

January 2015

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**Unanticipated:
Healthcare Experiences of Gender Nonbinary Patients
and Suggestions for Inclusive Care**

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Thesis for the MPH degree in Social and Behavioral Sciences at Yale School of Public Health

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April 2015

Abstract

Transgender populations face substantial barriers to healthcare access, exacerbated by a lack of inclusive research. The health needs of those who are gender nonbinary or genderqueer, identifying outside the binary of man and woman, are especially poorly understood. Using a primarily qualitative online survey, data on gender identity, health access, and healthcare experiences were collected from 81 gender nonbinary participants, and analyzed using a mixture of quantitative and qualitative methodologies. A number of interesting findings emerged, including that 90% of participants across age groups began identifying as gender nonbinary within the last 6 years, 77% reported interest in some aspect of medical transition, and 75% had avoided healthcare because of the cost. Connections between geography, health access, disclosure of gender identity and quality of healthcare experiences were explored, as well as suggestions provided by participants for ways to improve healthcare experiences for gender nonbinary patients. Results of this study indicate that gender nonbinary people often feel invisible and unwelcome in health settings, due in part to widespread assumptions of gender and sex's inseparable and binary natures, and that this discomfort in health settings, as well as economic and geographical factors, may negatively impact nonbinary patients' access to healthcare. Suggestions for improved care include increased education of providers on trans and gender nonbinary identities and health needs, inclusion of non-binary gender and pronoun options on intake forms and medical records, and de-emphasizing gender in healthcare.

Introduction

Transgender health is an emerging field, spurred by activism from the trans community to both reclaim discussions of transgender health from medical experts who have long pathologized this population, and to highlight the ways that the unique needs of transgender and gender non-conforming individuals have been erased through token inclusion in the "LGBT health" umbrella (Hanssmann, 2009). LGB and trans health concerns are not wholly unlinked; as Mananzala and Spade argue, there is "a long history of sexual and gender outsiders finding community together, resisting oppression together, and often understanding their identities through and against each other" (2008). However, while LGB(T) health research begins to expand into mainstream policy and practice (IOM, 2011), the research on transgender health that does exist often suffers from poor sampling practices, lack of community involvement, and reliance on outdated medical understandings of trans identity (Kuper et al., 2012; Scheim & Bauer, 2015), resulting in writing and policy that artificially homogenizes this diverse population (Scheim & Bauer, 2015).

In an effort to begin to address one component of this erasure and to center the voices of trans and gender non-conforming people in the research that affects their

lives, this study seeks to qualitatively explore the health experiences of a geographically diverse sample of gender nonbinary people. The category of gender nonbinary, or simply “nonbinary,” people, also often referred to as genderqueer, encompasses those in the transgender community who do not identify as the gender they were assigned at birth, but also do not identify, as binary trans women or men do, as the “opposite” gender (see table 1 below for an overview of trans-related terminology that is used in this paper). Nonbinary individuals may understand themselves as having no gender, a third gender, a fluid gender, multiple genders, or an androgynous gender (among other possibilities); what unites them as a group is disidentification with the modern Western gender binary (Lugones, 2009) of “man” and “woman”¹ (Gates, 2010).

Though the literature on nonbinary experiences is scant, there is evidence that simply existing within a mode of identity that destabilizes a social norm as strongly felt as our gender binary can result in not only health risks, but the failure of health institutions to appropriately recognize and address these risks. This study seeks to build upon this evidence by using the methodology of the online qualitative survey to quickly and accurately gather richly detailed data from a geographically dispersed and classically “hidden” population.

Table 1. Trans-related terminology in this paper, alphabetized	
Term	Definition
AFAB/DFAB	Assigned female at birth/designated female at birth
AMAB/DMAB	Assigned male at birth/designated male at birth
Binary trans	Describing a transgender person whose gender is binary, identifying with the binary gender “opposite” the sex they were assigned at birth; i.e., a trans woman or trans man.
Cisgender (cis)	Describing a person whose gender identity aligns with the sex they were assigned at birth; not transgender; i.e., cis(gender) woman, cis(gender) man.
Cissexism	Assuming everyone to be cisgender; analogous to heterosexism
Gatekeeping	Requirements put into place by medical professionals to control who gets access to medical transition care such as hormones and surgery. Examples include mandated therapy, living for a year as one’s “desired gender,” and conforming to stereotypical gender roles.
Gender binary	The idea that there are only two valid genders, man and woman.
Gender dysphoria	Feelings of discomfort or distress stemming from a disconnect between one’s body and their gender. Also a formal psychiatric diagnosis (see DSM V)

¹ As with all transgender identities, a person’s identification as nonbinary refers to their gender identity, and does not speak to their sexual orientation.

Gender nonbinary	An umbrella term for people who identify outside of the man/woman binary
Genderqueer	An umbrella term for people who identify outside of the man/woman binary, but may also be used as a more specific identity term (i.e., one with a “queer” gender)
Medical transition/ transition care	Referring to medical processes, including but not limited to hormone replacement therapy (HRT) and gender affirming surgery, that some trans people seek in order to alleviate symptoms of gender dysphoria.
Queer	An umbrella term for identities outside of the heterosexual and/or cisgender norm
Transfeminine	Describing a person who is AMAB and whose gender has a prominent feminine component (inclusive of binary and nonbinary genders)
Transgender (trans)	An umbrella term describing a person whose gender identity does not align with the sex they were assigned at birth
Transmasculine	Describing a person who is AFAB and whose gender has a prominent masculine component (inclusive of binary and nonbinary genders)
Transphobia	Fear or hatred of, or discomfort with, transgender people; analogous to homophobia
Transsexual	Usually but not always referring to a binary trans person who has undergone or hopes to undergo gender affirmation surgery
<i>Adapted from: (Stringer, 2013; GLAAD, 2015)</i>	

The number of people with a nonbinary gender identity in the general US population is unknown. The best numbers available for the percentage of people who identify as transgender come from a 2007-2009 population-based survey in Massachusetts, where respondents were asked if they were transgender; 0.5% responded that they were (Conron et al., 2012). However, while the question asked did not explicitly define “transgender” as binary, its wording could be interpreted as binary, and it is possible that the survey instrument missed many nonbinary respondents. Convenience-sampled surveys including a broad definition of transgender participants in their sample have found anywhere from 13% (Harrison et al., 2012), to ~20% (Scheim & Bauer, 2015), to well over half of their sample (Kuper et al., 2012) identifying as genderqueer or otherwise nonbinary. However, despite inclusivity of nonbinary identities in recent research on transgender health and experiences (Grant et al., 2010; Kuper et al., 2012; Shor, 2014; Scheim & Bauer, 2015), there is still very little research that aims to specifically investigate the needs of nonbinary populations (Alleyn & Jones, 2010; Schulz, 2012; Harrison et al., 2012; Budge et al., 2014).

Additionally, what is actually meant by “health needs” is often poorly defined within trans health as well as in the wider LGBT health literature. As Epstein describes in

his 2003 paper, the literature on and activism around LGBT health has largely been split between two goals: describing and combatting the discrimination and insensitivity that LGBT people face within the health system, and rendering LGBT health needs visible by including LGBT people in nationwide, population-based health surveys. Epstein argues that defining a group by shared external oppression is easier to operationalize and more politically prudent in the long term than attempting to define them through a shared health profile which is often more closely linked to behavior than identity. This tension has been present in the burgeoning trans health field as well, complicated by the fact that many trans people do in fact require access to specialized medical care specific to their identity (i.e., transition care such as hormone therapy and gender affirming surgery), in a way that LGB people generally do not (Hanssmann, 2009). Moreover, as Bauer argues based on a qualitative study of trans health experiences, informational erasure and institutional erasure are mutually reinforcing in constructing the health care system as a hostile setting for trans patients (2009).

With this context in mind, this paper focuses primarily on the goal of making visible, describing, and critiquing the health care experiences of nonbinary patients, addressing the question posed by Harrison, et al. in their 2012 paper exploring the experiences of genderqueer respondents of the National Transgender Discrimination Survey: “How does nuance or multiplicity in gender identity and expression play out when interacting with gender policing structures and forces?” However, a secondary goal of this project is to facilitate future data collection on this poorly studied population by allowing for self-labeling of gender identity and thereby sidestepping the common problem of inaccurate or out of date gender identity options.

Nonbinary patients, binary healthcare

Health care institutions have largely been built on binarist, heterosexist, and cissexist assumptions (Bauer et al., 2009), and the limited literature on gender nonbinary people’s experiences in health care settings indicates that nonbinary people often do experience the health system as a “gender policing structure” (Alleyn & Jones, 2010; Schulz, 2012). In an unpublished dissertation from 2012, Sarah Shulz conducted qualitative interviews with 28 genderqueer and transmasculine people, who discussed challenges in communicating with health care providers, dealing with gender markers on insurance and in medical record systems, and discomfort in gendered health settings such as gynecologists’ offices. Shor (2014) found that the top barriers to care for trans people were: cost, not having access to gender neutral restrooms, paperwork at the facility not reflecting their gender identity, not confident that the provider would use the correct pronouns, difficulty finding a trans-friendly provider, and not being able to find providers knowledgeable on transgender health issues. This section will explore the existing literature on nonbinary, trans, and LGB people’s health care experiences,

including lack of provider education, barriers to transition care, and the challenge of disclosure.

Medical education on LGBT health needs is still woefully inadequate (Obedin-Maliver et al., 2011), and transgender patients in particular are often burdened with the need to educate their health care providers. In the National Transgender Discrimination Survey, 50% of trans respondents reported having to teach their provider about transgender care (Grant et al., 2010). This reversal of the normal patient-provider relationship is not without consequence: a qualitative study of trans patients and their providers found that in the face of uncertainty, providers often stigmatized their patients in order to reinforce their own medical power and authority (Poteat, German, and Kerrigan, 2013). Successful communication with poorly educated medical providers takes a great deal of energy (Brotman et al., 2002), assertiveness (Cant, 2006), and formal education (Welle et al., 2006).

This education is likely even harder for those who do not fit into the gender binary at all. The medical world's conception of "transgenderedness" is still largely shaped by the simplistic narrative (or "fairytale," as author Chrissy Alleyn puts it) of a patient who feels that he or she has been "born into the wrong body" and seeks medical care in order to change his or her body (hormonally and surgically) to the shape of that of the "opposite sex" (Spade, 2003; Alleyn & Jones, 2010). This singular transgender narrative shapes both doctors' ideas of what "correct" or "true" transgender patients look like (Schulz, 2012; Poteat, German, and Kerrigan, 2013), as well as the guidelines that they rely in in their practice (APA, 2013; Lev, 2013). Medical "gatekeeping" has long been a fixture of the medical transition process for trans patients, including requirements for months or years of psychotherapy, conforming to gender stereotypes of their "desired sex," and often dangerous months-to-years-long "real life tests" (Spade, 2003; Lev, 2009). It was only very recently that the World Professional Association for Transgender Health (WPATH) updated their Standards of Care (largely seen as the gold standard medical guidelines for trans health care) to acknowledge the diversity of transgender identities and needs regarding transition care, and to make formerly mandatory gatekeeping processes optional (though continuing to shy away from condemning them fully) (WPATH, 2011).

