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Strategies used by transmasculine and non-binary adults assigned female at birth to resist transgender stigma in healthcare

Kristie L. Seelman^a  and Tonia Poteat^b 

^aSchool of Social Work, Georgia State University, Atlanta, GA, USA; ^bDepartment of Social Medicine, University of North Carolina at Chapel Hill, Chapel Hill, NC, USA

ABSTRACT

Background: Transgender stigma is rampant within healthcare systems in the United States. Transgender adults assigned female at birth – including those identifying as transmasculine or non-binary – face unique barriers, such as stigma when accessing sexual and reproductive healthcare labeled as being for “women.” However, transgender and non-binary people are not passive victims to this stigma, and the medical community would benefit from understanding the actions this population takes to resist and reduce transgender stigma in healthcare. Yet, little research has attempted to understand such actions.

Aims: This qualitative study aims to explore how transmasculine and non-binary adults are actively resisting and reducing the impact of transgender stigma in healthcare.

Methods: In-depth semi-structured interviews were conducted with 25 transmasculine and non-binary adults assigned female at birth who were living in a metropolitan area in the mid-Atlantic United States. The research team analyzed qualitative interview data using content analysis.

Results: The 25 participants ranged in age from 21 to 57, with an average age of 33 years old. Six themes were identified related to resisting and reducing transgender stigma in healthcare: (a) using social support; (b) persistence to meet one’s own needs; (c) avoiding mainstream healthcare; (d) advocacy; (e) doing one’s own research; and (f) strategic disclosure of transgender/non-binary identity. We detail how privilege and intersectionality connect to the use of these strategies.

Discussion: Findings indicate there is value in using peer advocates and peer health literacy; in developing and nurturing support groups related to transgender/non-binary health; in developing “allies” employed within the healthcare system; in creating and maintaining lists of culturally responsive health providers and resources about navigating the healthcare system; and in offering trainings related to self-advocacy and health-related activism. These findings can be used to inform future health prevention and intervention efforts with transmasculine and non-binary adults.

KEYWORDS

Transgender men;
non-binary; healthcare;
stigma; resistance

Transgender and non-binary (trans/NB) adults face significant stigma within healthcare settings, from a lack of access to transition-related care, to encountering healthcare providers who are transphobic or are unsure about how to help trans/NB patients, to outright discrimination, harassment, or abuse based upon their trans/NB identity (James et al., 2016). Yet, there has been scant research examining the healthcare needs and experiences of subgroups of trans/NB adults in healthcare, such as those who identify as transmasculine (assigned a female sex at birth and identify as a men/transgender men) or for those

who identify as non-binary and were assigned a female sex at birth (NB/AFAB). Some of the unique stigma that transmasculine/NB AFAB individuals may experience in healthcare include: trying to access sexual and reproductive care in settings labeled as being for “women;” experiencing violence from others in various settings when perceived as effeminate men; and trans men being often perceived as cisgender men and experiencing fatigue with having to frequently disclose their identities (for example, see Cruz, 2014; Namaste, 1996; Paine, 2018). Further, both trans men and those identifying as NB/AFAB are likely

to delay care due to fear of mistreatment (Cruz, 2014). However, trans/NB people are not passive victims to this stigma, and the medical community would benefit from understanding the actions this population takes to resist and reduce transgender stigma in healthcare in order to plan effective health interventions. The present study aims to address this gap in knowledge through a qualitative study with 25 transmasculine and NB/AFAB adults in an urban area in the mid-Atlantic United States.

Background

Numerous studies have documented that the healthcare system in the United States is generally unprepared for meeting the needs of trans/NB adults in an affirming, responsive manner (e.g., James et al., 2016; Knutson et al., 2016; Obedin-Maliver et al., 2011; Paine, 2018; Taylor, 2013), including for adults who are transmasculine and NB/AFAB. The types of care that trans/NB adults AFAB may need include culturally responsive sexual and reproductive healthcare that does not assume that all patients look like or identify as women; gender-affirming hormone therapy and/or surgeries; HIV prevention services; obstetrical care and birth control options; and information about the long-term impacts of testosterone use, among other general healthcare needs (Obedin-Maliver & Makadon, 2016; Scheim et al., 2016). Unfortunately, trans/NB individuals of all gender identities consistently report that many providers lack expertise in trans healthcare (James et al., 2016; Knutson et al., 2016; Poteat et al., 2013) and 24% of trans/NB respondents in a national survey said that, in the past year, they had to teach their providers about transgender people to receive appropriate care (James et al., 2016). Others have noted the general lack of trans/NB content in medical education (Obedin-Maliver et al., 2011). There is a particular need for primary care providers who are knowledgeable about trans/NB patient care (Shires et al., 2018).

Trans/NB patients also face stigma based upon their gender identity and gender expression, including discrimination, exclusion, and violence in healthcare. In the 2015 US Transgender Survey (N = 27,715), one-third of respondents experienced

mistreatment in healthcare in the past year, such as being asked unnecessary or invasive questions about being transgender, having a provider refuse to provide care, or being verbally harassed or physically assaulted (James et al., 2016). Among trans men, 42% had negative healthcare experiences in the past year (James et al., 2016). In a study of 34 gender non-conforming cisgender LGB adults, transmasculine adults, and non-binary adults AFAB (Paine, 2018), participants spoke of experiencing “embodied disruption” in healthcare settings in which providers frequently either assumed they belonged to a binary identity or could not decide how to categorize them. These experiences were so stigmatizing that participants frequently did everything they could to avoid such embodied disruption in the future, including not seeking out healthcare when needed.

White Hughto et al. (2015) have developed a socio-ecological model of transgender stigma that details how such stigma occurs at multiple levels: structural (e.g., policies and practices that maintain barriers to care; lack of competent providers), interpersonal (e.g., discrimination, violence), and individual (e.g., internalized transphobia, anticipated stigma). These authors note that both interpersonal and structural stigma reinforce unequal access to healthcare for trans/NB people (White Hughto et al., 2015). Given that trans stigma is widespread – including within healthcare services – and has a link to health behaviors and outcomes, there has been a good deal of research on these problems. Yet, there is less research analyzing how trans/NB people are surviving, resisting, and reducing transgender stigma in healthcare. One might posit that such behaviors may both create change in healthcare systems to reduce stigma as well as help address the consequent health issues that affect trans/NB people.

