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Trans, Gender Non-Conforming, and Non-Binary Experiences with the US Health Care System

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In comparison to the general United States population, members of the transgender[1] community that are prevented from receiving gender conforming care are 18 times more likely to attempt suicide (Giffort & Underman, 2016). However, when they are allowed to access gender conforming care, the suicide rate drops to a similar level as the general population (Giffort & Underman, 2016). This statistic demonstrates that access to health care has a significant impact on transgender health outcomes; unfortunately, there are several systemic and discrete obstacles that prevent the transgender community from accessing quality health care. In order to find solutions to health care obstacles and improve the health of the transgender community, the obstacles must first be identified. Obstacles to care will be examined in two settings: preventative care and gender conforming care. These two settings are being used because preventative care is the most frequently accessed setting by the transgender community and transgender individuals are the exclusive patients in gender conforming care. Therefore, obstacles in these settings have the most significant impact on the transgender community and solutions are most needed in these areas. After reviewing literature on health care obstacles and the health implications of those obstacles, the following question will be investigated through in-depth interviews: What are solutions proposed by the transgender community to overcome obstacles to health care access?

Preventative Care Obstacles and Health Implications

One of the most challenging obstacles faced by the transgender community when accessing preventative care is finding providers and offices that are respectful and free of

[1] For the purposes of this research, transgender is used as a descriptive of those whose gender identity "transcends, breaks, transgresses, cuts through, or otherwise deviates from traditionally established gender categories" (Wagner, Kunkel, Asbury, & Solo, 2016). When discussing gender identities that deviate from cisgender collectively, transgender will be used as an umbrella term. In instances where a statement applies only to a specific subset of the transgender community, the labels trans, gender non-conforming, or non-binary will be used. Trans in this paper refers to the community typically identified by society and the medical community as transgender.

discrimination. Many people still face disrespect in the form of staff using deadnames and improper pronouns, binary intake forms, and lack of gender inclusive bathrooms (Giffort & Underman, 2016; Wagner et al., 2016; Wylie & Wylie, 2016). This disrespect occurs even in the offices of relatively inclusive providers, conveying the message that health care lacks empathy for the transgender community. Outside of inclusive offices, this lack of empathy may manifest itself as hostility and discrimination. The fear of facing discrimination in a health care setting leads to one in five transgender people not seeking health care in the past year (Transgender Health, 2015).

Although disrespect and discrimination are the biggest obstacles faced by the transgender community when accessing any health care, another barrier in preventative care is the inaccessibility of appropriate care. Appropriate care encompasses health providers being self-educated about trans health concerns, such as the side effects of hormone replacement therapy, and about what health conditions coexist with or are the result of transitioning. The National Transgender Discrimination survey (2016) found that 50% of transgender people surveyed had to educate their health care providers about transgender health concerns; this number rose to 62% for transitioned individuals (Giffort & Underman, 2016). In addition, health care providers that are unacquainted with the transgender community often assume that current health problems a patient is seeing them for, such as ADHD, chronic joint pain, and the flu, result from a transgender identity, even if the conditions existed pre-transition or have no gender basis (Tamarkin, 2015; Wagner et al., 2016; Wylie & Wylie, 2016).

Fear of discrimination and lack of appropriate preventative health care have serious health implications. Avoiding health care due to fear of discrimination, even when health care is needed, can lead to poorly managed mental health conditions like depression, suicidality, post-

traumatic stress disorder, and substance abuse (Reisner et al., 2016). Poor management of chronic mental health conditions leads to less healthy years of life and a shorter lifespan for the general United States population, which includes the transgender community (World Health Organization, 2015). Compared to the cisgender population, the transgender community disproportionately experiences mental health conditions and is more likely to lose healthy years of life and have a shorter lifespan due to a poorly managed mental health condition (Transgender Health, 2015).