Individuals who identify as trans but who do not fully identify as the "opposite gender," who want hormones but not surgery, surgery but not hormones, or neither hormones nor surgery, often still face pressure to "transition fully" or feel that they are in "uncharted territory" with regards to health care (Schulz, 2012). As Alleyn and Jones note, medical providers' adherence to a singular binary trans narrative is a self-fulfilling prophecy: if non-binary trans patients know that they need to produce a binary narrative in order to access the care that they need, they will present their gender as binary in health care settings. With this in mind, it is unsurprising that research on non-binary identities and health needs is so limited.

Along with lack of provider education, discomfort associated with disclosure of sexual orientation and/or gender identity is a major theme of the literature on LGBT health access and experience (Allen et al., 1998; Eliason & Schope, 2001; Brotman et al., 2002; Cant, 2006; Hoffman et al., 2009). Nondisclosure has been found to affect LGB patients' mental health and result in avoidance of routine medical care (Brotman et al., 2002), while the ability to "come out" in a supportive environment was linked with the achievement of a "positive self-concept," leading to better health outcomes (*ibid.*). Similarly, Schulz (2012) wrote that participants felt that coming out was necessary to receive the best care possible, and that positive disclosure experiences made them feel "like a whole person."

Brotman and colleagues' finding that bisexual participants felt particularly stigmatized in health care settings, feeling a "sense of disenfranchisement and invisibility," may be particularly instructive in hypothesizing about the effect of nonbinary-ness on healthcare experiences. Preliminary evidence from the National Transgender Discrimination survey indicates that respondents who wrote in their own gender (rather than selecting "man" or "woman") were more likely to have experienced harassment and discrimination, and more likely to have postponed needed medical care, despite being more educated than their binary trans peers (Harrison et al., 2012). Budge, Rossman and Howard found that in their sample of 64 genderqueer individuals, 53% screened positive for clinical depression and 39% for clinical anxiety (Budge, Rossman, & Howard, 2014).

Internet research: Accessing nonbinary voices

Much previous research on transgender and gender nonbinary populations has been limited by small and geographically limited samples (Shulz, 2012; Welle et al., 2006). Other common methodological issues include highly nonrepresentative sampling methods such as sampling from populations seeking transition care in clinical settings (Kuper et al., 2012). Due to these constraints, many researchers have been moving towards recruitment and/or instrument distribution methods that are at least partly Internet-based (Grant et al., 2010; Kuper et al., 2012; Shor, 2014; Scheim & Bauer, 2015). However, no previous research in this population has attempted to marry the convenience and reach of Internet sampling with the depth of information made possible through qualitative survey design.

The idea of the primarily qualitative online survey was inspired by Jowett and Peel's 2009 online qualitative survey of LGB people's experiences of chronic illness. This methodology seemed appropriate for both the population and the research question at hand. There is considerable research showing that queer and trans people, particularly young people, have been using the Internet as a mode for community-building, information-sharing, identity-formation, organizing, and socializing for decades (Broad, 2002; Shapiro, 2003; O'Riordan & Philips, 2007; Fink & Miller, 2014), making them a group well-suited to an online survey that other populations might perceive as too long or arduous to complete.

The unique methodology that shaped this project will be explored in detail in the next section, followed by the results of the survey and a discussion of major themes and implications for future research and practice. While experiences within health settings are only a small element of the larger forces that shape trans and nonbinary people's health access and health risks (Hanssmann, 2009), this paper hopefully represents a step towards greater understanding of the needs of nonbinary people in health care, and perhaps more broadly, in all institutions that are not set up for those whose identities lie outside of the gender binary.

Methods

The online survey

The survey instrument used to collect the data presented below was developed using Qualtrics survey-building software following IRB approval (see Appendix A for the full text of the survey).

The survey collected qualitative data not only from responses to questions regarding participants' healthcare experiences, but also from demographic questions that are often designed as multiple choice lists with preset answer options, but in this survey were left open-ended. This across-the-board qualitative methodology aimed to approximate the richness of data possible with a true qualitative interview, with the understanding that qualitative responses could later be broken down into simpler components and coded into categories for analysis. Thus, questions such as "How would you describe your race/ethnicity?" and "Do you identify as trans?", as well as more complex questions such as "Do you feel that those around you understand and support your gender identity?" were all open-response. A few questions provided multiple-choice options: this was done either to facilitate survey flow or simplify analysis. Multiple-choice questions included an optional open-response box where possible.

The survey contained 45 total questions and was split into 4 parts: demographics, gender, health access, and health care experiences. Part 1 began with questions establishing inclusion criteria. Participants were required to be ≥ 18 for informed consent purposes, and because this survey focused on experiences within the US health system, and the Internet is without geographic limit, they were also required to be US residents in order to continue the survey. During data collection, a third inclusion criteria item was added in order to attempt to correct for poor racial diversity in responses, with a corresponding addendum to the survey instructions (see recruitment section for further explanation). In the added item, participants were asked if they were white (excluding mixed race/ethnicity) or no, and those who indicated that they were only white were sent to the end of the survey. Unfortunately, this item was added too late in the data collection process to have much impact on the ultimate racial diversity of the sample: only 7 more potential

respondents (4 of whom were non-white and completed the survey) attempted the survey before it was closed.

Other demographic information collected included age, gender identity, sexual orientation, race, intersex status, trans identification, birth assignment, education, financial and housing status, and the relative rurality/urbanity of area of residence. In part 2, participants were invited to write about their gender identity's stability over time and when they began to identify as nonbinary, as well as "out"-ness, support, and community. Part 3 included questions about both physical and mental health access, including cost as a barrier to care and perception of access to quality care. Participants were also asked whether they had utilized LGBT clinics, whether they had used surgery or hormones to alleviate gender dysphoria, and whether they would like to access surgery and/or hormones in the future. In the final section, participants were asked to discuss both negative and positive health care experiences, comfort in health care settings, and disclosure to health care providers, and were also asked for ways that health care settings could improve experiences of care for nonbinary patients.

This survey was incentivized using a lottery for 2 \$50 giftcards. In order to protect participants' confidentiality, participants who completed the survey were prompted to follow a link to a second survey, where they could enter an email address in order to be entered into the lottery. After winners were drawn, the list of email addresses was destroyed.

Recruitment

Participants were recruited through social media, primarily the popular microblogging platform Tumblr, as well as through Facebook and Reddit. Posts were targeted to genderqueer and nonbinary audiences through methods including tagging and strategic posting within Facebook and Reddit communities of queer, trans, and nonbinary users. Posts advertising the survey were tailored to the specific platform and community in which they were posted, but all gave an overview of the purpose of the research, the content of the survey, the target population, and the incentive. The qualitative methodology of the survey was also emphasized so that participants would be prepared for an interview-like experience, rather than a standard quantitative survey. On Tumblr, readers of the post were asked to share it with their own followers in order to maximize recruitment. See Appendix B for the full text of the original Tumblr post.

The survey was first posted on February 9, 2015. It became apparent within the first week of data collection that survey respondents were overwhelmingly young, white, and assigned female at birth (AFAB). In order to attempt to diversify the sample along the axes of age, race, and gender assignment, additional effort was made to post the survey in Tumblr blogs and subreddits that were explicitly designated for nonbinary people of color or trans/nonbinary people assigned male at birth

(AMAB), and subsequent posts across all platforms emphasized the need for older people, people of color, and AMAB people as survey respondents. While these tactics were slightly successful in recruiting more older and AMAB respondents, racial diversity remained stagnant. Therefore, as described above, on February 16 the survey was closed to white respondents. The survey was closed to all respondents on March 2nd.

Respondents

The “Gender Nonbinary Experiences of Healthcare” survey was accessed by 159 people. All who began the survey said “yes” to the informed consent question, and 19 dropped out before providing their age. 27 respondents were sent to the end of the survey for failing to meet the inclusion criteria: 16 were under age 18, 8 were not US residents, and 3 responded that they were white after the survey was closed to white respondents (see above). Participants who completed at least 75% of the survey were retained and included in the analysis: 30 dropped out before this point and their responses were discarded; 21 dropped out after and were retained. Results from 2 completed surveys were discarded: one respondent identified explicitly as a binary trans woman, and one respondent took the survey twice (their second attempt was discarded).

81 respondents were ultimately included in the analysis overall. All percentages below are based on the number of people responding to each question (which may be fewer than 81 in instances where some participants declined to respond), except where otherwise stated.

Analysis

Analysis of the data was conducted both quantitatively and qualitatively. In order to provide quantitative counts of demographic and health-related responses, as well as to make basic quantitative analysis possible, many “short answer” responses were recoded using Microsoft Excel and SPSS into dummy variables. For instance, responses to the open-ended question “Do you identify as trans?” were coded as 1=yes, 2=no, and 3=unsure/ambivalent. A parallel process of thematic qualitative analysis was conducted using Dedoose, an online qualitative analysis software platform. The goal of the qualitative analysis process was to use nested coding to thematically categorize respondents’ experiences of the interaction between their nonbinary gender and the health care system, while retaining the nuances of the written responses. Both quantitative and qualitative results are presented thematically below.

Demographics

Survey respondents ranged in age from 18 to 43, with an average of 24. The sample skewed young, with 75% of respondents under 26 years old. 57 respondents (71.3%) identified their race as white only, 9 (11.3%) as Latinx, 5 (6.3%) as Native American, 4 (5.0%) as East Asian, 2 (2.5%) as black, and 1 (1.3%) as South Asian. 8 (10%) of these respondents were mixed-race. 32 (39.5%) of respondents live in a large/major city, 21 (25.9%) live in a small city, 19 (23.5%) live in a suburban area, and 1 (11.1%) live in a rural or small-town area.

As can be seen in table 2 below, only 33 respondents (40.7%) self-described as unequivocally financially secure, while 71 (87.7%) said that they had consistent and adequate housing, and 63 (77.8%) felt safe at home. Participants could also choose to describe their financial and housing situations: 25 (30.8%) chose to describe their financial security, 6 (7.4%) described their housing stability, and 12 (14.8%) described their safety at home. Those who chose to describe cited experiences and fears of discrimination, as well as abuse and sexual violence, student loans and underemployment as challenges to their financial and housing stability.

Question	%Yes	%No	%Describe	
Do you feel financially secure?	40.7%	29.6%	30.8%	“I grew up very poor and trying to obtain an education has financially ruined me. This is compounded by workplace discrimination I've dealt with based on gender and sexuality.”
Do you have consistent and adequate housing?	87.7%	4.9%	7.4%	“I have never been homeless, though I've often had to stay in abusive situations for months unless someone could help me move out into a better place.”
Do you feel safe at home?	77.8%	8.6%	14.8%	“the shelter staff does a poor job of quelching the transphobic and homophobic atmosphere” “[my partner and I] present as a heterosexual couple in the building outside of the apartment.”