The work of other scholars (Logie et al., 2011) documents how stigma is intersectional – that is, for populations with multiple marginalized identities, such as trans people of color and trans people who are living with HIV, differing forms of stigma can overlap and be interdependent with one another, uniquely affecting one’s overall experience of marginalization and oppression. A national survey of U.S. adults indicated that

individuals with multiple disadvantaged statuses (e.g., being a person of color, a woman, and overweight) tend to report more discrimination and experience such discrimination as being more stressful than their privileged peers (Grollman, 2014). Further, those exposed to more than one type of discrimination had worse self-reported health and functional limitations than those experiencing no discrimination or only one type (Grollman, 2014). One would expect similar patterns of the relationship between disadvantage statuses and discrimination in healthcare for trans/NB adults. Indeed, negative experiences in healthcare are more common among marginalized subgroups of trans/NB people, including those with disabilities and trans people of color (James et al., 2016; Kattari et al., 2015; Kattari & Hasche, 2016). Due to anticipated stigma based on such experiences, many trans/NB adults avoid healthcare (Fredriksen-Goldsen et al., 2014; James et al., 2016; Seelman, Colón-Díaz, et al., 2017). A statewide survey in Colorado found that trans adults with lower income were more likely to delay care than those with higher income (Seelman, Alvarez-Hernandez, et al., 2017). Others have found that experiencing transgender discrimination in healthcare is correlated with substance use for coping as well as mental health challenges (Clements-Nolle et al., 2006; Reisner et al., 2015). Additionally, some scholars theorize that masculine norms about help-seeking may be a barrier for transmasculine adults in seeking out healthcare when needed (Seelman, Kattari, et al., in press).

Despite facing transgender stigma in healthcare and other barriers to access, trans/NB people AFAB are finding ways to navigate such environments. Yet, little research has explored the strategies used by trans/NB individuals AFAB to resist and reduce transgender stigma in healthcare. Though not focused specifically on trans/NB people, past research (Barker, 2008) indicates that when certain populations or health conditions are not well understood or are dismissed by the medical field, patients are often doing a lot of their own health research and bringing their “embodied expertise” into their interactions with health care providers, challenging the usual doctor-patient relationship in which the doctor is

seen as the “expert”. Similar findings have been documented in a study by Poteat et al. (2013) who interviewed 55 transgender adults and 12 health-care providers, documenting that that typical power relations are often challenged in interactions between transgender patients and providers when the providers are lacking knowledge about effectively serving this population. Patients and providers consequently can either further contribute to interpersonal stigma (e.g., trying to reestablish the medical provider’s power, even when such individual lacks trans-specific knowledge) or resisting stigma (e.g., listening and responding to the patient’s stated needs).

What we might expect to find is that trans/NB adults AFAB are bringing their expertise based on lived experiences into these interpersonal interactions to help address systemic lack of knowledge and discrimination in the healthcare system. Given that trans men report that they often delay needed healthcare, we might expect that one strategy used to reduce stigma is simply to attempt to find support and care outside of the mainstream medical system. A growing body of research on transgender resilience addresses strategies that may also be relevant to healthcare settings. Past studies with trans/NB youth and adults (sometimes grouped with cisgender LGBTQ individuals) have documented the importance of: developing and nurturing social support with trans/NB peers and allies; engaging in activism, collective action, and large-scale systems change; being optimistic; establishing personal agency; un-silencing the variety of marginalized social identities they hold; and making decisions by context to maintain personal safety, such as not disclosing one’s identity as trans (Asakura, 2017; Bockting et al., 2019; Singh et al., 2011).

Gaps and current study

Research has consistently documented that transgender stigma impacts the healthcare experiences of trans/NB adults, including those AFAB. This subgroup of the trans/NB community faces unique factors, such as trans men often being perceived as cisgender men and having to frequently disclose one’s identity to avoid being invisible. Yet, it is important not to treat

transmasculine and non-binary adults as being passive to such oppression, instead recognizing their agency and the strategies they have and are already using to challenge stigma. However, these strategies have not been explored in relation to healthcare experiences and specifically among trans/NB adults AFAB. The present study attempts to fill this gap in the research by addressing the question: What strategies do transmasculine and non-binary adults assigned female at birth use to resist and reduce the impact of transgender stigma in healthcare?

Methods

This qualitative study was part of a larger research project on gender and health conducted in a mid-Atlantic city in the United States. Semi-structured interviews took place between January and July 2011 with 25 transmasculine or non-binary adults assigned female at birth, aged 18 or older. To participate in the larger study, individuals had to live in the metropolitan area where the study was taking place and currently identify as transgender and/or a gender different than their sex assigned at birth. For the present analysis, we focus on the subset whose sex assigned at birth was female ($n = 25$).

Participants were recruited via flyers in the lesbian, gay, bisexual, and transgender (LGBT) health center, announcements at trans support groups, and word-of-mouth. Eligibility screening was conducted by phone. Those who met the inclusion criteria for the study were invited to interview at the project office, which was in an area of the city accessible via public transportation. A member of the research team described the study's procedures, risks, and benefits to individuals before obtaining the person's verbal consent (no written consent forms were used). Each participant engaged in one audio-recorded, in-depth semi-structured interview, lasting between 45-180 minutes, with an average length of 90 minutes. Interviews elicited detailed narratives, including stories about childhood, family, and intimate relationships, school and work environments, and experiences accessing healthcare. Example interview questions related to healthcare were "What are some of the healthcare experiences

you've had?", "What advice would you give healthcare providers?", and "How do you cope with negative healthcare experiences?". Each participant was given \$25 remuneration. All audio recordings were transcribed verbatim, with identifying information removed. The interviewers jotted down reflexive notes during the interview process, which were later typed and placed into the same document file as the transcription for each participant.

