasudavisius, Rowe, Head, & Bauer, 2012).

Participants also encountered issues of bias and stigma, such as medical and mental health providers being transphobic or cisnormative in their practices. The range of experiences of bias and stigma were vast – being denied care, snide remarks, verbal harassment, being called names, and outright abuse. This was not only from medical and mental health providers, but from office personnel, nurses, pharmacy staff, and others who patients may encounter in these settings. Some participants reported explicitly feeling that mental health providers served as "gatekeepers" who had the ability to block them from receiving gender affirmative medical care, leaving participants disempowered and with few resources to overcome such challenges.

Recommendations for Addressing Barriers to Gender-Affirming Care

Based on the types of barriers that participants reported in this study, we recommend a number of ways providers can help reduce these challenges faced by TGNC people. For one, being a culturally competent provider is a responsibility of all medical and mental health professionals – not just individuals who specialize in working with TGNC communities. Individuals have a responsibility to explore and challenge their biases towards marginalized groups. Providers also should seek to improve conditions more broadly within their organizations and professions (Sperber et al., 2008). For example, one way is to ensure that patients feel welcome before the provider even interacts with them. Providing forms that ask about patients' gender identities, name (not limited to a legal name, as some people may not have changed their name legally), and pronouns (Alegria, 2011) is a simplistic way of helping TGNC patients to feel welcome. It is vital that front line personnel be trained to use patients' affirmed names and gender pronouns to avoid unintentional outing of patients in settings such as waiting rooms. When directly interacting with TGNC patients, providers should avoid disrespectful language. Phrases like "biological," "real," or "born as a boy/girl" should not be used and more affirming terminology such as "assigned female/male at birth" should be utilized. Additionally, providers should be aware that medical terminology for the body, especially related to primary and secondary sex characteristics, may be upsetting for TGNC individuals. Providers should be flexible and try to use the patient's terminology when possible and can help by explaining why their questions are necessary.

Outside of their interactions with providers, TGNC individuals also reported issues in their interpersonal relationships related to acceptance. As such, many individuals may have people in their lives who try to stop them from pursuing gender-affirming care, such as parents or partners, or may experience a lack of support that is needed in aftercare for procedures such as top surgery. It is important for providers who are working with TGNC patients to be aware of the support/interpersonal issues they may be encountering and how this may impact their care (Alegria, 2011; Klein & Golub, 2016; Pflum, Testa, Bongar, Balsam, & Goldblum, 2015; Simons, Schrager, Clark, Belzer, & Olson, 2013; Wilson, Chen, Arayasirikul, Raymond, & McFarland, 2016). These interpersonal challenges may be particularly salient for individuals who are under the age of 18 and dependent on their parents' consent. Providers will benefit their patients by engaging families and providing supportive referrals instead of simply closing a conversation about gender-affirming care when parents are hesitant to consent.

These barriers and the many manifestations of stigma encountered by TGNC individuals can, understandably, evoke intense emotional responses, which can often be barriers to care in and of themselves. Providers may be able to find ways to make their settings more affirming, helping to decrease those emotional responses. For example, medical and mental health professionals can be sure to incorporate questions into their assessments about all patients' gender identities (not just when they assume someone is TGNC; Alegria, 2011). Steps such as this can open opportunities for patients to discuss their genders even if they are experiencing some fear or anxiety as this can create a more welcoming and comfortable environment. For providers who are looking to improve their competence regarding transgender healthcare and needs, there are a number of resources that may assist in this process (see Table 3 for a list of resources).

At a broader policy level, there are a number of improvements that can be made so that TGNC people encounter fewer barriers to care. In response to the barriers related to individual provider behaviors, professional organizations can take a stronger stance in ensuring that their members are engaging in culturally competent, affirming practices. Professional organizations can institute guidelines for working with TGNC clients, such as those created by the American Psychological Association (2015). In addition, professional organizations can issue resolutions that oppose discriminatory practices and laws that target TGNC individuals (e.g., Anton, 2009). Relatedly, it is important that employment discrimination issues be addressed as this has implications for access to healthcare and the financial barriers participants reported. Federal and state policies that prohibit discrimination based on gender identity and expression will help to address this particular issue. And, finally, having access to healthcare was a common barrier that participants reported. In order to address this, substantial changes are needed in terms of healthcare options for TGNC people and some healthcare plans may still have exclusions on gender-affirming care, which should be removed. Guidelines are needed that prohibit these exclusions and ensure that all TGNC people have access to health insurance overall, as well as health insurance that does not selectively exclude gender-affirming care.