Participants were invited to fill out a text box to describe their sexual orientation, and only 34 respondents (42.5%) used just one word to describe their sexual orientation (percentages below include all responses, and do not add to 100%). Perhaps unsurprising in a sample of people whose genders are nonbinary, 63 respondents (78.8%) described their sexual orientation as involving sexual and/or romantic attraction to multiple genders or sexes (queer, bisexual, pansexual,

polysexual, panromantic, etc). Sixteen respondents (20.0%) identified along the asexual/aromantic spectrum. Thirteen (16.3%) specified attraction to people of a particular gender or sex (including nonbinary genders), using phrases such as “Attracted to women and DFAB nonbinary people;” “Primarily attracted to other gender-non-conforming individuals;” “I do not find female organs attractive but I find male organs attractive. Gender isn't an issue for me, its usually designated sex.”

Gender Identity

Participants were also allowed a blank text box in which to describe their gender identity. Table 3 below gives an overview of terms (some of which have been grouped into categories) that respondents used to describe their gender identities. As only 19 participants (23.5%) used one word to describe their gender identities; percentages in the table do not add to 100.

Term or category of terms	Number (%) of respondents using a word within this category
“Nonbinary”	23 (28.4%)
Lack of gender (“agender,” “genderless,” “neutrois”)	35 (43.2%)
“Genderqueer”	29 (35.8%)
Gender fluidity (“gender fluid,” “fluid,” “genderflux”)	19 (23.5%)
Transgender (“trans” “MTF,” “FTM”)	10 (12.3%)
“Androgynous”	7 (8.6%)
“Demiboy,” “demigirl”	4 (4.9%)
“Bigender”	2 (2.5%)

Some examples of participants’ full responses include:

“i typically describe my gender as non-binary, as i am not always sure as to whether i am specifically genderfluid or agender.”

“Non-binary hard femme”

“Non-binary, alien, muddied, ‘not a guy’”

“Androgynous; neither; decline to state; ‘none of your business.’”

“I use the word alexigender (meaning a gender identity that is constantly changing between states for which accurately descriptive words do not exist) when i need a single label. Alternately, I am a nonbinary genderfluid trans woman.”

When asked if they identify as trans, 45 respondents (55.6%) gave an unqualified “yes,” while 14 (17.3%) gave an unqualified “no” and 22 (27.2%) expressed uncertainty or ambivalence about claiming the trans label.

Fifty eight respondents (71.6% of the sample) were assigned female at birth, and 19 (23.5%) were assigned male at birth, with 4 (4.9%) declining to respond. None of the participants identified as intersex, but 5 participants did say that they were unsure, or that they had concerns or test results that indicate that they could be intersex.

Gender identity over the lifetime and in historical context

Participants were asked: “How long have you been consciously identifying as non-binary/genderqueer, regardless of whether you have ‘come out’ to others?” While some participants gave more specific answers than others; most responses were able to be converted into quantitative estimates of how many years ago the participant began consciously identifying as nonbinary; only 5 responses were too vague to quantify and were excluded from analysis.

As seen in figure 1 below, a histogram of years participants have been identifying as nonbinary, almost 90% of participants have been identifying as nonbinary for ≤ 6 years, or since 2010 (fig. 2). The number of years of nonbinary identification was then subtracted from current age, creating a new variable representing age at nonbinary identification. As shown in figure 3, age at nonbinary identification approached a normal curve, with a mean of 20.5 years old, and a standard deviation of 4 years. Figures 4 and 5 are scatterplots showing the relationship between participants’ age and age at nonbinary identification (fig. 4) or calendar year of nonbinary identification (fig. 5). Taken together, the shape of the data within these graphs indicate that calendar year is a more important driving factor for consciousness of gender identity than age: it seems that with the exception of some older participants, most participants began to identify as nonbinary within the same range of years regardless of current age, rather than within the same range of ages. This indicates that, even for many older participants, it is only within the last 5 or 6 years that a nonbinary gender identity has been an option that was available to them.

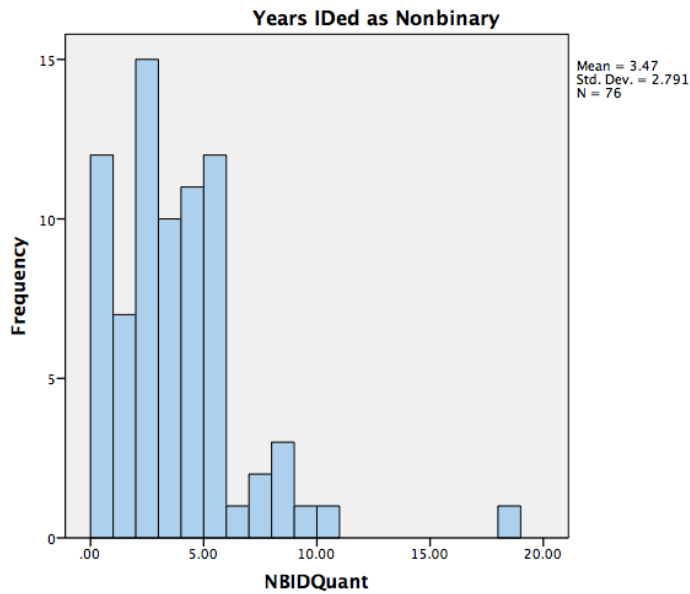


Figure 1. Histogram of number of years participants have identified as nonbinary.

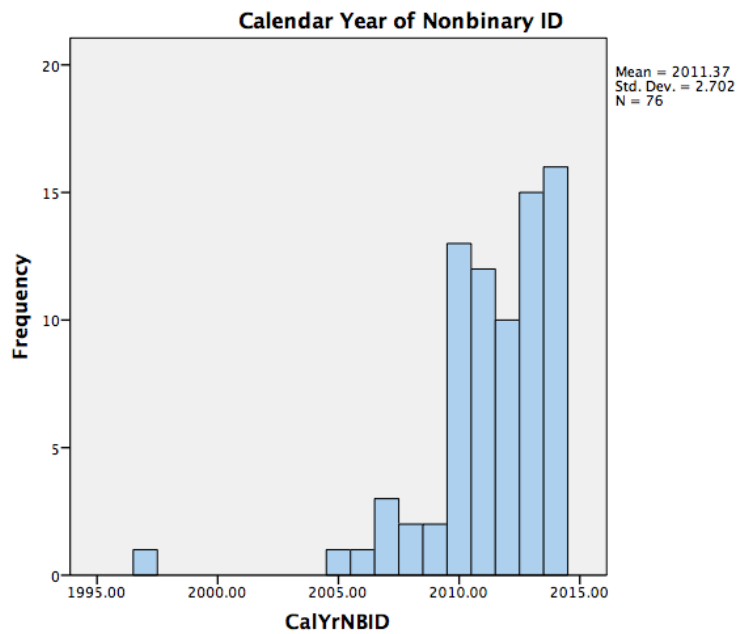


Figure 2. Histogram of the calendar years in which participants began identifying as nonbinary.

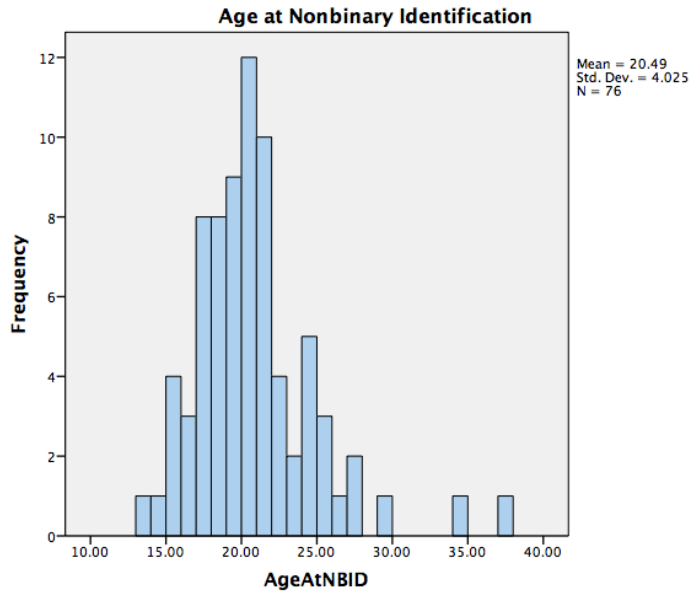


Figure 3. Histogram of the age at which participants began identifying as nonbinary

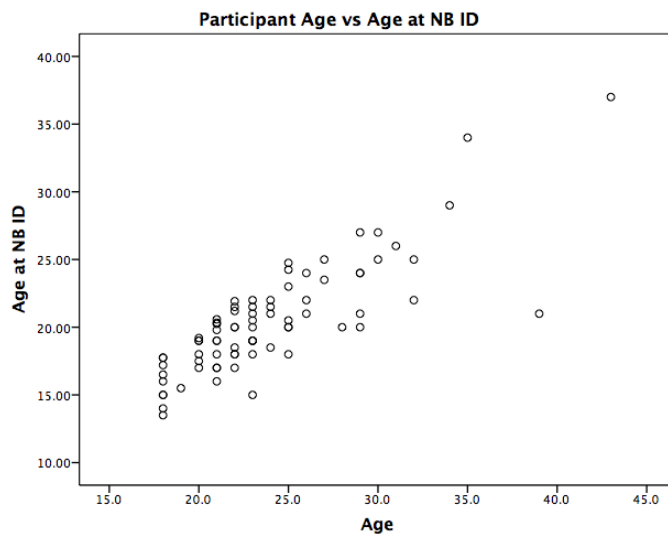


Figure 4. Scatterplot of participants' age vs the age at which they began identifying as nonbinary

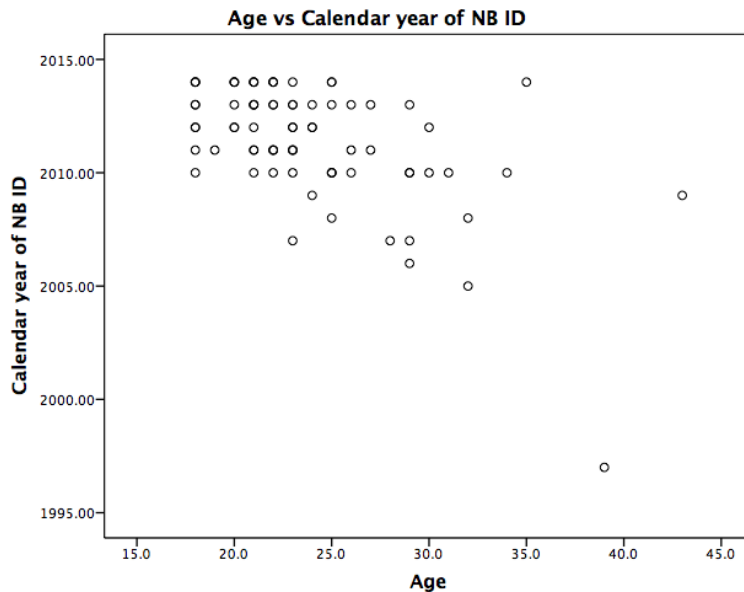


Figure 5. Scatterplot of participants' age vs the calendar year at which they began identifying as nonbinary.