This study's procedures were approved by the Institutional Review Board at Johns Hopkins University. No individual identifiers were collected during the data collection process to encourage confidentiality of participant data.

Data analysis

The research team analyzed the qualitative data from 25 interviews using content analysis, which included the analysis steps detailed by Bengtsson (2016), including *Decontextualization*, *Recontextualization*, *Categorization*, and *Compilation*. Three team members reviewed a subset of the data (3 interviews each), conducting open coding that was driven by the a priori research question. Each team member attached open codes to meaning units within the data (Decontextualization) that related to this research question, and then started developing a list of over-arching themes that helped group related open codes together (Recontextualization). The team discussed these initial codes and over-arching themes, eliminated some and combined other themes, and then created a final codebook based upon the group's consensus about key themes and definitions of those themes (Categorization). Using this codebook, the first author then reviewed and coded all 25 interviews. No new themes were added during this stage of the coding, but some were eliminated if they did not incorporate more than a few meaning units or encompass the experience of more than a few participants or if they overlapped substantively with other themes. The first author then reviewed the coding output for each theme and the initial theme definition, removing meaning units that did not seem to fit, and deciding on a final, succinct theme definitions based on the data (Compilation; Bengtsson, 2016).

Table 1. Sample demographics ($N = 25$).

	<i>n</i>		<i>n</i>
Gender Identity^a		Educational Attainment	
Man/male	18	High school graduate	1
Genderqueer	3	Associate degree/Some college	10
Trans/transgender	3	Undergraduate degree	8
Trans Man/FTM ^b	2	At least some graduate school	6
Race/Ethnicity		Has Regular Source of Medical Care	
White	12	Yes	20
Black/African American	6	No	4
Multiracial/multi-ethnic	6	Not asked	1
Not asked	1	Health Insurance	
Sexual Orientation		Private (via employer or family member's employer)	13
Bi/pansexual or "non-discriminating"	8	Medicaid or other program for low-income adults	5
Queer	8	CHIP ^c	1
Straight/heterosexual/attracted to women	7	Veterans' health care + another public program	1
Gay	1	None	3
Not asked	1	Not asked	1
Age	Range: 21 - 57 Mean: 33		

^aThe total count for the gender identity categories is greater than the sample size because some participants reported using more than one gender identity term.

^bFTM = Female-to-male.

^cCHIP = Children's Health Insurance Program.

Sample

Participant demographics are detailed in Table 1.

Results

We identified six themes related to strategies used by trans/NB adults AFAB to resist and reduce transgender stigma in healthcare. These include: (a) using social support to navigate healthcare systems; (b) persistence within healthcare systems to meet one's needs; (c) avoiding mainstream healthcare; (d) advocacy; (e) doing one's own research; and (f) strategic disclosure of trans identity. Because of how stigma is an intersectional experience based upon more than one aspect of one's identity (Logie et al., 2011), we also highlight how privilege and intersectionality relate to these findings. Although the interviews did not include a standard question on pronouns, some participants shared their pronouns during the interview. When reporting findings, we use pronouns that match those used by the participant; if we did not have pronoun information for an individual, we refrain from using pronouns for that person.

Using social support to navigate healthcare systems

Social support was identified as a theme in slightly over half of the interviews. Participants noted four primary ways they used social support

to help navigate oppressive healthcare systems: (a) to deal with transphobia, discrimination, and poor treatment within healthcare systems; (b) to better understand the transition process and how to engage with healthcare systems to facilitate transitioning; (c) to support one's emotional health as part of interactions with an oppressive healthcare system; and (d) to support other transgender and non-binary friends going through similar struggles.

Dealing with transphobia, discrimination, and poor treatment within healthcare systems

Regardless of whether one was seeking medical care directly connected to one's trans/NB identity, poor treatment in medical care was common. In such situations, having supportive friends and family members present often helped participants navigate a difficult situation or communicate effectively with providers. A 28-year-old mixed race genderqueer adult offered an example:

[The medical providers] were really bad with my pronouns... They asked me a lot of questions about being transgender. They asked me questions about which direction I was transitioning; like M to F or F to M... Even though I was telling them I was on testosterone, they didn't even get it... It doesn't matter what gender you are, you have the bone that's right behind your ear, and if it's infected there's a problem and it should not matter. Like I get needing to know what medications I'm on. But I disclosed that... And I didn't see how it was relevant for them to ask me those questions. I answered them, but I

was noticeably upset... I was also in massive amounts of pain. So, I was kind of [lying] there, and I just relied on my partner to get them to shut up, and to actually treat me. It was really frustrating; and yes, it was really frustrating for her, too.

In cases like the one described, a support person advocated alongside of the patient, prompting the medical staff to focus on the primary problem reported by the patient. Another participant – a 24-year-old White man – similarly described how supportive friends and family often play a role of advocate, particularly when the patient might not be able to fill this role themselves:

Right after I had started my transition... I had a kidney stone, and I didn't know that's what it was, and my friend took me to the doctor and thankfully I was unable to speak because I could not stop throwing up. So, my friend was the mediator for all communication, and she was more comfortable with any communication in terms of trans issues, so it wasn't a problem... because she did it all for me.

These examples demonstrate that social support was very important to participants in dealing with the transphobia and mistreatment that come with interpersonal stigma and minimizing the harmful impact this stigma would have on their lives.

Understanding the transition process and how to engage with healthcare systems to facilitate transitioning

Friends and partners, including other trans/NB individuals, were key supports in helping trans/NB adults AFAB understand the options available to them for transitioning and methods for interacting with healthcare systems to best meet their needs, since such information was not often directly offered by the healthcare system or larger society. A 22-year-old Black man discussed coming to the decision to seek hormones and to transition:

For a while, I didn't think that it was a possibility for me. I was kind of, like, maybe ashamed of those feelings. But then I met my friend, and he been through the whole process, and I got to see his outcome and what he looks like and the life that he leads and the happiness that he has. And he basically showed me the steps and told me what to do. And since I had the information, I took it and I followed it and did it because I wanted the same thing for myself.

