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Experiences of Nonbinary and Gender Nonconforming Individuals Within the Healthcare System

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Abstract

Though nonbinary and gender nonconforming people are becoming increasingly recognized in North America, specialized healthcare—specifically gender-affirming procedures—are not becoming available to them. Researchers have examined the subjective experiences of these individuals as they have navigated the healthcare system in order to further understand possible limitations for nonbinary and gender nonconforming populations. Methods include assessing the procedures available to participants and their interpersonal experiences with healthcare professionals and family members. Scientific resources on this topic are limited, and the results are overwhelmingly represented by self-report. Furthermore, the content of the results is majorly negative toward the participants' experiences. Participants report verbal abuse and physical attacks in healthcare settings, medical procedures being unavailable or difficult to access, and a lack of support from family and various healthcare professionals. Continuing research in more objective formats and with greater specificity toward the subject is prompted.

Keywords: Nonbinary, gender nonconforming, gender-affirming care, healthcare

Transgender individuals are people who identify as a gender that is not usually associated with their sex at birth (American Psychological Association, 2018). They are becoming increasingly familiar in pop culture, with celebrities such as Caitlyn Jenner and Jazz Jennings—both transgender women—being well-known throughout North America. Both Jenner and Jennings are binary transgender individuals, meaning that they identify within the two discrete, normative gender categories—male and female (American Psychological Association, 2018). In contrast, there is a less well-known but increasingly prevalent group of people with nonbinary and gender non-conforming identities. Nonbinary and gender nonconforming (NGNC) people do not identify as the gender typically associated with their sex at birth, but they also do not identify with the other normative binary gender—male or female (National Center for Transgender Equality, 2018). Despite being less well-known, there are still several celebrities who identify as NGNC—such as Sam Smith or Bex Taylor-Klaus, both of whom identify as nonbinary and use they/ them pronouns rather than the binary he/ him or she/ her pronouns. Even though experiences vary greatly between transgender and gender nonconforming (TGNC) people who may identify inside or outside the gender binary, they are often addressed and discussed together in popular literature with little emphasis placed on their differences.

The current population of NGNC people is unknown, but in recent years more people seem to be identifying overall as TGNC, with some reports up to 1,600 individuals per 100,000 people (Deutsch, 2016a). With this growing population, the demand for specialized healthcare is also growing, but clinics and health centers are not changing to meet this demand. In a survey performed by the National Center for Transgender Equality and the National Gay and Lesbian Task Force, of 6,436 TGNC people 19% of respondents reported being outright denied healthcare from doctors or other healthcare providers due to their identity as TGNC (Grant et al., 2011). In this same survey, 28% of respondents reported being verbally harassed at a medical facility, and 2% reported being physically assaulted in a doctor's office (Grant et al., 2011). One participant described an experience in which they

were forced to undergo a pelvic exam despite only going to the doctor for a sore throat. Furthermore, the doctor invited others into the room during the exam and let them look at the participant while talking about their genitals (Grant et al., 2011). These experiences can make a place as vital as the hospital feel like a hostile environment to TGNC individuals who are looking for care, especially gender-affirming care.

Gender-affirming care is made up of practices and procedures that are meant to respect and assist TGNC people as they transition physically or socially to their affirmed gender, or their gender identity. One of the most common first steps in TGNC individuals' transition is receiving hormone replacement therapy (HRT), which is often the supplementation of cross-sex hormones. For example, a transgender man who was assigned female at birth (AFAB) may receive testosterone shots in order to masculinize his body (Deutsch, M. B., 2016c) and a transgender woman who was assigned male at birth (AMAB) may receive estrogen in order to feminize her body (Deutsch, M. B., 2016d). Other procedures are more extreme and more permanent, including top surgery, in which the breast tissue is removed or augmented; bottom surgery, which can include vaginoplasty, phalloplasty, and metoidioplasty, in order to alter the sex organs to a physical presentation that is more validating of their identity; and aesthetic procedures like facial feminization/masculinization, which changes the facial structure to look more like their desired gender (Deutsch, 2016b; Chen et al., 2019). With all of these options, the most commonly accepted path to transitioning is receiving HRT, then top surgery, and then bottom surgery—but this norm becomes an issue for NGNC people who do not wish to transition to the “other” binary gender (Clark et al., 2018, p. 159). Many NGNC people do not want to undergo procedures to achieve the idealized “total” transition and would rather pick and choose among the different procedures to affirm their gender.