A number of respondents (n=13, 16.0%) discussed knowing that they were different before discovering a label that fit them, though since the question did not explicitly ask about this phenomenon, it is likely that there were more respondents who had experienced this course of identity formation, but did not note it in their response.

Participants were also asked “Has your gender identity been stable over time, or has it been fluid? If it has been fluid, what other words or labels have you used to describe your identity?” Some participants said that their gender identity had always been stable; others described an evolution from identifying as cis to identifying as trans, with some identifying comfortably as cis in the past, and some uncomfortably; still others described their gender identity as being consistently fluid. Thirteen participants (16.0%) had identified in the past as a binary trans person (i.e., either a trans woman or trans man), and 17 (21.0%) described moving through many different nonbinary labels.

Support and community

When asked about how “out” they are about their gender, and whether their family, friends, partner(s), co-workers, etc. know about their gender identity or preferred pronouns, few participants responded as being either totally closeted or totally “out” about their gender identity. Most were selectively closeted, telling those who they trusted (usually friends) about their gender, and allowing others (often family and coworkers) to assume that they are either cis or binary trans.

Most participants reported feeling support from at least some of their friends and/or family. However, as many noted, support is not the same as understanding.

“I find it REALLY hard to explain to cis people what the deal is with my gender identity, even if they're an amazing ally and totally well-intentioned. It's kind of impossible most of the time to communicate fully across that boundary”

Participants were asked whether they felt connected to a community of nonbinary people, whether online or in person. Seventeen (21.2%) felt connected to a primarily in-person community, 30 (37.5%) primarily to an online community, 11 (13.8%) to both online and offline communities, and 22 (27.5%) did not feel connected to a community at all.

Healthcare Experiences

Healthcare access

The majority of participants—57, or 70.4%—responded that they have a primary care provider. When asked where they go if they need healthcare, 36.7% said their primary care provider, 29 (24.1%) said a campus health center, 14 (17.7%) said a LGBT clinic or LGBT-friendly provider, and 17 (21.5%) said a free clinic, urgent care, ER, or pharmacy clinic. Sixty one participants (75.3%) had avoided health care because of the cost.

Seventy one participants (87.7%) had ever seen a mental health provider of some kind, and 55 (64.7%) had avoided seeking mental health care because of the cost. Only 5 respondents (5.8%) had both never seen a mental health provider and never avoided seeking mental health care because of cost; it can be inferred that the other 94.2% of the sample had at least desired to seek mental health care at some point. When asked whether they thought they would be able to access quality and affordable mental health care if they needed it, 28 (35.0%) said yes (though many indicated that it would be difficult), 37 (46.2%) said no, and 15 (18.8%) were unsure or ambivalent.

Many respondents discussed the importance of location in being able to access quality healthcare, whether that location be a large, liberal city or a college campus. A few respondents discussed having to cross state lines in order to see an LGBT-friendly provider, and some discussed feeling totally unable to see a provider in their town because of concerns about discrimination and confidentiality.

“I do have a PCP I go to fairly regularly, who I have been seeing since before I came out as neutrois. That is however a relatively recent development (within the last 4 years), enabled by moving to a city with an accessible LGBT clinic.”

“I do feel lucky that I'm in the core of the state where things are much more liberal and accepting. Any further west, or if I were out east within the state, and I would be out of luck.”

“[When I need healthcare, I go to] Missouri, even though I live in Kansas². There aren't any doctors that are listed as trans or LGBT friendly in my area.”

“My town is very Christian and would not support me. I would be very uncomfortable [seeking mental health care].”

Some participants discussed avoiding medical settings because of past experiences of discrimination or discomfort.

“...I try not to see [my PCP] regularly because she referred to my transgender identity as a ‘phase’, though she did say she will ‘support me through any phase of my life’. Also, her and the rest of her staff do not use my preferred name or proper pronouns even though they are in my file and I have requested it verbally twice.”

Do you have a primary care provider? “no. i'm uninsured and have had terrible experiences with doctors my entire life.

When you need health care, where do you go? “[sex worker health organization] or to herbalist friends”

Medical transition

One third of participants (n=27) had used either surgery or hormones to help alleviate gender dysphoria. When asked if they plan to or if they would like to use surgery and/or hormones to help alleviate dysphoria, 61 participants (77.2%) expressed at least some interest, while 14 (17.7%) expressed no interest, often explaining that they did not feel that their dysphoria would be alleviated by hormones or surgery, and 5 (6.3%) indicated that they had already completed all gender-related medical interventions that they would like.

Although participants were not asked about specific medical procedures, ones that were mentioned included hormone replacement therapy (HRT), orchiectomy, “top surgery” (mastectomy), hair removal, and genital reassignment surgery. Participants who had accessed medical transition care were significantly older than those who had not: those who had accessed medical transition had a mean age of 26.6 and those who had not had a mean age of 22.6 ($t(79)=3.55$, $p=0.001$).

² Names of states have been changed to protect confidentiality

Participants had varied experiences in accessing transition-related care. Some were able to avoid extensive gatekeeping and having to lie about their nonbinary gender by receiving transition care at informed consent clinics (see discussion section), or by having particularly understanding and flexible providers. Others had less positive experiences:

“I DID have to answer questionnaires to gain access to medical transitional resources that required that i identify with traditionally masculine things. I lied.”

“I am willing to present myself as binary for ease of access to medical care, but even with doctors' letters, a changed ID, and a half inch stack of supporting documentation stretching back at least 3 years, I have a hard time gaining access to transition-related care.”

“My endocrinologist just thinks I am a transgender male because I did not tell him I am non-binary, thinking he may not give me hormones. He is the only one in a 5 hour drive radius that will prescribe hormones to transgender clients.”

Location, insurance restrictions, and cost were all major barriers to participants' access to transition care. Many participants did not desire a “full” or “linear” transition, seeking medical intervention only for specific physical features that caused them dysphoria, or seeking to attain a mixture of masculine and feminine features that complement their gender identity.

“I initially never wanted to go on T or any surgeries... But my voice dysphoria became unmanageable and was greatly affecting my everyday life that I feel I had to start T to manage it. I will only take T for as long as I need for my voice to reach a comfortable range.”

“for the record – [hormone replacement therapy] did help a lot with my dysphoria and actually going OFF T and has been the final bit that i think finally 'cured' me of physical dysphoria (i retain a lot of features T gave me but also have the fat distribution of somebody estrogen-dominant).”

Other transition-related concerns that participants mentioned included a lack of reliable information on medical transition, and future fertility. Three AFAB respondents discussed postponing top surgery and/or hormones to allow for future childbearing and breastfeeding. Three other AFAB participants told providers who denied them desired care because of fertility concerns that were not shared by the patient:

“My OBGYN is completely unwilling to sterilize me, despite my insistence that were I to become pregnant suicide would be a viable option if an abortion was not possible.”

Disclosure to healthcare providers

Just over half of participants (n=43, 57.3%) had disclosed to a healthcare provider that they are gender nonbinary. Among those who had not disclosed, common reasons for nondisclosure included fear of negative reactions, uncertainty of how to bring it up, and feeling that it would be too difficult to educate their healthcare provider about nonbinary gender identities. Some simply felt that their gender identity was not pertinent to their care and that there was no need to disclose.

Those who had disclosed their nonbinary gender to healthcare providers encountered a wide range of outcomes, from explicit hostility to warm acceptance. Many were met with dismissal or with ignorance and confusion.

“i have disclosed to numerous mental health professionals (including "lgbt-friendly" ones) and have been ignored every single time and occasionally reminded that i'm "really" a girl. none have made even a passing effort to understand or affirm my gender.”

“All of them [HCPs who have been disclosed to] have made faces that either indicate disgust, confusion, or mockery. They also don't seem to understand it and are very dismissive. They also don't alter their speech and refuse to acknowledge pronouns other than he/she, or preferred names.”

“Generally positively/open, though there have been some cases where I have had to explain things, and there was some back and forth before I got to a point where I felt like it was fully accepted.”

Respondents who had utilized gender-related surgery and/or hormones were significantly more likely to have disclosed their gender identity to a health care provider than those who had not: 83.3% of those who had used surgery and/or hormones had disclosed, vs 45.1% of those who had not (odds ratio= 6.1, 95% CI: 1.8, 20.3). Unfortunately, participants were not asked about the temporality of their disclosure relative to their medical transition, but some participants did discuss disclosing either in order to start the medical transition process or because they thought that their medical team should know about their hormone use.

Many of these participants found that their openness was met with confusion and judgment.

“[My primary physician] conflated non-binary gender identity with bisexuality, then proceeded to assume my goals in transition to be the same as a trans woman.”

“When I have some important health issue I say that I'm in HRT for being sure they take it into account but then of course I have to explain why... [They react] as if I where doing something totally bad or unhealthy.”

Comfort and discomfort in health care settings: Invisibility and hypervisibility

Many participants experienced health care settings as adhering to a rigid male/female binary, and discussed feeling invisible, even if they had not had explicitly negative experiences: “I don't feel actively uncomfortable, but I also certainly don't feel welcomed or accepted (or even anticipated).” Specific sites of discomfort included gender-segregated bathrooms and waiting rooms, as well as with intake forms and medical records with no space to record a non-binary gender identity.

Some participants' comments touched on a paradox: feeling invisible before disclosure and hypervisible after: “I fear the perpetual discomfort I will feel after they know, and I hate having to consistently repeat it to every person I see in a hospital due to things not being properly documented on paperwork. I feel like a sideshow freak.”

Much of participants' feelings of invisibility or hypervisibility, as well as comfort or discomfort, hinged their perception of on the legibility of their queerness or genderqueerness to others. Some participants felt more comfortable being “read” as cis or as binary trans and therefore not feeling the need to explain themselves to a healthcare provider. Some found being read as visibly queer affirming, even if the nuances of their gender identities were still not understood. Others felt that their lack of visible queerness undermined their gender-related concerns in healthcare settings, or that their visible queerness opened them up to possible discrimination and discomfort.

“I present in the typical female way and since I am AFAB, I guess it doesn't matter that I'm genderqueer. People will assume that I am female and that isn't always a bad thing.”

“[I feel comfortable] predominantly because I feel like gender is a pretty small part of my identity in comparison to, say, being a teacher, a parent, a community member, etc. I don't mind female pronouns even if they seem odd, because I don't have the energy to go on a pronoun crusade. When people see me they generally know that I'm queer by my appearance, and I feel comfortable interacting with that as something understood.”