Strengths and Limitations

There were several strengths to this study. For one, the sample was diverse in their gender identities. This is important given the assumptions that are often made that transgender men and transgender women are the only individuals who seek transition related care. Additionally, this study elaborates on the challenges faced broadly by TGNC individuals and was able to highlight some of the unique experiences of people who are genderqueer or non-binary. Also, our sample was diverse in age, ranging from 16 to 73 years old. Lastly, our open-ended questions allowed for participants to elaborate on their experiences and provide specific details of the barriers encountered.

Although there were strengths to this study, it is not without limitations. Even though our sample was diverse in certain respects, the sample consisted of mostly White participants who were female assigned at birth. Because of the racial limitations of our sample, we were not able to explore racial differences in the barriers that participants reported. Racial minority TGNC people are likely to experience additive marginalization due to racism and thus, their experience of barriers to gender affirming care may be influenced by this as well. There is a dearth of research on the experiences of genderqueer and non-binary individuals who were male assigned at birth and, unfortunately, this group was underrepresented in our study too. In addition, we were not able to gain sufficient information about barriers to puberty blockers because of the age of our sample. Future research exploring this area is especially needed given that participants described this as a “missed opportunity” that they wished they had been able to pursue. In addition, there may be fluidity of gender identities over time (e.g., some people may identify as genderqueer or non-binary at one point in their development and then as trans men or trans women at other points in their development) and this study cannot account for these shifts or how they may relate to desire for various forms of gender-affirming care.

Conclusions

With the increased awareness and documentation of barriers to gender-affirming care, there are many steps that individuals, organizations, and professions can take to improve care and ultimately help address health disparities for TGNC individuals. Although other research has documented that obtaining competent health services can be challenging for TGNC individuals (Grossman & D’Augelli, 2006; Kenagy, 2005; Sperber, Landers, & Lawrence, 2008), this study was able to highlight some of the specific barriers to gender-affirming care in a gender diverse sample that have not been accounted for in other research. This has been an understudied area (Lombardi, 2011), but the details of these barriers provide insights into changes that need to be made in order to improve access to care and, as a product of that, improve the well-being and health of TGNC individuals.

Acknowledgments

The authors would like to thank the members of the Trans Health Community Advisory Board who assisted with this project for their time, feedback, and dedicated involvement in this work.

Funding: The project described herein was supported by a grant from the National Institute on Drug Abuse (1F32DA038557).

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Table 1

Sample Demographics

Characteristic	*n* (%)
Gender Identity	
Transman/Trans man	77 (30.1%)
Transwoman/Trans woman	60 (23.4%)
Man	23 (9.0%)
Woman	6 (2.3%)
Genderqueer	35 (13.7%)
Non-binary	28 (10.9%)
Agender	6 (2.3%)
Androgyne	3 (1.2%)
Bigender	2 (0.8%)
An option not listed	16 (6.3%)
Sex Assigned at Birth	
Female	180 (70.3%)
Male	73 (28.5%)
Difference of Sex Development	
No	204 (79.7%
Yes	7 (2.7)
Unsure	45 (17.6%)
Sexual Orientation	
Gay	24 (9.4%)
Lesbian	11 (4.3%)
Bisexual	37 (14.5%)
Queer	80 (31.3%)
Pansexual	54 (21.1%)
Asexual	17 (6.6%)
Heterosexual/Straight	17 (6.6%)
An option not listed	16 (6.3%)
Race/Ethnicity	
White	202 (78.9%)
Asian	5 (2.0%)
Black/African American	3 (1.2%)
Latino(a)	7 (2.7%)
American Indian/Alaskan Native/Indigenous	0
Native Hawaiian or other Pacific Islander	0
Multiracial	37 (14.5%)
Education	
Less than high school education	20 (7.8%)
High school diploma or GED	26 (10.2%)
Attended college, but no degree	88 (34.4%)

Characteristic	*n* (%)
Technical school degree	5 (2.0%)
Associate degree	15 (5.9%)
Bachelor's degree	69 (27.0%)
Master's degree	26 (10.2%)
Doctorate or professional degree	7 (2.7%)
Annual Income	
Less than $10,000	116 (45.3%)
$10,000–19,999	53 (20.7%)
$20,000–29,999	17 (6.6%)
$30,000–39,999	17 (6.6%)
$40,000–49,999	19 (7.4%)
$50,000–69,999	19 (7.4%)
$70,000–99,999	9 (3.5%)
More than $100,000	4 (1.6%)

Note. There were 3 missing responses regarding sex assigned at birth and 2 missing responses for race/ethnicity. For gender, all participants were transgender or gender nonconforming, thus the identities of "man" or "woman" can be interpreted as referring to an affirmed identity of participants instead of their sex assigned at birth.