Such “steps” included finding a therapist to talk to about gender identity and to receive a letter of support for using hormone therapy and/or undergo gender-affirming surgery(ies).¹ Participants spoke to the importance of receiving encouragement from loved ones about researching their own medical options. This was shared by a 27-year-old mixed race man:

I met my future husband, then boyfriend, who also has an interest in, like, gender play, basically. He likes androgyny... He really encouraged me to explore it more and said he would support me all the way in any endeavor, which really helps, just having someone who will say, “I don't care if you look like a girl, I will call you “he” if you want that. I don't care what you look like”... Having his support kind of gave me that push, I guess, to really seek out, to go and research what kind of medical and psychiatric help I could find in the region.

Having the social and informational support from others, especially within the trans/NB community, facilitated patients' abilities to navigate a system that was not forthcoming with information about the steps or care needed for transitioning. As will be detailed later, such social support linked closely with “doing one's own research” about trans/NB healthcare.

Emotional support

Participants also shared examples of ways that they received helpful emotional support from their peers related to navigating an oppressive healthcare system. A 24-year-old man of mixed ethnic background reported:

I think peer-to-peer support is good, too. Because if you can get together at the barbecue or something and you talk to other transsexuals who say, “Oh yeah, I had that problem and the doctor was so mean, and then I went home and I was upset for three hours, and I ate Oreo cookies and then I got over it.” Well, okay. Alright, so... this is like normal, everyone is going through this, and so we can kind of help each other. You realize your experiences are normative, you know, and so that helps too, I think. So, it's like good therapy and peer support.

Importantly, knowing that one is not alone in experiences of marginalization and oppression can be a way of dealing with these experiences – even though, ideally, the healthcare system

should get to a place where marginalization is not “normal” for trans/NB people.

Providing support and information to others

Some participants spoke of being a source of support and information to *other* trans/NB adults. Some were doing some important behind-the-scenes work with trans/NB adults who were avoiding mainstream healthcare and putting themselves at risk by self-medicating or avoiding preventive care. A 23-year-old African American man informed other trans men about getting pap smears: “Get it together, make sure you don’t have anything, one. Two, you want to make sure you’re healthy all the way out, all the way through. The last thing you need is another complication that could have been prevented.”

A 25-year-old White man, warned others about not getting hormones off the street:

I’m pretty medically intelligent. I’ve strongly advised them not to [get hormones off the street]. I’ve also advised them of some of the ramifications that could happen to them physically if they continue that ... For the female-to-males, what’s pretty typical with that case of getting testosterone from another individual is that they’re so eager to change quicker and quicker and quicker and ... they think “Oh, the more that I take more frequently, the quicker my results are going to be coming.” And so they don’t realize that there are some pretty serious things that could be happening to them if they are overdosing on testosterone. So luckily, I’ve been able to kind of go in behind the scenes and everything where this is happening without any physician present or anything and let them know “Look. Here’s what you’re going to be setting yourself up for if you continue this.”

Such individuals’ stories indicate that people within the transmasculine/NB community – particularly those with strong medical knowledge – are acting as *de facto* medical outreach educators when the mainstream healthcare system is failing this population. These individuals are stepping in to encourage re-engagement with healthcare systems for particular types of care.

Persistence within healthcare systems to meet health needs

Persistence was a theme appearing across more than half of the interviews. Participants spoke of

persisting in seeking healthcare that could meet their needs, working their way through barriers and restrictions. There were two primary ways this emerged: persistence to have transition-related care covered under one’s insurance, and persistence in receiving general medical care.

Persistence to have transition-related care covered by insurance

Participants spoke about several barriers to getting insurance coverage for transition-related care, including requirements to have a letter from a mental health professional in support of transitioning and needing to use their sex assigned at birth on medical documents in order to having surgical care covered. On the first point, a 30-year-old Black man indicated that he and his therapist both agreed that he did not have much to work on in therapy, but he had to go through the hoops to get the appropriate paperwork for surgery:

[The therapist] said, “Well there’s not too much [we] can talk about.” Being that I’m not like depressed or so forth, so the next time I would see her, it would be just ... [a] couple visits to sign off some paperwork for the surgery and that would be it ... I was just going because it was required of me.

This participant’s actions suggested that he would persist in going through such hoops to obtain the surgical care he needed. Another participant, a 46-year-old White man, spoke about having to present as female in order to have a double mastectomy covered by his insurance:

[My top surgery] was covered under insurance if I presented as female to the top breast surgeon at a very Catholic hospital. So it was sort of a “don’t ask, don’t tell” sort of a thing that the gynecologist I was hooked up with, who agreed to do my hysterectomy, sort of said, “Well, this guy is a friend of mine. Don’t tell him. He won’t ask you, and he’ll get it done.”

Both of these examples also speak to the value of being allied with empathetic healthcare providers who can help one get the care one needs.

Persistence in receiving general medical care

Some participants spoke of having to persist in various ways in order to receive general medical care – such as emergency room care, preventative care, or a sick visit with a doctor. One participant,

a 21-year-old White man, discussed having to disclose that he was trans during intake in order to be “fast-tracked” for an appointment somewhere:

It was really hard to get into [health clinic] at first. I called and I asked for an appointment, and they're like, “Well, you have to call back in a month because we're totally booked up.” So I called back in a month, and I was told that I was supposed to tell them that I'm trans, because then they'll fast-track me... So I ended up getting [a student support staff person] to e-mail [health clinic] with my name. And then once that happened, I got a call like two days later for an appointment...

Persistence also consisted of identifying allies—what one participant called “the gems”—within the health system who could help them navigate transphobic hurdles to appropriate care. A 41-year-old mixed ethnicity man described one “gem”:

... There's like one person, who's like the gem... you just kind of stick with them. And so, if you need something with the paperwork or whatever, and let's say it's supposed to go to person X, but you know this gem person is very understanding and what not. So you call them and you say, “Oh by the way, there's paperwork, and I filled it out, but how about I give it to you, and then you give it to the psych.” Because then if the psychiatrist is like, “What the heck is this? There's two parents and it's mixed up, and where's the father and this and that,” the gem person will say, “Oh you know it's a family with two women as parents.” And the psychiatrist is like, “Oh, okay.” Because they're talking to another professional... So you can kind of remove yourself and let the gem person take care of [it]... So, like, if I have a problem with the insurance department, like with the forms... I call [the gem].