In general, participants discussed feeling that their existence in medical settings disrupted the assumptions that health care providers have about how bodies should be gendered and the relationships that patients should have to their bodies.

“It's the assumption that because I have a vagina that people read me as a person who is female who is getting checked up for feminine things that makes me uncomfortable. Does that make sense? I'm not a woman. I don't identify as female. A trans guy could be getting checked up for the exact same things.”

“[I] don't like having to figure out if i can trust a doctor or not based on their assumptions of my body. I once had a doctor who thought i couldn't have a UTI because he assumed i was male (this is why i began going to women's clinics)”

“There were some uncomfortable points when I didn't transition in exactly the order/way that my health care providers were used to seeing (for instance, I had top surgery before starting testosterone because the surgery was more important to me).”

Positive experiences

Participants' descriptions of positive experiences in healthcare settings demonstrate that respectful, quality care is indeed possible for patients who identify outside of the gender binary. 43.3% of participants indicated that they had had positive experiences in health care settings related to their gender identity (67.1% of participants reported having negative experiences). Positive experiences were characterized by providers who were sensitive to their nonbinary patient's needs, even if they did not have prior experience with nonbinary or trans patients.

“I've had lots of doctors who treated me with respect, only asked relevant questions, used the correct pronouns, and made sure that I was not called from the waiting room with the wrong name.”

“I did have one OB-GYN experience that was positive. When I was a sophomore, I had an IUD placed, and it was horribly traumatic; I broke down crying while the RN was placing the IUD because I was having the very part of me that then made me feel the most uncomfortable acknowledged. I explained to her what was wrong, assured her it had nothing to do with pain or anything, and she comforted me through the process. She also called me after hours to give me as many trans resources as she had access to at that time. She was really very kind to me, and I appreciated it immensely”

Experiences in LGBT clinics

Almost a third of participants had sought care in a clinic that advertises itself as LGBT-specific. Over half of these used an LGBT clinic as their primary care provider, and just under half used an LGBT clinic for transition-related care. Participants also used LGBT clinics for mental health counseling, STI testing, and in one instance, dentistry. When asked how their experiences at LGBT clinics compared to those at mainstream medical settings, almost all participants indicated that their experiences at LGBT clinics had been at least somewhat better. LGBT clinics were more likely to ask about gender and pronouns on intake forms, have providers who “at least have some sort of clue about trans/nb101,” and generally have a feeling of being “more positive, more open, more respectful.” As one participant noted, simple changes such as a space for pronouns on medical charts can result in a drastic shift from invisibility to visibility, discomfort to comfort in medical settings.

“[LGBT clinics have] BEEN WAY BETTER. People have still made mistakes, but the simple fact that my chart says "non-binary, they/them/theirs" has drastically increased my trust in my care providers and my comfort seeking healthcare. I feel "seen" in the LGBT clinic, whereas I feel invisible everywhere else. It makes an immense difference.”

Increased comfort in health settings can in turn lead to improved health access for marginalized populations:

“I came home happy from the doctor's office even though that had not happened for a long time, and told my roommate how awesome it was, and he went and got a screening for a serious medical issue that might have saved his life so [the LGBT clinic is] loads better.”

However, though better, LGBT clinics are not perfect. Several patients reported that they still did not feel that their nonbinary identities were understood at LGBT clinics, and that providers assumed that they were binary trans, or that they were a queer cis person. This was especially apparent in transition care.

“Even in an LGBT-specializing clinic, my doctor isn't quite sure how to advise me on non-binary transition. Mostly my transition resembles MtF, but I've had some awkward moments with my doctor when I've tried several times in different sessions to explain what I'm trying to do, and he generally doesn't understand.”

“I do I think LGBT clinics need to work rapidly to grow their understanding of trans identities and to figure out what sort of care non-binary people might need that differs from binary trans care. They could utilize other hormone options that they currently do not offer, and

facilitate conversations with surgeons about the needs of non-binary individuals.”

“i’m also a sex worker, which is the nail in the casket for receiving good care, even in queer contexts.”

Improving healthcare experiences for gender non-binary patients

In the last section of the survey, participants were asked to give their own suggestions for how doctor’s offices and clinics (and, for those who had utilized such services, hospitals/ERs and mental health care settings) could improve care for nonbinary patients. Responses were organized into 10 major themes listed below.

1. *Educate providers and staff.* Almost all participants emphasized how important it is for health care providers to be educated about the existence of non-binary gender identities, and how to provide respectful and quality care to gender nonbinary patients.

“Learn trans 101, and learn the vocab. Ftm, mtf, top surgery, all that. Learn not to say 'pre-op'. MAKE SURE EVERYONE IS ON BOARD. I've been in lots of offices where the doc was fine but the administrative staff or a nurse was awful.”

“...providers often don't know much about non-binary trans issues before I come in. I find going through the education process, when it's necessary, to be pretty wearying. Even though it usually does not go badly, it still feels like a lot of extra work that most people go through, so that certainly raises my discomfort level.”

“Normalize the notion of trans/non binary people existing by incorporating it into general protocol. Like I don't want to be treated specially or be a spectacle or have to go out of my way to come out to my doctor”

“I just wish I could go to the doctor and not have to explain my illness and my self. Like my self is the illness.”

One participant, a medical student, thought that educating doctors might be challenging, since medical students and residents are always trained by older, established doctors. “Doctors learn fast and practically, via ‘watch one, do one, teach one.’ With such a hierarchical and experienced-based structure, how can we teach older attendings to teach younger residents about non-binary patients when it seems so new-fangled?” They noted that teaching doctors to mirror their patients’ language, including pronouns and how they refer to their body parts may not be difficult, but actually “understanding what ‘genderqueer’” is seems to be much harder.”

2. *Improve intake forms and medical charts.* Providing a space for a patient's non-binary gender (along with pronouns and other pertinent information) to be indicated on intake forms and medical charts was a common suggestion from participants who indicated that this would make them feel seen and understood, and would make the disclosure process easier.

"Actually collect information on gender identity and pronouns!!! You can't provide comprehensive quality care to a patient when you don't know HUGE pieces of information about them and the way they experience the world, like their gender. All forms should include options for non-binary genders (and trans identification)"

"I am rarely treated with respect and it is awkward to continuously have to come out to each staff member instead of it just being written in my file or explained by the receptionist/doctor/etc."

"Ask EVERY patient, even those who appear cis, how they'd like to be referred to (e.g. another name) and what their pronouns are. It's okay to explain why you're asking."

3. *De-gender care.* Many respondents noted that there is rarely a medical need to emphasize, or even discuss, gender in most medical settings, but that many medical settings, especially those dealing with sexual and reproductive health, are highly gendered.

"I think there needs to be another set of words aside from "male and female" for "has a penis" or "has a vagina." I'm tired of being misgendered on account of my biology."

"I think they could focus less on male/female care and focus more on the specific patient's needs."

4. *Don't pathologize.* Participants reported being treated as if their gender identity was indicative of illness or delusion.

"My main fear about disclosing to any professional is that they will assume there is something wrong with me for not IDing as my assigned sex. either psychologically or hormonally."

"Being trans or non-binary does not necessarily mean you are full of anguish all the time. They should be aware of the day-to-day challenges, but being trans isn't a horror story."

5. *Listen, respect, accept.* Most participants felt that basic respect and openness on the part of health care providers, even without any other informational or institutional improvements, would greatly improve their health care experiences.

“I wish that therapists would simply be good therapists with regard to this; by that I mean that they should mirror a patient's language in describing themselves and not assume that they're seeking to transition, or that they should just "make peace" with the body they have... Simply respecting the identity of the person in question and respecting their decisions would go a long way.”

“They could leave their personal opinions at home.”

“LISTEN to us. Take what we say as VALID.”

6. *Resist assumptions.* The majority of participants' negative experience were less a result of overt hostility or transphobia, and more a result of cissexist and binarist assumptions. Participants wrote that providers resisting assumptions that all patients are cis, or are binary trans, would improve their quality of care.

“Many doctors know assumptions are bad, and have accidentally hurt a patient or let a patient die because of an assumption they made. How can we make doctors see that gender is an assumption?”

“Don't assume anything. If treating something unrelated to the patient's sex or gender, don't inquire as to unnecessary details. If treating something related to the patient's sex or gender, inquire until everything necessary is understood so potentially harmful assumptions aren't made.”

7. *Create gender-neutral accommodations.* Some participants felt uncomfortable not only in their interpersonal interactions in health care settings, but also within gender-segregated physical structures.

“In health care settings, there usually aren't facilities (particularly restrooms) for people who are neither male nor female”

“A lot of ERs create waiting areas inside the ER divided by "gender." It's really uncomfortable when you do not look like your assigned sex and have to wait in an area with people who are confused as to why you are there.”

8. *Diversify hiring practices.* Several participants noted that more sexual and gender diversity among health care providers and clinic staff may lead to more inclusive care.

“[LGBT clinics are] far more inclusive and understanding. They're usually staffed by actual lgbt people, which is a huge comfort.”

“Hire more non-binary people”

9. *Advertise competence.* Participants noted that it would be easier for them to find quality care and feel safe in health care settings if they knew which providers were competent in queer and trans health.

“If a doctor knows about genderqueer/non-binary issues, putting up signs or wearing a pin to signify this would be great.”

“Something as simple as a brochure or poster in the clinic saying “we know about nonbinary gender identities and will work with you.””

10. *Invest in research and policy.* Several participants recognized that the “upstream” levels of health care, research and policy, have an important impact on their experiences at point-of-care.

“Please, dear god, someone do some research on healthcare in lgbtq populations. The data isn't out there. We don't have the information we need. How will testosterone affect me long-term? We just don't know.”

“No one seems to be investigating the surgical needs of non-binary people.”

“Also advocate for better policy so all people can afford healthcare.”

“When health research and clinical developments are based on data that fails to look at differences across sexuality and gender (for example, when trans women are lumped into the category of MSM for research and EMR purposes, and then that research is used to create a new HIV intervention), heteronormativity and cisnormativity are further entrenched in our healthcare system and those of us whose identities fall outside the desirable norms receive worse healthcare that isn't at all tailored to our unique needs.”

Discussion

Diversity of sample

Despite the steps described in the methods section that were taken to attempt to increase the diversity of respondents along the axes of age, race, and sex assignment at birth, the ultimate sample that was used for analysis was quite skewed in favor of young, white and AFAB respondents. Some of this skew may be due to recruitment methodology: users of online communities, particularly Tumblr, are certainly younger than the general population.

However, there is also some evidence that, especially in terms of age and sex assignment at birth, this skew may be indicative of the demographics of people who identify as gender nonbinary. Findings from the National Transgender Discrimination Survey, the largest survey to date of trans people in the US, found a similar breakdown of age, race, and birth assignment among those who wrote in their own gender as this survey did, with 73% of those who wrote in their own gender assigned female at birth, 70% identifying as white only, and 29% under 24 years old (89% under 44). This was in sharp contrast to those who did not write in their own gender³: only 35% of this more binary population was assigned female at birth, and 17% under 24 (68% under 44). This population was more likely to be white (77%), and less likely to be multiracial (11% vs 18%) as well (Harrison et al., 2012).