Table 2

Frequency of Responses Regarding Gender-Affirming Care Procedures (N = 256)

Gender Affirming Procedure	Total		Trans Men		Trans Women		Genderqueer		Non-Binary	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Hormone Therapy										
No, and unsure if would like to in the future	35	13.7%	3	3.0%	1	1.5%	14	40.0%	9	33.3%
No, and would not like to in the future	20	7.8%	0	0.0%	0	0.0%	8	22.9%	5	18.5%
No, but would like to in the future	43	16.8%	20	20.2%	12	18.2%	3	8.6%	4	14.8%
Yes, from a specialized gender clinic	47	18.7%	27	27.3%	13	19.7%	3	8.6%	2	7.4%
Yes, from a general doctor's office or clinic	101	39.5%	49	49.5%	35	53.0%	5	14.3%	7	25.9%
Yes, from friends and others not in a medical setting	8	3.1%	0	0.0%	5	7.6%	2	5.7%	0	0.0%
Top Surgery										
No, and unsure if would like to in the future	61	23.8%	7	7.1%	24	36.4%	17	48.6%	4	14.3%
No, and would not like to in the future	33	12.9%	0	0.0%	16	24.2%	5	14.3%	5	17.9%
No, but would like to in the future	103	40.2%	53	53.5%	21	31.8%	8	22.9%	12	42.9%
Yes, I have undergone top surgery	58	22.7%	39	39.4%	5	7.6%	5	14.3%	7	25.0%
Bottom Surgery										
No, and unsure if would like to in the future	95	37.1%	57	57.6%	18	27.3%	7	20.0%	7	25.9%
No, and would not like to in the future	76	29.7%	11	11.1%	5	7.6%	27	77.1%	17	63.0%
No, but would like to in the future	69	27.0%	25	25.3%	36	54.5%	1	2.9%	2	7.4%
Yes, I have undergone bottom surgery	14	5.5%	6	6.1%	7	10.6%	0	0.0%	1	3.7%
Puberty Blockers										
No, and unsure if would like to in the future	6	2.3%	1	1.0%	2	3.0%	2	5.7%	0	0.0%
No, and would not like to in the future	29	11.3%	9	9.1%	3	4.5%	6	17.1%	5	17.9%
No, but would like to in the future	7	2.7%	2	2.0%	5	7.6%	0	0.0%	0	0.0%
Yes, and I'm still on them	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Yes, and then I started cross-sex hormones	2	0.8%	2	2.0%	0	0.0%	0	0.0%	0	0.0%
Yes, but then I stopped and went through the puberty of my sex assigned at birth	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
Not applicable because of my age	211	82.4%	85	85.9%	56	84.8%	27	77.1%	23	82.1%

Note. There were 2 responses missing regarding hormone therapy, 1 for top surgery, 2 for bottom surgery, and 1 for puberty blockers. The category of "trans men" includes individuals who indicated that their gender was transman, trans man, or man. The category of "trans women" includes individuals who indicated that their gender was transwoman, trans woman, or woman. The categories of "genderqueer" and "non-binary" specifically include individuals who endorsed these identities and no further grouping was conducted to create these two categories.

Table 3

Resource List for Providers working with Transgender Individuals

Name of Resource	Description	Website
The Institute of Medicine's report on The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding	This is a largescale review of the available literature on the health and well-being of LGBT people, with specific information about the available literature on the experiences of transgender individuals.	http://www.nationalacademies.org/hmd/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx
World Professional Association for Transgender Health Standards of Care	These are the Standards of Care as outlined by the World Professional Association of Transgender Health. This document includes information about gender dysphoria, mental health, and various forms of gender-affirming care (e.g., hormone therapy).	https://s3.amazonaws.com/amo_hub_content/Association140/files/Standards%20of%20Care%20V7%20-%202011%20WPATH%20(2)(1).pdf
Informed Consent for Access to Trans Health (ICATH) collaboration	ICATH proposes an alternative model to that within the Standards of Care, whereby individuals can engage in an informed consent process to access trans-affirming care as opposed to the recommendations of attending therapy to access care.	https://icath.info/
Transgender Medical Consultation Service	This is a national consultation service that allows providers to seek guidance on working with transgender clients.	http://project-health.org/transline/
National Center for Transgender Equality's Summary of Trans Healthcare Rights	This website details the rights of transgender individuals seeking healthcare.	http://www.transequality.org/know-your-rights/healthcare
Center of Excellence for Transgender Health at the University of California San Francisco	The Center of Excellence for Transgender Health has a variety of resources, including information on routine care, HIV prevention, cultural competency, mental health, and policy work. They also provide a number of primary care protocols for individuals working with transgender patients.	http://transhealth.ucsf.edu/