Each of the examples provided here within the theme of “persistence” demonstrate that patients looked for ways to keep taking action to make sure their needs were met, even when confronted with the transphobic, heteronormative, and cisnormative practices of the healthcare system that they were not able to quickly change or easily challenge. Frequently, allies within the healthcare system played a key role of support for such patients in finding paths to ensure health needs were being met.

Avoiding mainstream healthcare

Another strategy used by transmasculine and non-binary adults AFAB to resist stigma was to

avoid accessing mainstream healthcare altogether, particularly as a strategy of protecting one's emotional well-being. This topic was discussed by just over half of the participants. Multiple individuals discussed sexual and reproductive healthcare as particularly anxiety-provoking, traumatic, and/or extremely painful. Some used avoidance to deal with such reactions, as shared by a 41-year-old mixed ethnicity man:

I just stopped going. I know you're supposed to go once a year, but I stopped because they were making me very uncomfortable because if I had to explain things that I didn't need birth control or that I was not interested in getting pregnant... Or just even the way that they examine you, not realizing that can be very uncomfortable for someone... I guess, if you're regularly in touch with your body and doing things like using tampons and having sex, like, that it's not uncomfortable or it's not a far leap to have a gynecologist also touching you there and doing whatever they have to do. But if you identify as male it's very— it can be very uncomfortable physically, let alone socially and emotionally.

Others spoke about avoiding transition-related care in mainstream medical settings, including accessing hormones or post-surgical care. Some said they knew people who accessed testosterone off the streets after doctors refused to give them a prescription. Another participant, a 38-year-old White man, was experiencing complications after a double mastectomy and was wary of going to the emergency room:

When I got out of the shower, I had probably a melon-sized swelling that was really hard, and eventually I got in touch with [the doctor] because she called me the day after surgery... She incorrectly, over the phone, said, “Oh it's just a seroma... I know it's scary but don't worry about it,” etc. We had to end up calling her back because I was fainting and bleeding profusely and she said, “This is actually positive because you want some of the fluid to come out,” and things like that. My fiancé and myself we were still really nervous, and we didn't know how we were going to make it until the next morning because I asked [the doctor], “Should I just go into an emergency room?” And I had mixed feelings about that. Well, [the doctor] didn't have any means to see me, she didn't have any sort of 24/7 care... she could only get an anesthesiologist on certain days. She did not want me to go to an emergency room, she wanted to address it herself, and I understand that and frankly I didn't want to go into an emergency

room. How do I even begin to explain this surgery? And I want my chest to look right... If it were not for a trans-specific surgery, I wouldn't have to go through that, and that made me angry... The next day I went in... [and] immediately I could tell from the tone and when she saw it she knew that... she was wrong, and it needed to be addressed immediately. It was excruciatingly painful.

In such circumstances, it can become a life or death situation in determining whether to seek emergency care.

Some participants avoided mainstream healthcare because they found it to be traumatizing or ineffective. Other participants found the costs of healthcare services to be very prohibitive and therefore chose to use alternative (cheaper) treatment options. A 28-year-old White genderqueer adult shared:

I went to [health clinic] and... it was going to be \$100 for every [talk therapy] session, so right now I go to Zumba classes at [location] with my friend [name] and just exercising really helps and I'm going to acupuncture once every two weeks. And those things combined equals still less than having therapy every week... I'm like "Well, I can't go to a therapist," so I just make projects for myself so I'm still doing self-care but just different than talk therapy.

This was one example of intersectionality at work – how trans adults' decisions and actions about healthcare were impacted by other dimensions of their lives (e.g., socioeconomic status) beyond their trans identity.

Some participants had a cultural background in which people generally do not go to the doctor unless they are very sick. For example, a 27-year-old mixed race man spoke of growing up in another country that encouraged the attitude of "I'll just wait a little longer and only go to the doctor if I feel miserable." He has had to counteract these cultural lessons in order to seek trans-related medical care.

Advocacy

More than half of participants also spoke of putting forth an effort to improve the healthcare system (advocacy with the larger system) – both for trans/NB as well as other patients – and trying to improve healthcare for themselves (self-advocacy).

Actions of advocacy within the larger healthcare system included: trying to improve the competency of healthcare providers; challenging transphobic, racist, and other discriminatory policies and procedures; promoting trans-related care to other trans people; and improving the environment for all patients. For example, a 23-year-old African American man was active in a transgender support group but noticed "a lot of guys of color don't know about the meeting" because it was not being adequately advertised. He took it upon himself to be the "marketing, advertising guy. I'm the go-to guy about all the programs in the area... I wear that hat proudly."

Another participant, a 26-year-old Black trans adult, encountered a provider who was insensitive about trans patients, so took up the work of challenging and advocating for change:

I actually spoke to her afterward. "You're going to have more clients like me. What are you going to do for best practices? These are unacceptable standards of care." And she was explaining to me, "Well, this is the first time something like this has happened." I'm like, "Granted, but you need to prepare yourself for different types of people walking into your office." Because I tend to be really vocal when things go awry.

Sometimes participants noticed other issues with the health system that impacted other marginalized groups, such as autistic people, that they wanted to advocate to change. A 41-year-old mixed ethnicity man shared:

A lot of people on the [autism] spectrum have sensory issues. So, if the waiting room has really bright lights and the TV is blasting... it could be very uncomfortable for us to sit and wait there... I was like, "This is the most un-relaxing place on earth." So other people could get crazy about it, me, I just keep advocating. Like maybe you need a quiet room for some people. And, again, I keep saying it starts out as for us, but it's really for everybody because there's other people who might need to a quiet room, too. Or maybe we should turn off the TV... You just advocate and negotiate as politely as you can and try to make a difference, you know, to get people to understand that who make all of these presumptions...