Given that nonbinary gender as an available identity is a fairly new concept in modern Western culture, and certainly more recent than the medicalized narrative of the binary transsexual (Spade, 2003), it makes sense that age skews young in nonbinary samples—the data from this survey also showed that across ages, most participants started identifying consciously as gender nonbinary within the last 5-6 years. The dominance of white and AFAB people in nonbinary samples and communities, and the accompanying invisibility of nonwhite⁴ and AMAB⁵ nonbinary

³ Given the way the NTDS collected gender identity data, those who did not write in their own gender in Q3 (the comparison population in Harrison, et al.'s 2012 paper) were more likely to identify as binary trans, though the distinction between those who wrote in their own gender and those who did not is not exactly nonbinary vs. binary.

⁴ Discussions on race in nonbinary communities often point to the fact that many nonwhite cultures worldwide have historically had nonbinary gender systems (i.e., systems with more than 2 genders, or systems where genders are more fluid), and that these nonbinary systems often provided justification for brutal Western colonial projects. See <http://www.binaohan.org/blog/on-nonbinary-invisibility/>

⁵ For examples of such discussions on sex assignment disparities in nonbinary communities, see threads such as: https://www.reddit.com/r/asktransgender/comments/2ybcaa/why_is_it_that_the_vast_majority_seemingly_all_of/ and <http://emptyclosets.com/forum/gender-identity-expression/159345-non-binary-people-im-curious.html>. As Reddit user “zebragr1” at the first link notes, “I think this also goes to the larger issue of the narrow gender role imposed on DMAB people, and the general societal intolerance for gender variation in ‘men’. There’s a threshold where DMAB people

people, have been topics of intense and illuminating discussion within queer and nonbinary communities, but have yet to become topics of formal research or theory. Some work on male bisexuality indicates that the status of hegemonic masculinity as a narrowly defined and perpetually threatened category leaves less room for men (and by extension, perhaps, those assigned male at birth), to claim liminal or nonbinary identities (Steinman, 2011; Yost & Thomas, 2012). This is echoed in literature on differential policing of gender expression among those assigned male and female at birth (McCreary, 1994): Kane (2006) found that while parents of preschoolers welcome what they perceive as gender nonconformity among daughters, they are more likely to react negatively to behavior from sons that diverges from the hegemonic ideal of masculinity. Specific explorations of the invisibility of AMAB nonbinary people that build upon these frameworks constitute a much-needed future direction for research and theory.

Lack of racial diversity across transgender and nonbinary samples is also troubling. Queer and trans people of color (“QTPOC”) are far from absent in community and social justice organizing online (Fink & Miller, 2014; Khoo, 2015), but are rarely well-represented in online samples of trans and nonbinary people (Harrison et al., 2012; Kuper 2012), including this one. Health research on trans and nonbinary people of color is incredibly scant, and what does exist mostly focuses on risk and disease: violence, HIV transmission, substance abuse, and poor mental health (Xavier et al., 2005; Kenagy, 2005). Huang and colleagues found a similar trend in the literature on LGB people of color in a 2009 content analysis. As they noted, “On one hand, these topics may reflect important health concerns and risks for LGB people of color. On the other hand... it is clear that the narrow scope of these topics does not reflect the full range of LGB people of color’s life experiences, including healthy behaviors and well-being.” They also found that the qualitative and theoretical literature, as opposed to the empirical literature, attended to a broader range of issues including identity formation, experiences of racism, and identity intersections. Given these findings, it is clear that research and theory that centers the voices and experiences of trans and nonbinary people of color, not just their risk profiles, is sorely needed in this field. In addition, there should be more conversation among researchers on how to ensure racial diversity in online and convenience sampling.

Gender identity

Similarly to Harrison and colleague’s analysis of those who wrote in their own gender on the National Transgender Discrimination Survey (NTDS) (2012), this survey found that allowing participants to write in their own genders resulted in a fascinating “cache of data that speaks to the nuances of identity formation among

can keep their dysphoria in check, or are even able to make a decision not to fully transition, instead perhaps just dealing with small instances of private crossdressing, or releasing the dysphoria pressure into fetish play.”

transgender and gender nonconforming people at this moment in our communities' evolution." While respondents' descriptions of their gender identities were incredibly varied and often deeply personal, table 3 in the results section shows that many drew on a shared and limited vocabulary of terms in building their identity descriptions. This particular set of identifiers is quite different from identifiers that were in wide use among trans and nonbinary people just a few years ago (Kuper et al., 2012; Harrison et al., 2012), and which may still be in use among older trans folks. Over a decade ago, Broad described the Internet as a vehicle for collective identity formation among transgender people (2002); it is clear that this process is as dynamic today as it was then. Additionally, the finding that most participants regardless of age began identifying as nonbinary within the last 6 years indicates that the collective formation of this identity is probably still at its early stages, and that the identity data collected here is just a snapshot of how gender nonbinary people identify at this moment in time. The larger lesson learned in this process was not that the terminology captured here will be valid in perpetuity, but rather that asking people how they identify, rather than assuming that previously valid terms still apply, is an effective and accurate method of data collection for a population that is in constant flux.

Another notable finding from this survey was that just over half of respondents were confident in identifying as trans, and almost 20% did not identify as trans at all. This will be important those involved in research, policy, and programmatic work to note when defining their population of interest; though "transgender" or "trans" are commonly understood as umbrella terms that include nonbinary genders, it is clear that a significant proportion of nonbinary people may be unintentionally excluded from research, programs, interventions or information aimed at trans people.

Medical transition

There remains an assumption within the literature that those with a genderqueer identity, or transgender identity as opposed to transsexual identity, are less likely to desire medical transition, especially bottom surgery (Blackston, 2012). In this sample, however, 33% of participants had already sought medical intervention, and 77% expressed interest in medical intervention at some point in the future.

Participants' experiences with transition care underscore the need for continued growth of the "informed consent" model of transition care. This specific model of care (not to be confused with the general informed consent process which governs all research and medical care) emerged in the early 1990s due to growing dissatisfaction with the "gatekeeper" model of trans health adhered to by nearly all mainstream medical organizations. In 1993, the 2nd International Conference on Transgender Law and Employment Policy put forward a competing document to the World Professional Association for Transgender Health (then the Harry Benjamin International Gender Dysphoria Association) Standards of Care: the Health Law

Standards of Care for Transsexualism, which recommended that, as long as there were no medical contraindications, physicians providing both hormone therapy and genital surgery should only require a “patient’s signature of an informed consent and waiver of liability form.” Since then, so-called “informed consent clinics” or “informed consent providers” have proliferated (Deutsch, 2011), and the model was presented as a legitimate option by the WPATH SOC 7 in 2011. Several participants in this study cited the informed consent model specifically as facilitative of positive transition care experiences, and conversely other participants noted that gatekeeping requirements had led to delayed care and lack of trust in their providers. However, there is very little published research on the informed consent model—prevalence, accessibility, efficacy and quality are all unknown, and despite official steps taken away from gatekeeping models of care (WPATH, 2011), even recent published literature continues to assert a pathologizing, binary, and arduous model of transition care for patients seeking medical intervention (Unger, 2014). Such requirements do not benefit trans patients in general, and are particularly detrimental to nonbinary patients (Spade, 2003; Alleyn & Jones, 2010; Blackston, 2012).

Healthcare Access

Participants of this study reported high rates of avoidance of healthcare due to cost, and additionally discussed avoiding care due to experiences or fears of discrimination. This parallels findings of the National Transgender Discrimination survey, where respondents who wrote in their own genders reported lower incomes, despite higher educational attainment, and increased postponement of medical care due to fear of bias compared to those who did not write in their own genders (Harrison et al, 2012).

Though much of the literature discusses discrimination and insensitivity in healthcare settings as a factor leading to avoidance of care (Brotman et al., 2002), the findings from this survey underline the necessity of conceptualizing avoidance of care as two-pronged: motivated both by ignorance and discrimination within healthcare settings as well as by factors such as underemployment and housing instability (Harrison et al., 2012), which affect both patients’ ability to pay for care as well as their ability to be selective in their choice of provider. Figure 6 below shows a flowchart of factors impacting healthcare access based on survey data.

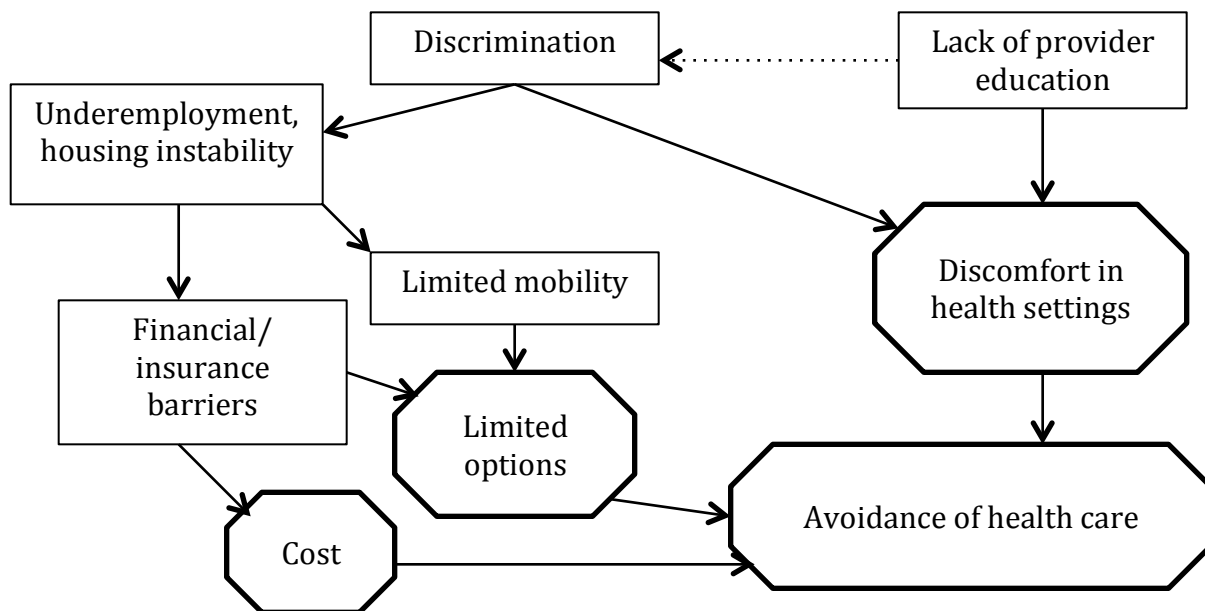


Figure 6. Flowchart of factors impacting healthcare access for nonbinary patients.

Mental healthcare access for gender nonbinary patients is also an important issue, especially given existing research on exceedingly poor mental health within this population (Budge et al., 2014). Almost 90% of the sample reported having ever seen a mental health professional, but almost half said that they would not be able to find quality and affordable mental healthcare if they needed it.