Decisions regarding transition opportunities differ for adolescents versus adults, particularly in the ability to give informed consent to receive procedures. Many TGNC adolescents are not old enough to give consent to receive transitional care, so they must rely on their

guardians who may have different opinions on their transition (Kimberly et al., 2018). On the other hand, TGNC adults are able to give informed consent without consulting their guardians and generally have more control over the professionals they see and the procedures they choose to undergo. The other difference between opportunities for adults and adolescents is related to preventative measures. Much of the current transition procedural norm comes from “reversing” the effects of puberty: removing the development of breasts, undergoing facial feminization, and going through other similar procedures. However, pre-pubertal TGNC youth have the option to start puberty blockers, which are gonadotropin-releasing hormone agonists (GnRH agonists), to prevent the development of these secondary sex characteristics (Kimberly et al., 2018). This is an option that is not available to most adult and older adolescent TGNC people because they have already gone through puberty (Puckett et al., 2017). This has created a conversation about whether puberty blockers should be made widely available for TGNC adolescents, or if underage people should be forced to develop as typical and then have the option of procedures to alter or reverse the effects of puberty.

Despite the growing NGNC population and the types of issues mentioned prior, information about the actual needs and experiences of these individuals is not widely available. I will analyze and discuss the current research on gender-affirming healthcare practices available to adolescent and adult NGNC individuals, and the subjective experiences of NGNC people navigating the healthcare system as seen through their interactions with family members and healthcare professionals. This includes differences in experience between minors and adults, family and friend support systems, further discussion of puberty blockers, violence and perceived ignorance in a clinical setting, and self-treatment. I will also discuss the limitations in the current research and implications for future research and policy.

Methods

I accessed the material from three databases—PsycInfo (EBSCO), Medline (EBSCO), and Scopus (Elsevier)—using the following keywords: nonbinary or non-binary or “non binary” or

Experiences of Nonbinary and Gender Nonconforming Individuals

genderqueer or “gender queer” or “gender fluid” or genderfluid or “gender nonconforming” or “gender nonconformity” or gender-nonconforming, and healthcare or “health care” or hospital or “health services,” and gender-affirming or “gender affirming.” Many of the articles included information on binary transgender people, but where possible, I attempted to only use results from nonbinary or gender nonconforming participants. In cases where the source included information on both binary and NGNC people, only the information about NGNC participants will be included. I restricted inclusion to articles written in the English language between 2009 and 2019 and focusing on North American NGNC youth. This left 11 articles, which were then further narrowed to five based on content relevant to NGNC individuals.

Results

Adolescent and Adult Comparisons

The experiences of adult and adolescent NGNC people can be very different. Adults have autonomy to seek out healthcare on their own but may not be able to receive care for many reasons. Clark et al. (2018) conducted a study that included a group of older youth between the ages of 19 and 25. Interestingly, this group—all of whom were legal adults—reported forgoing medical care at nearly twice the rate of the younger (aged 14–18) individuals. One reason for this was because of poor familial relationships. In another study by Goldberg et al. (2019), a nonbinary participant responded that they could not obtain healthcare because they did not have a support network to care for them during recovery. Lack of support is an often-cited barrier, with one youth stating that “[their] dad would never allow it” (Clark et al., 2018, p. 164). Though family support is more often a barrier for NGNC adolescents, for reasons mentioned later in this literature review, it can also greatly impact NGNC adults who are not financially secure or would be unable to care for themselves after a procedure. Another major reason for inability to receive care, or choosing not to, is that many NGNC people report being disregarded by healthcare professionals when they speak about pursuing transitional procedures