Some participants saw problems in the healthcare system as something that they could directly address and try to change, whether related to trans/NB people or other groups of patients who

typically encounter stigma in healthcare. After experiencing barriers to care themselves, they were empowered to act to improve the healthcare system to benefit all future patients.

When confronted with stigma in healthcare, many participants engaged in self-advocacy—using their voice to state their needs, name transphobia or a lack of quality care, and call for improvements for their own care. Examples included advocating to get their medication when a pharmacist did not believe they “matched” the name on the prescription based upon appearance; repeatedly calling a clinic to get an appointment rather than be put on a long waitlist; asking to be addressed with the correct names or pronouns or with the title of “parent” rather than “mother”; challenging inappropriate questions about one’s sexual history; and pointing out racist treatment, such as doctors treating White patients more quickly than Black patients.

A 41-year-old mixed race man talked about self-advocacy in the context of a physical exam in a sexual and reproductive health care office:

She paid no attention to my gender stuff... I think she just actually stopped using gender when referring to me with the like assistant person ... She didn't even like look at me, like I didn't feel like she looked in my eyes ... I just felt really dismissed. And then so she goes in with like the biggest speculum, and I told her beforehand, I was like “I don't have penetrative sex very often, if at all” ... And so I told her that ahead of time, so she starts off with the biggest speculum, it was so fucking painful, I felt like I was being raped. I mean, that's how much it hurt, it felt like I was a virgin ... I started sweating ... oh my gosh, my eyes were like tearing up, it was horrible ... And she was really impatient, she was like “Just relax, just relax”, I was like “That's not going to help” ... I'm like “This ain't happening.” You know, I'm telling her like “This isn't working”, so then she goes to the smallest one, and then, you know, we get somewhere ... It was fucked up. I was very angry, I was very, very angry.

In this case, even though this patient had provided sexual history information, the doctor was impersonal (no eye contact) and abrupt in manner and not attuned to the pain expressed by the patient during the exam. It took the patient’s self-advocacy—stating “That’s not going to help” and “This isn’t working”—to prompt the doctor to change her speculum. This is an example of a

patient trying to challenge ineffective care that is based upon transgender stigma (not understanding or anticipating the specific sexual and reproductive healthcare needs of a trans/NB patient AFAB).

Doing one's own research

Another strategy for resisting stigma was to do some research on one’s own to try to reduce the likelihood of experiencing transgender stigma in healthcare, a theme that appeared in more than 80% of the interviews. This included doing research to identify knowledgeable and culturally responsive healthcare providers, researching one’s own healthcare needs and symptoms of problems, identifying the standards of care for trans patients, and understanding strategies – such as safer sex methods – that could help reduce one’s health risks (health literacy).

Although the participants were interviewed within a major metropolitan region – where trans-sensitive providers are likely more prevalent – it was not uncommon for them to struggle finding a culturally responsive provider. A 46-year-old White man shared, “I must have called about 10 to 15 physician offices surrounding the area where I lived, and they all pretty much said, ‘We don’t treat transsexuals,’ and hung up on me.” Others spoke of having to travel far distances to access decent care. To find providers, participants used strategies such as joining trans-related e-mail lists, asking other trans/NB peers for suggestions, looking for providers with a stated commitment to trans/NB people, and getting information from local trans support groups. Other strategies included cold calling offices or asking insurance companies, but these efforts were not consistently helpful.

Some of the desired characteristics of providers included being knowledgeable about trans/NB healthcare, being open and willing to learn about trans/NB patients, not relying on trans/NB patients for education, having an accessible location and affordable services, having one or more identities in common with the patient, and being an “all-in-one” clinic where patients could receive routine and trans-specific care. For example, a 41-year-old mixed race man noted, “If I have

insurance ... I'm going to look for a woman and ideally somebody Black just because I want to like give them the business, <laughs> you know? And maybe because they might ... not make certain assumptions about my health." A 23-year-old White man shared:

I really wanted somebody that I could go to for everything, including my trans issues. I didn't want to have to run around to several different primary care doctors... Convenient to my house was the next [priority]. I was looking for somebody who did a sliding scale.

Because so many of these individuals had experienced or anticipated transgender stigma in the form of uninformed and insensitive providers, they often did their own research to try to find someone who would be ready to offer trans-affirming care.

To navigate a system in which many healthcare providers were not knowledgeable about transgender care, trans/NB individuals learned about healthcare on their own, sometimes bringing that knowledge directly into interactions with providers. Others were involved in educational roles for community health or advocacy organizations and brought their knowledge into the healthcare system as well as shared it with other trans friends. This information may have been related to HIV/AIDS and STI prevention and care, hormone therapy, transitioning, or mental healthcare. A 39-year-old White trans man discussed:

So the way that I deal with uncertainty or fear is to gather information... I was involved in ACT UP... I did make it part of my job in getting my education to figure out what was out there and what methods would help prevent [STI] transmission both in terms of actions and in terms of things like physical barriers, condoms, spermicides...

Similarly, a 28-year-old White genderqueer adult noted that, "All the HIV education I have is just because most of my friends are in healthcare... I haven't ever been to a [city] healthcare facility where they talked to me extensively about HIV. Not even a gynecologist..." Some participants – while they may have felt "different" in terms of their gender throughout their life – did not know transgender identities existed until they did their own research. A 30-year-old Black man said:

I just didn't know it existed until probably about ten years ago... when I started researching. And then as I got more familiar with it and researched a little more, then I figured I would start leaning towards that direction. But then I met with a friend of the family and they was going through it and so I was like "Well how do you get started?" That was where I was stuck at. I know about it, now how do I get started? So when he told me how to get started then I was like "Okay, sounds good. I'll check it out."

Efforts toward health literacy helped inform trans/NB adults about services they could seek out, as well as health risk factors – such as STI transmission – that were not being adequately covered by their providers.