Improving healthcare experiences for nonbinary patients

Participants reported that most mainstream health settings, as well as some settings that were advertised as LGBT-specific or LGBT-friendly, were not set up to accommodate patients with nonbinary genders. Although some participants felt that their gender identity was largely irrelevant to their healthcare needs, many others, especially those who had used hormones or had surgery or who were seeking medical transition, felt actively alienated from healthcare settings. Figure 7 demonstrates the connections between clinic and provider characteristics, comfort in health settings, disclosure, positive or negative experiences, and healthcare seeking or avoiding behaviors. The middle column summarizes participants' suggestions for improving care as idealized characteristics of healthcare settings at both the clinic/practice level and the provider level. The left column represents the chain of events for a nonbinary patient when these characteristics are absent, and the right column represents what may happen when they are present.

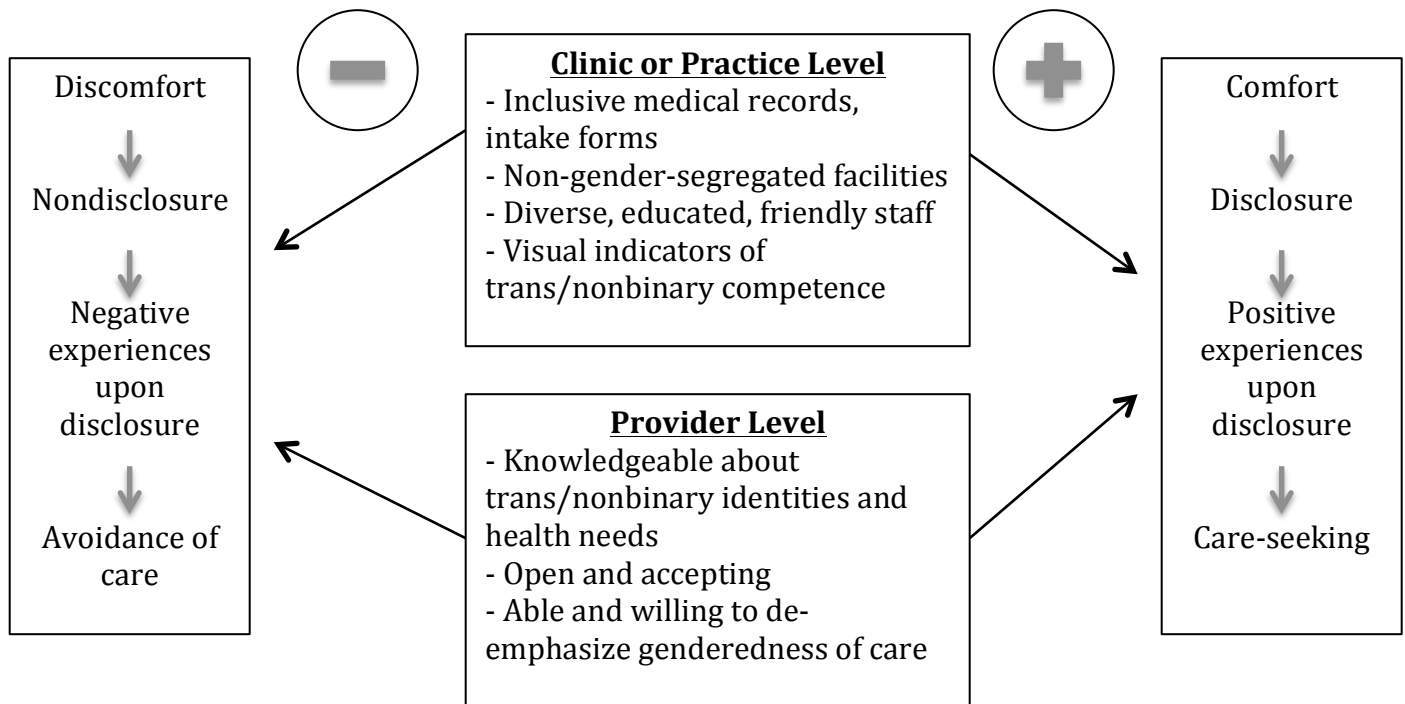


Figure 7. Relationships between clinic/provider attributes, comfort, disclosure, experiences, and healthcare access.

Two of the “best practices” in the middle column, inclusive medical records/intake forms and de-gendering care, merit closer examination. The collection of so-called SOGI (sexual orientation and gender identity) data in both medical settings and large-scale epidemiological research as a solution to the dearth of data on LGBT health needs has begun gaining traction in recent years (IOM, 2011; Cahill & Makadon, 2014). Here it has been shown that this practice has the potential to improve healthcare for gender nonbinary patients by making them “seen” not only at the data collection-level, but also within their direct interactions with healthcare providers. In addition, many of the challenges faced by researchers and policy-makers when trying to include sexual and gender minorities in large-scale data collection come from the inherent difficulty in constructing SOGI items as standardized and stable categories. As Hanssemann writes (2009), and as has been discussed above, “As ‘transgender’ is a provisional, contextual, and mutable term to describe identity and experience, it is challenging to gather meaningful data using it as a stable analytic category.” However, when using SOGI items at the clinic level to improve patient comfort and direct provision of care, creating “stable analytic categor[ies]” becomes less important. Clinics and practices that wish to improve patient comfort and visibility by adding gender identity fields to their intake forms and medical records should feel comfortable doing so in a way that makes sense for their population and provision of care— perhaps ending the practice of having

separate “male” and “female” forms, adding a field for preferred pronouns, leaving gender fields blank, or adding an “other” option along with male/female in gender items—rather than waiting for standardized guidelines on SOGI data collection to be released. Moreover, though practices that do not provide care to LGBT populations specifically may worry about the comfort of cis, heterosexual patients when encountering non-standard gender identity fields on intake forms, Cahill and colleagues found that their sample of majority heterosexual and cisgender patients at community health centers overwhelmingly supported and understood the importance of the inclusion of SOGI items on intake paperwork (2014). It seems that the main barrier to this type of data collection is institutional will.

The idea of “de-gendering” care also warrants further explanation. As participants of this survey described, and as has been found in previous studies (Hagen & Galupo, 2014), explicit discrimination is not the only way in which medical settings are made hostile to trans and nonbinary patients; they also often experience constant erasure through widespread conflation of genitals, and the healthcare needed by those with specific genitals, with gender and gender norms. Providers (as well as policymakers and political activists) often subconsciously ascribe to body parts gendered meaning that their patients may not recognize as valid. Participants in this study wrote about the need for genitals and reproductive structures to be treated as neutrally as other body parts. Additionally, providers should be aware that many patients’ experiences of gender dysphoria center around these oft-gendered body parts, and that exams of these parts (pelvic exams, breast exams, prostate exams) should be conducted with special sensitivity to the emotional needs of individual patients (PPSFL, 2006).

Some health settings, such as “women’s health” clinics that offer reproductive and sexual health services primarily for people with “female” reproductive organs, are often intrinsically gendered, to the detriment of both “ends” of the transgender spectrum. AFAB trans and nonbinary people may avoid seeking care in highly feminized settings due to discomfort, despite needing the services that such health centers provide, and AMAB trans and nonbinary people, who may feel more comfortable in feminized settings, are rarely served by women’s health centers. Practices that provide services that are often viewed as gender-specific, and would like to become more inclusive of trans identities, should consider carefully who their actual population of interest is (people who identify as women? People with vaginas? People who are at increased risk for certain reproductive and/or sexual health concerns?), and then consider how the segments of that population that are not cisgender can be made to feel more comfortable in their care. A 2006 report from Planned Parenthood of the Southern Finger Lakes provides extensive suggestions for making reproductive and sexual health centers more trans inclusive, and though it does not explicitly discuss nonbinary identities, most of its suggestions are applicable to nonbinary patients as well (PPSFL, 2006).

Conclusion: Future directions

As several participants of the “Gender Nonbinary Experiences of Healthcare” survey noted, echoing Bauer and colleagues’ (2009) finding of mutually reinforcing informational and institutional erasure, in order for many of these healthcare improvements to be possible at the level of individual practices and providers, both their necessity and potential pathways of implementation must be made visible at the level of research, education and policy. This was an exploratory study, designed to cast a wide net in examining the healthcare experiences of those who do not identify within the gender binary. The field of transgender health is still largely under-researched, and due in part to decades of pathologizing medical research, the experiences and language of trans people themselves often remain at the margins. This study sought to center the voices of those who identify as gender nonbinary, using a promising and easily translatable qualitative, Internet-based methodology.

This methodology is not without its limitations: as has been noted in previous Internet-based research, this sample was not representative of the general US population of gender nonbinary people, skewing younger and whiter than the general population, and likely differing in other ways related to the specific populations that are active in online trans and nonbinary communities, and are willing to dedicate their time to sharing their experiences for the benefit of research (Kuper et al., 2012). It should also be kept in mind, however, that this reasonably diverse sample was able to be recruited using social media in about 3 weeks. With better foresight and planning, a longer data collection period, and a strong understanding of the dynamics of online queer communities, Internet-based recruitment of diverse trans and nonbinary samples should be well within the realm of feasibility.

The respondents to this survey described complex and often ambivalent relationships to the health care system, expressing feelings of invisibility, alienation, trepidation, and, too rarely, comfort and safety. They traced clear paths between healthcare experiences, disclosure, and health access, often tying their understandings of their healthcare experiences to systemic factors such as mobility, insurance limitations, and economic constraints. Ultimately, participants drew on their experiences to provide an eloquent and comprehensive enumeration of potential sites of improvement for clinics and providers to ensure that healthcare is inclusive of the entire gender spectrum, and that they might feel “seen” and respected as patients.

The findings described here on gender identity, health access, disclosure, comfort, and improvement of care should all be explored further with a variety of samples and methodologies. In particular, those who build research, theory, policy and programs around trans and nonbinary populations should focus on the experiences of subpopulations whose lives are rarely reflected in the literature: nonbinary people of color, nonbinary people who were assigned male at birth, older nonbinary people, and nonbinary people who live in rural areas. Additionally, comparative

studies that seek to carefully describe the areas of overlap and divergence in experience between populations that are often conflated: LGB, binary transgender, and nonbinary populations, will help to illuminate the specific ways in which heterosexism and cissexism function within the healthcare apparatus to marginalize the needs of gender and sexual minorities. Finally, future research should not neglect the larger economic and legal hurdles that impede trans people's health, wellbeing, and healthcare access, with the understanding that quality, inclusivity, affordability and accessibility are not separable attributes of healthcare for those marginalized by society.