(Goldberg et al., 2019; Lykens et al., 2018). Though NGNC adults have the legal right to request and consent to certain methods of care, they are likely to be outright denied the care that they request or be belittled and distrusted (Goldberg et al. 2019). In contrast, adolescents have to seek out healthcare with their guardians, unless they turn to self-treatment, such as buying hormones off the Internet or attempting silicone injections on their own (Kimberly et al., 2018). Self-treatment can be very dangerous but is popular in TGNC people who are younger or of a lower socio-economic class. The topic of self-treatment will be further discussed later.

In the U.S., guidelines on whether a minor can access healthcare without parental consent varies from state to state (*State Laws on Minor Consent for Medical Care*, 2019). Due to this, many TGNC youths lose autonomy or control in their own health care, which can be problematic for youth with unsupportive parents as they will remain unable to receive any transitional care until they are of a legal age. The lack of a supportive and stable family environment greatly affects access for youth. Situations such as homelessness, being in government custody, or a lack of familial support for gender transition goals can all prevent NGNC youth from accessing the different transitional procedures that they need (Clark et al., 2018). Circumstances such as these often prevent NGNC youth from accessing most treatments because they are unable to receive parental consent. For some procedures, many places throughout Canada and the United States have lower ages of informed consent for healthcare, but the regulations are inconsistent. In Canada, most provinces and territories allow youth to consent to healthcare from age 14 (Clark et al., 2018), though many people have gone through puberty by the time they are 14—negating the option for preventative measures—while in the United States each state has their own policy surrounding informed consent, resulting in an inconsistency in treatment access (*State Laws on Minor Consent for Medical Care*, 2019). Due to this, finding treatment as an NGNC youth can be challenging.

NGNC youth have the opportunity to access a transitional method that is not available to older NGNC persons. Puberty suppression is a transition method that is only effective in very young NGNC people

Experiences of Nonbinary and Gender Nonconforming Individuals

because once puberty has taken place, it cannot be reversed through hormones. Puberty blockers can be useful for transition, but the long-term effects are not well known, and there are few studies available on the topic (Kimberly et al., 2018). On the other hand, suppressing puberty can allow people who are questioning their gender more time to explore their gender identity before any permanent changes to their bodies occur. This also means that if someone decides to further transition to a gender other than their assigned gender at birth, there are often less procedures needed to remove or alter secondary sex characteristics (Kimberly et al., 2018). A major obstacle to the use of puberty blockers is that there is little information about the long-term mental and physical effects of stalling the development of the body. Because of this, informed consent comes into play when deciding at what point an adolescent can be allowed to go through puberty suppression. Currently, there is a discussion about the ethics in deciding whether a youth is making an informed choice, or if they are acting on a whim when making a life-altering decision (Kimberly et al., 2018).

Further issues come with a lack of access. Even in cases where, theoretically, a youth could gain use of puberty blockers, many people cite issues of limited access (Kimberly et al., 2018; Clark et al., 2018). This forces many NGNC people to go through the pubertal changes of their assigned sex, making transitioning in the future more complicated (Clark et al., 2018). In the case of adults, puberty blockers were often something that many participants saw as a missed opportunity—either because they understood their gender identity after puberty took place, or because they did not know it was an option for them (Puckett et al., 2017). Research indicates that puberty suppression is an opportunity that many wished they could have taken advantage of but were unable to (Puckett et al., 2017; Clark et al., 2018). There is a popular aphorism that states that an ounce of prevention is worth a pound of cure, and in the case of NGNC people, that belief holds true. For many NGNC adults, access to puberty suppressants in their youth could have prevented the much more invasive transitional methods they used later in life.