Strategic disclosure of trans identity

Just over half of participants spoke of making decisions about when and where to share information about their trans/NB identity. Some participants wanted to disclose their identity whenever receiving medical care so that they could be transparent with providers and avoid confusion. Others said that sharing such information was often helpful in receiving appropriate care, although could still prompt differential treatment, as indicated by a 25-year-old White man:

I had to go to [hospital] ER... Coming in there, I remember they were trying to go in and pull my shirt off because unfortunately, I was covered in blood... and I had to tell them "Look, here's what's going on. I'm wearing a gynecomastia compression vest. Please go and pull the curtain." I will say, of course, the fact that I had a Level-2 head trauma, they were definitely really quick to go with what I was just telling what we needed to do for right now, rather than really questioning it, which was really nice. And they were concerned about my privacy and things like that. I definitely don't think that my treatment was affected in any way, other than I ended up having a team of people around me that were very curious about "Let me get a look at the transgender guy we've got in here," so I was more like a guinea pig for being able to have a lot of questions asked...

In other circumstances, participants decided not to share their trans status, either because it was not relevant to the care they were receiving, would be highly uncomfortable to share, or was anticipated to result in transphobic responses. A 48-year-old Black trans person shared:

So I know [the doctor's] a Christian ... so I'm not going to say anything about trans. I stick with [this doctor]. I ain't trying to have a say because she's the best. She's like the top at [hospital] when it coming to colon cancer. And it took me forever to get an appointment with her. So I'm not going to say, "I'm trans, respect me, that's who I am." Sometimes you have to keep your mouth shut to get decent help and it's sad.

Thus, depending on the context of a particular healthcare setting or the type of needed care, participants determined whether disclosing their trans status would facilitate better care or prompt further transgender stigma. A patient's choice not to disclose trans status was often done to reduce the likelihood of discrimination, poor care, or denial of service from a provider whose competence for serving trans/NB patients was either unknown or known to be lacking.

The roles of intersectionality and privilege in challenging stigma

Across all of these themes, there was an important role played by the intersectionality of participants' identities and experiences in how they resisted and reduced stigma in healthcare. Many noted other forms of stigma in healthcare related to other dimensions of themselves— such as being polyamorous, a person of color, someone raised in a non-Western culture, having a disability, being low-income, or not having health insurance. One example of intersectionality came from a 41-year-old mixed ethnicity man whose therapists were reluctant to support a gender transition plan:

Because I'm on the autism spectrum, I ran into a situation where therapists didn't really want to see me or give the letter [to support gender transition] or anything because they have these very outdated notions about disability. And if you have a learning disability or autism or a cognitive disability, traumatic brain injury, et cetera, they say, "Well, how do I know that you're really making a choice? How do I know that you're really capable of making that choice?" ... As if we can't have self-determination about our lives because we may have challenges in communicating or socializing. I mean just because you have those challenges doesn't mean that you can't tell that this or that or the other thing is going on with you.

This story highlights the need for providers to have knowledge about various disabilities such as

autism and how to counteract ableist oppression as part of supporting trans/NB patients. There is no "one" way of experiencing being trans/NB; to tackle trans stigma fully, there is a need for ensuring culturally responsive care across identities and addressing oppression in all its forms.

Participants' privileged positionalities – such as being White, having access to money, or being able-bodied – also impacted the options available to them in navigating the healthcare system. For example, several participants spoke about being able to spend money out-of-pocket to receive the therapy they needed to transition or being able to buy a plane ticket to fly several states away to get a pap smear from someone they trust to do it well – that "it's worth it" to spend money in this way.

A 41-year-old mixed ethnicity man discussed how trans people who display themselves as educated and middle or upper class simply have more permission to advocate for themselves and the system works according to how they behave:

If you go in there and you're well groomed, middle class, some education, even if it's just high school or whatever, you can advocate yourself... You talk nicely. You make the appointments. You write them down. You remember when the appointment is. So they're used to that... With my short-term memory, until I got this iPhone, I was constantly having trouble remembering appointments, getting to them, et cetera. That doesn't mean I'm less motivated or less deserving of care. And it doesn't mean that I can get excused from the rules either. Like if you don't show up a number of times you're going to lose your spot. But okay, the answer is: what's a strategy that you can use? Like how can we help you? ... Well, if get an electronic thingy and it texts you the day before your appointment, okay, so now you're all right. It's helping people. What strategies can we use so that you can make choices and you can participate in your care and you can do the things that you need to do?

This person calls for systems that can meet people where they are and help them with maintaining their health, in this case with automated appointment reminders. As part of challenging transgender stigma, there is a need for incorporating lenses of intersectionality and privilege to help understand the multiple layers of stigma participants may experience and to uncover how

not all strategies for challenging stigma are feasible for all trans/NB people.

Discussion

The goal of this study was to investigate strategies transmasculine and non-binary adults assigned female at birth use to resist and reduce stigma in healthcare, as this population faces unique barriers to accessing care. These individuals are more than just victims of stigma; they are advocates, improvisers, self-care experts, survivors, and collaborators in challenging injustice. Recognizing the agency, resiliency, and persistence of this population will aid in constructing effective prevention and intervention efforts to address the health disparities they face in ways that respect and reflect their lived experiences and the wisdom developed within this community.

Several of the findings from the current study connect to past research about trans/NB people's access to healthcare and/or trans/NB resiliency. Other studies have documented how trans/NB people use a support network for emotional and instrumental support in relation to sociopolitical changes and exposure to hate crimes, discrimination, and violence (Bockting et al., 2019; Veldhuis et al., 2018), in their gender identity development processes (Budge et al., 2017), and as part of resilience processes more broadly (Asakura, 2017; Singh et al., 2011). Past evidence has suggested that social support matters for health for trans youth (Veale et al., 2017) and trans middle-aged and older adults (Fredriksen-Goldsen et al., 2014). The present study adds to this literature with examples of how transmasculine and non-binary adults AFAB value the support of friends, partners, family, and peers in dealing with transgender stigma in healthcare and understanding the transition process and how to obtain needed care. These supportive people may offer comfort, help challenge poor quality care among providers, or act as mediators of communication. Additionally, some participants were also active supports of *other* trans/NB people – providing information and health advice, for example, that may not be effectively offered by medical providers. In formulating interventions, then, there would be value in taking

actions that can build and nurture social support among trans/NB adults.