Acknowledgements

I am deeply thankful for the unwavering patience, support, and gentle critiques of my two faculty advisors, Ali Miller and John Pachankis, without whom a thesis project of this magnitude would have been utterly overwhelming. I would also like to thank the 159 people who began the survey and the 81 who were included in the final analysis for the trust that they placed in me as a researcher, and the many others who passed along my recruitment postings to their friends and followers. This project also would have suffered without the informal advising of my friend and colleague Hilary O'Connell, who graciously acted as a resource and sounding-board through every step of the process. A final thanks to all of my professors and classmates at Yale College and Yale School of Public Health, without whom I would not have the knowledge or skills to complete this project, and to all of the brilliant queer and trans writers and artists online who have deeply shaped my understanding of gender, community, and justice, and without whom I would not have the knowledge or moral understanding to complete this project.

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Appendix A: Full text of the online survey

Notes: All questions are open response unless multiple-choice options are noted. All multiple-choice questions are single-answer only. Survey flow functions are noted in brackets throughout.

Informed Consent

Health Outside the Binary: Genderqueer Experiences of Health Care
Investigator: Hannah Mogul-Adlin

Purpose:

You are invited to participate in a research study designed to examine the experiences that people who are genderqueer, gender non-binary, or gender non-conforming have in health care settings, including doctor's offices, clinics, or hospitals. While researchers are beginning to study discrimination that trans people face in the health system, most of this research has focused on the binary trans experience (individuals identifying as trans women/MTF or trans men/FTM). This study is focused on how the health system does or does not work for individuals whose genders do not fit into the categories of man or woman.

Procedures:

Participation in this study will involve completing an online survey about your experiences in health care settings. This survey is qualitative, meaning that many of the questions are open-ended and require typing a response. We anticipate that your involvement will require 30-60 minutes, depending on how detailed your responses are. After completing the survey, you may choose to be entered into a lottery to win one of 2 \$50 gift cards to amazon.com. Entering the lottery requires following a link to a separate survey where you will enter your email address. Your email address will not be linked to your previous responses.

Risks and Benefits:

Many of the questions are personal in nature and may cause you to experience distress or discomfort. There are no physical risks associated with this study. However, in addition to the possibility that some questions may make you uncomfortable, there is the possible risk of loss of confidentiality. Every effort will be made to keep your information confidential; however, this cannot be guaranteed.

Although this study will not benefit you personally, we hope that our results will reveal future research directions in LGBT health and add to the academic knowledge about gender non-binary experiences of health and health care.

Confidentiality:

All of your responses will be held anonymously. Only the researchers involved in this study and those responsible for research oversight (such as representatives of the Yale University Human Research Protection Program, and the Yale University Human Subjects Committee) will have access to any information that could identify you. When we publish any results from this study we will do so in a way that does not identify you unless we get your specific permission to do so. We may also share the data with other researchers so that they can check the accuracy of our conclusions but will only do so if we are confident that your confidentiality is protected.

Voluntary Participation:

Your participation in this study is voluntary. You are free to decline to participate, to end your participation at any time for any reason, or to refuse to answer any individual question. Refusing to participate will involve no penalty or loss of benefits.

Questions:

If you have any questions about this study, you may contact the investigator, Hannah Mogul-Adlin at hannah.mogul-adlin@yale.edu.

If you would like to talk with someone other than the researchers to discuss problems or concerns, to discuss situations in the event that a member of the research team is not available, or to discuss your rights as a research participant, you may contact the Yale University Human Subjects Committee, 55 College Street, New Haven, CT 06510, 203-785-4688, human.subjects@yale.edu. Additional information is available at <http://www.yale.edu/hrpp/participants/index.html>

1. Agreement to Participate:

I have read the above information, have had the opportunity to have any questions about this study answered and agree to participate in this study.

Yes

No [selecting no sends participant to end of the survey]

Survey Instructions

This survey is only intended for people who identify in some way outside of the gender binary; i.e., people who do not identify as either men or women. If your gender is binary (cis or trans man or woman), please do not continue this survey!

This survey is different than traditional online surveys in that there are very few multiple choice questions-- most questions allow you to type a response. For some questions, a yes, no, or one-word answer may be sufficient, but others require longer responses. If you feel that you can't answer a question, or if it makes you uncomfortable, feel free to skip it (or to write that!). The more in-depth you can make your answers, the better this project will be able to communicate your

experiences and needs to health care providers and policymakers. Treat this survey as if it were an in-person interview, and please write as much as you feel comfortable, especially in the sections that ask about your health care experiences.

Update 2/16/2015: Given the overwhelming number of white respondents, this survey is now closed to white (non-mixed race) respondents in order to ensure a diversity of responses, and a question has been added to reflect this.

Part 1: Demographics

2. How old are you?
[Entering an age <18 sends participant to end of the survey]
3. Are you a US resident?
 Yes
 No [selecting no sends participant to end of the survey]
4. [Added 2/16/15] Are you white?
 Yes [selecting yes sends participant to end of the survey]
 No (including mixed-race/ethnicity)
5. How would you describe your gender?
6. How would you describe your sexual orientation?
7. How would you describe your race/ethnicity?
8. Are you intersex?
9. Do you identify as trans?
10. Do you identify with any of the following terms:
 DFAB/AFAB (Designated Female At Birth/Assigned Female At Birth)
 DMAB/AMAB ((Designated Male At Birth/Assigned Male At Birth)
 Other: _____
11. What is the highest degree you have attained or are currently working to attain?
12. Do you feel financially secure?
 Yes
 No
 Describe (optional): _____
13. Do you have consistent and adequate housing?
 Yes

- No
 Describe (optional): _____
14. Do you feel safe at home?
- Yes
 No
 Describe (optional): _____
15. What best describes the area you live in?
- Rural/small-town
 Suburban
 Small city
 Large/major city

Part 2: Gender

16. Has your gender identity been stable over time, or has it been fluid? If it has been fluid, what other words or labels have you used to describe your identity?
17. How long have you been consciously identifying as non-binary/genderqueer, regardless of whether you have “come out” to others?
18. How “out” are you about your gender? Do your family, friends, partner(s), co-workers, etc. know about your gender identity or preferred pronouns?
19. Do you feel that those around you understand and support your gender identity? Please describe.
20. Do you feel connected to a community of non-binary people, whether online, in person, or both? Please describe.

Part 3: Health Access

21. Do you currently have a primary care provider (a doctor or nurse who you see regularly)? If not, why not?
22. When you need health care, where do you go?
23. Have you ever avoided seeking medical care because of the cost?
24. Have you ever seen a mental health provider (therapist, counselor, psychologist, psychiatrist, etc)?
- Yes
 No

25. If you needed mental health care (therapy, counseling, psychiatric medication, etc.), do you think that you would be able to easily find someone who could provide you with quality, affordable mental health care?
26. Have you ever avoided seeking **mental** health care because of the cost?
27. Have you ever been hospitalized or used emergency room services?
 Yes
 No
28. Have you ever used an LGBT-specific clinic?
 Yes
 No
29. What kinds of things have you gone to an LGBT clinic for? [only displayed if yes was selected for Q. 28]
30. Have you ever used hormones and/or surgery in order to alleviate gender dysphoria (feelings of discomfort or distress stemming from a disconnect between your body and your gender)?
 Yes
 No
31. Do you plan to or would you like to use hormones and/or surgery in order to alleviate gender dysphoria (feelings of discomfort or distress stemming from a disconnect between your body and your gender)?

Part 4: Health Care Experiences

32. Have you had any **negative** experiences in health care settings (doctor's offices, clinics, hospitals, ambulances, etc.) related to your gender/sex being nonbinary? Please describe.
33. Have you had any **positive** experiences in health care settings related to your gender/sex being nonbinary? Please describe.
34. As someone with a nonbinary gender, do you generally feel comfortable in health care settings? Why or why not?
35. Have you ever disclosed your nonbinary gender identity to a health care provider (doctor, nurse, paramedic, counselor, etc.)?
 Yes
 No

36. What kind of health provider did you disclose your gender identity to? [only displayed if yes was selected for Q. 35]
37. How did the provider react? [only displayed if yes was selected for Q. 35]
38. Why have you never disclosed your gender identity to a health care provider? [only displayed if no was selected for Q. 35]
39. How do you think they would react if you did disclose? [only displayed if no was selected for Q. 35]
40. What could doctor's offices or clinics do to improve nonbinary patients' experiences of care?
41. What could hospitals or ERs do to improve nonbinary patients' experiences of care? [only displayed if yes was selected for Q. 27]
42. What could mental health providers do to improve nonbinary patients' experiences of care? [only displayed if yes was selected for Q. 24]
43. Did you find it difficult to access "transition-related care" (i.e., hormones, surgery, etc) as a nonbinary person? [only displayed if yes was selected for Q. 30]
44. How have your experiences at LGBT-specific clinics compared to your experiences at mainstream medical clinics? [only displayed if yes was selected for Q. 28]
45. Is there anything else you would like to add about your healthcare experiences as a nonbinary person?

Thank you so much for taking the time to complete this survey! If you would like to be entered into a random lottery to win one of 2 \$50 gift cards to amazon.com, please copy and paste the following link into a new browser tab or window. The link will take you to a separate survey where you can enter an email address where the gift card can be sent. This will help protect your confidentiality: your email address will not be linked to the responses you wrote for this survey.

Once you copy and paste the following link into a new browser tab or window, please click next to complete this survey.

[survey link for lottery info collection]

Appendix B. Full text of the original Tumblr recruitment post.

Survey on Non-Binary Healthcare Experiences in the US

[Heading linked to online survey]

Hello tumblr friends and followers!

As some of you know, I'm doing my thesis for my master's in public health on the health care experiences of people who are gender non-binary. We live in a binary world with an extremely binary health/medical system, and I'm interested in exploring how folks whose genders are outside of the man/woman binary navigate their health care. I finally got approval from the IRB to release the survey, and I need responses fast! Please help! **If you are a US resident aged 18 or over, and identify as in some way outside of the gender binary of man/woman (genderqueer, agender, bigender, multigender, non-binary, etc.), please take [this survey](#)**[link to online survey]! **Everyone, please reblog!**

What is it?

This is an online survey that is qualitative, meaning that most of the questions have open-ended answers. It's kind of like if you were doing an interview, except that it's online and you're typing, not talking.

What is it about?

I want to know about your experiences in the doctor's office, in the hospital, etc. as a non-binary person. You will be able to talk about both positive and negative experiences, as well as your own suggestions for how the health care system can better accommodate your needs.

Who is it for?

This survey is for US residents aged 18 or over, whose genders do not fall within the man/woman binary. It is not for binary trans men or women, or for cis men or women. If you are not someone who can take this survey, please boost!

What do I get out of this?

You get to help researchers, policy-makers, academics, etc. (i.e., the people who control what healthcare in the US looks like) understand what it is like to be you, navigating a system that hasn't for the most part acknowledged your existence. You get my undying love for helping me finish my thesis. And you can get entered into a lottery to win one of 2 \$50 amazon.com giftcards. (I wish I could pay each and every one of you that responds, but I can't.)

Thank you thank you thank you! Feel free to message me if you have any questions, or to email me at the email address provided at the beginning of the survey.