Qualitative Experiences

Positive Experiences

Throughout the literature, there were very few mentions of positive experiences within gender-affirming care. The good experiences were typically minor, such as others' use of the correct pronouns and education on different gender identities that made NGNC patients feel welcomed and understood. Goldberg et al. (2019) conducted a study in which one participant said their provider understood the idea that gender can be fluid and would check with the participant every once in a while to know whether their name or pronouns had changed. Experiences as simple as this were enough to make healthcare experiences positive for many NGNC people. Unfortunately, only 16.66% of the respondents in this study endorsed any positive experiences with mental health professionals.

Negative Experiences

The experiences within healthcare relayed by NGNC respondents were overwhelmingly negative. Many of the experiences overlapped with the major issue being disrespect for important parts of NGNC identities, such as pronouns. This disregard can be intentional or due to ignorance about the topic. In a study by Puckett et al. (2017), one genderqueer participant described their experience with a trans-specialized provider who did not understand the patient's desire to receive testosterone HRT without identifying as male or taking it in a dosage or regimen that is not standard to the practice. In this case, the patient felt as though they had to educate their healthcare provider on things that they, as a trans-specialized healthcare professional, should have known. Many TGNC people have reported feeling especially alienated by providers who should have been the best resource for them (Lykens et al., 2018). Misunderstanding NGNC identities, even with good intent, can be just as damaging. Often, healthcare providers will endorse or offer procedures that the patients neither asked for nor wanted, usually because the procedure was seen as the next obvious step in a binary transition (Lykens et al., 2018). According to Clark et al. (2018), NGNC participants were

Experiences of Nonbinary and Gender Nonconforming Individuals

less likely to have a family doctor, and if they did, the doctor was less likely to understand their trans experience (p. 164). In research by Puckett et al. (2017), a genderqueer participant reported that there was very little information available to those who wanted treatment that was not standard in a transition to the other binary sex. All of these experiences express a lack of knowledge about and resources for NGNC people, including how their needs may differ from binary trans peoples' needs.

Willful ignorance on the part of the medical provider can be even more alienating. Goldberg et al. (2019) discuss experiences with therapists who emphasize the gender binary or have narrow definitions of what it means to be transgender. This behavior can be invalidating and harmful for NGNC people as some have reported that they have been abused or belittled because of their identity. One genderfluid participant said that a mental healthcare provider suggested that they discontinue hormone therapy and live life as a woman, rather than their affirmed identity (Goldberg et al., 2019). Another agender individual said they met with a therapist who kept on using the phrase "inner little girl" when talking about them, rather than a gender-neutral phrase like "inner child" (Goldberg et al., 2019, p. 20). This participant also referenced other therapists who refused to use they/them pronouns and insisted on referring to the participant with the incorrect she/her pronouns (Goldberg et al., 2019). These negative experiences were reflected across the literature. In the study by Puckett et al. (2017), a nonbinary participant said that they were unable to find a healthcare provider that would discuss their body and chest in the context of their nonbinary identity, and a genderqueer person said that many mental healthcare providers they encountered would only allow binary trans people start HRT because the requirements for approval were heavily based in binary ideals.

One of the most common barriers for NGNC youth is finding a doctor that will prescribe hormones (Clark et al., 2018). NGNC youth have reported twice the odds of experiencing barriers to hormone therapy than binary youth (Clark et al., 2018, p. 164). In one study, a genderqueer participant said that they were told that they were too young to know what they wanted, despite being of legal age (Puckett et al., 2017). All of these instances indicate a pattern of healthcare

professionals' outright dismissal of the healthcare needs and wants of NGNC people, simply because they identify outside of the gender binary.

Healthcare providers have also, in some cases, insisted that NGNC youth's mental health issues stem from their gender identity (Goldberg et al., 2019) rather than understanding that one's mental state can be attributed to several different aspects of life. Participants in the study by Goldberg et al. (2019) indicated that professionals, and especially psychiatrists, were "skirting around" (p. 21) the topic of gender, avoiding speaking about it even when the participants addressed it directly. Other college-age participants reported having supportive and understanding therapists, but less knowledgeable on-campus healthcare professionals who repeatedly misgendered them or made inaccurate assumptions about their gender and identity. NGNC students in this study reported more misgendering by counseling and health professionals compared to binary students. These experiences suggest a discipline-wide pattern of disregard and lack of respect for people who identify outside the binary.