This study builds upon past research indicating the value of advocacy to challenge broader systems to promote equity and justice. Such advocacy took the forms of challenging incompetency, taking action to recruit more trans/NB individuals to support groups, and advocating for changes to policies and programs for marginalized populations – not only for trans/NB people but also people of color, people with disabilities, and other marginalized groups. Findings indicate that transmasculine and NB adults AFAB take action to improve the healthcare system for themselves as well as for patients in general. This connects with other research that has found that asserting personal agency and engaging in self-advocacy and broader activism are actions trans/NB people take to change healthcare systems or other oppressive structures, or as part of their resilience (Asakura, 2017; Singh et al., 2011; Taylor, 2013). A recent study indicated that lack of knowledge among providers was related to transphobic attitudes, rather than formal or informal education about transgender health (Stroumsa et al., 2019), suggesting the importance of challenging transphobia more broadly through self-advocacy and activism. Yet, at the same time, while advocacy may promote resilience for some trans people, we should not expect that all trans/NB individuals want to or can spend the time advocating for larger change or educating providers in the healthcare system. This “extra work” is unfairly placed on the shoulders of trans/NB patients, who are already facing many other stressors to accessing care (Taylor, 2013).

Our findings suggest that transmasculine and NB adults AFAB also do their own research as part of preparing for engaging with a stigmatizing healthcare system. They are doing research to find knowledgeable providers and educating themselves about trans health to better ensure their own adequate care (health literacy). They gather and share information and knowledge about healthcare issues, risk factors for trans men and NB adults, and the types of services they need. Past research has found that trans men often turn to their trans peers to find healthcare providers, to validate their own experiences, and

for knowledge and information (Taylor, 2013). Taylor also documented how trans men gather information about healthcare policies and practices, which helped guide them in understanding what actions they might need to take in order to access healthcare as a trans person. Such findings support the idea of creating a health information center – developed by trans/NB adults and based on their own lived experiences—that could offer educational resources to reduce the workload involved in doing one’s own research.

Other strategies found in the current study relate more to actions taken for self-care and safety – such as avoiding a provider or strategically disclosing one’s trans identity. Such findings link to what others have written about code switching among LGBTQ youth and their decisions about choosing when and where to disclose their identities (Asakura, 2017). While some trans/NB adults AFAB may find successful pathways to health promotion outside of the mainstream medical system—such as turning to a social support network or using exercise to promote mental health—there can also be heightened health risks to avoiding care. This is particularly true for medical emergencies, accessing hormones, and dealing with post-surgical complications, all of which were discussed by participants as situations when they or their trans friends have avoided seeking help due to fear of discrimination. Ultimately, what’s most important is promoting the care strategies that contribute to well-being for transmasculine and non-binary adults, whether inside of “mainstream” care or not, coupled with efforts to improve the cultural responsiveness of the healthcare system at large so that trans/NB adults are not forced to deal with discrimination or ignorance when needing to seek medical care. Providers may also benefit from education about how it is the patient’s decision when and where to disclose their trans status.

The present study also documented a commitment to “persisting” with a healthcare system that often is not culturally responsive. This included going through hoops to ensure that transition-related care is covered by health insurance. Others spoke about persistence to receive basic medical care, such as identifying allies within the healthcare system who can help them

get the best care as quickly as possible. Although such persistence was helpful in resisting and reducing transgender stigma, such efforts should not be kept only on the shoulders of trans/NB people (Taylor, 2013). Future interventions might also promote the existence of “allies” and advocates employed within the healthcare system who can be supportive of trans/NB patients and help guide them through bureaucratic hoops and hurdles that often interfere with effective trans/NB care.

Limitations and future research

Although there are strengths to the present study – such as the use of a diverse sample of transmasculine and non-binary adults AFAB – there are also some limitations of note. This study used a convenience sample from one mid-Atlantic urban area. Thus, findings are not transferable to all settings, particularly to transmasculine and non-binary individuals AFAB who are less connected to trans/NB support groups, those in rural areas, and those in other regions of the U.S. or in other countries. Although the study sample was more racially diverse than the general U.S. population, it was less so than the metropolitan area in which participants resided, indicating that the recruitment methods drew a sample that had more White individuals than might be expected for the area. The present study focused on strategies that transmasculine and non-binary adults AFAB use to resist and reduce stigma; these strategies may be similar to or have notable differences from strategies used by transfeminine adults and those assigned male at birth. For example, transfeminine adults may face different barriers, such as the intersection of misogyny and transphobia, discrimination based upon “beauty standards,” being more often perceived as trans, and trying to access HIV services that are advertised as being for men who have sex with men. Such a topic would be worth researching.

Future research could also explore how the strategies used by transmasculine and non-binary adults to counteract stigma in healthcare affect their current and long-term health. Access to rural healthcare for trans/NB adults is also less examined and worth additional research. Finally,

medical care is being greatly impacted by technological advances, such as the use of telehealth, big data, and artificial intelligence, especially with the emergence of the recent COVID-19 pandemic; yet, the consequences of such changes for trans/NB patients in relation to stigma have not been adequately analyzed and deserve future study.

Ethics

This study was approved by the Institutional Review Board at Johns Hopkins University. All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. To maximize confidentiality, no individual identifiers were collected, and no written consent forms were used. Prior to enrollment, all recruited individuals were read the contents of the oral consent form and given ample opportunity to ask questions before providing verbal consent for participation. Verbal informed consent was obtained from all participants included in the study.

Note

1. These data were collected before the publication of the most recent World Professional Association for Transgender Health's *Standards of Care* (version 7), which does not require a patient to obtain a letter from a mental health provider to proceed with hormone therapy.

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ORCID

Kristie L. Seelman  <http://orcid.org/0000-0002-4064-2927>
Tonia Potat  <http://orcid.org/0000-0001-6541-3787>

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