Self-Treatment

Those NGNC individuals who have had negative experiences with healthcare providers have reported resorting to alternative methods of treatment. In the interviews performed by Lykens et al. (2018), many participants reported modifying their treatment without discussing it with their care providers because they believed that the regimen given by the care provider would not achieve the transition they desired. The adult respondents reported their ability to modify their treatment without their physician knowing (Lykens et al., 2018), using methods such as administering smaller or larger doses than recommended and changing the schedule of administrations. Similarly, many trans people turn to illicit hormones and self-administration (Lykens et al., 2018). This is dangerous for several reasons, including the possibility that the hormones are poor quality or toxic, the inappropriate administering of doses, and a lack of professional guidance. This can also lead to contracting hepatitis C and HIV from needle sharing. Despite all of the risks of HRT self-treatment, it is a widely reported practice (Kimberly et al., 2018).

Experiences of Nonbinary and Gender Nonconforming Individuals

These results illustrate that best practices in the medical sphere are supported by education, access, and acceptance. Each negative experience was due to a lack in one or more of these categories. Poor access to HRT and puberty suppressant, medical professionals misunderstanding and disregarding NGNC patients, and parents refusing their NGNC children support throughout transition were the most commonly reported categories. Additionally, NGNC persons are frequently put in harmful positions, ranging from self-administration of controlled medication to physical abuse from medical professionals. Positive experiences included simple things such as respecting one's chosen name and pronouns. Such experiences were also provided at a fraction of negative experiences, suggesting that these experiences are also much rarer in the greater population.

Discussion

Limitations

The two most common ways that information was gained came from face-to-face interviews with NGNC individuals and online surveys distributed throughout different LGBTQ resource centers and pages online. Due to this, the types of data gathered are limited to personal accounts, and thus, are almost entirely subjective—making the conclusions drawn from each study ungeneralizable to most other populations or contexts.

The greatest limitation to this literature review was the lack of information about NGNC people specifically. After inclusion criteria, as noted prior, only five articles actually focused on the treatment and experiences of NGNC people. Many of the other articles were broadly about TGNC healthcare, but they showed greater emphasis on treatment for those with binary identities—often just mentioning NGNC people under the TGNC umbrella and never discussing their unique challenges. Further limitation came from the samples in the studies included, which were overwhelmingly white and AFAB. Of the 10 people interviewed by Lykens et al. (2018), eight were AFAB, two were AMAB, and half were white. Similarly, in Puckett et al. (2017), 78.9% of participants were white and 70.3% were AFAB. Furthermore, only 35.2% of the participants were NGNC; even within

an article that addresses NGNC challenges specifically, they are still a minority. These limitations should prompt further research into NGNC identities and how NGNC people experience something as vital as healthcare.

Conclusion

Healthcare is a vital resource for many people, and it is important that the system be effectively utilized by all types of people in order for them to maintain a healthy and happy lifestyle. Nonbinary and gender nonconforming people especially need the healthcare system to be a viable resource for them due to their life experiences outside the gender binary. In this literature review I intended to examine the ways that NGNC people experience the healthcare system, and how that may intersect with their age. Despite the limited amount of information available about NGNC people, the studies included in this literature review described overwhelmingly negative stories and experiences from many different NGNC people across North America, with only a small number of research participants relaying positive experiences. There is further understanding gained when looking at the intersection of age and gender identity, which highlights the restrictions placed on NGNC adolescents specifically, and how NGNC adults are affected in unexpected ways. Despite all of the information laid out in this document, there is still a need for further research into NGNC people, especially in regard to developing a system of best practices when providing care for gender minorities.

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Experiences of Nonbinary and Gender Nonconforming Individuals

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