Even when transgender patients feel comfortable or desperate enough to access care, the doctors treating them might not know about their gender identity. While some diseases, such as the flu, are not affected by differences in biophysical composition, other diseases, such as dental conditions, have patterns and treatments based on biophysical composition (Wagner et al., 2016). When seeking care, transgender individuals have to decide whether or not to inform their health care provider of their transgender status; if they choose to share this information, they may face discrimination and be turned away (Wagner et al., 2016). If they choose not to share their gender status, then they may face severe medical consequences if the provider pursues a treatment course meant for a biophysical composition the patient does not have (Wagner et al., 2016).

Gender Conforming Care Obstacles and Implications

Services that transgender people may access to conform their mental and physical gender include official name and gender marker changes, hormone replacement therapy, gender occupational therapy, breast augmentation or reduction, and sex reassignment surgery. Gender conforming care is medical support for the "biophysical transition that transgender individuals undergo to 'achieve comfort with the gendered self'" (Wagner et al., 2016). Even though there is the expectation that providers caring for the transgender community would be the most mindful

and accommodating of the community's needs, transgender individuals still face significant obstacles when accessing gender conforming care. One of the biggest obstacles in this facet of health care is the providers' adherence to traditional transgender care plans. Some providers still insist that transgender people change their gender role prior to starting hormone replacement therapy, which is no longer a requirement, or prescribe additional mental health services without evidence that the patient has mental health conditions other than gender dysphoria (Wylie & Wylie, 2016). The adherence to old care plans or prescription of unnecessary treatments creates feelings of distrust between patient and provider that may make the patient avoid seeking further care.

The inaccessibility or avoidance of gender conforming care have serious health implications for the transgender community. For transgender individuals who are unable to access gender conforming treatments, the suicide rate is 19-29%, compared to 1.6% for the general population (Giffort & Underman, 2016; Wagner et al., 2016). For transgender individuals who are able to access conforming treatments, the suicide rate drops to between .8-6% (Wagner et al., 2016). Access to gender conforming care also decreases the smoking rate from 37% to 27% (Giffort & Underman, 2016).

In the literature, lack of respect for divergent gender identities, discomfort, and fear were identified as obstacles the transgender community faces when accessing health care. Serious health implications such as higher rates of anxiety, depression, suicide, and less healthy years of life were clearly linked to those obstacles. Although the existing literature is thorough in identifying health care obstacles faced by the transgender community and emphasizing the importance of finding solutions by highlighting negative health outcomes, it does not address solutions that the transgender community wants to see implemented in order to make health care

more accessible to them. Rather, researchers have proposed their own solutions without consulting the community those solutions would impact. This research aims to bridge this gap in the literature by asking members of the transgender community about their proposed solutions.

Methods

For this research, self-identified transgender, gender non-conforming, non-binary, genderqueer, and similarly identifying participants were recruited through personal emails to respond to an online Qualitrics survey. The participants were also encouraged to spread the survey to other members of the transgender community. An online survey was used as the collection method so that participants could be anonymous and recruited from a wider geographic range. The survey reached nine participants in total; they were students at Michigan colleges and universities, ages 18-25, mostly white-identifying, and a mixture of trans, non-binary, and gender non-conforming. Consent was obtained through a form that required participants to respond before they could proceed to the survey. The survey questions covered three main topics: demographic information (e.g., *what is your gender identity?*), health care experiences (e.g., *"how has your gender identity affected your access and experience with healthcare?"*), and healthcare solutions (e.g., *"what changes to the U.S. health care system could be made in order to provide more competent care for those outside the gender-sex binary?"*). All survey questions were open-ended and optional in order to elicit authentic responses, allow flexibility for a diverse population, and minimize any negative impact on the participants.

Once responses were collected, they were sorted into structural codes and subcodes so that they could be analyzed thematically and related to themes that emerged in the literature review. The codes used to organize the data include demographic information, positive

experiences and emotions, and negative experiences and emotions (see Appendix A). The data was analyzed for recurring words and phrases; based on the patterns that emerged, subcodes were created. Some subcodes, such as *dysphoria after misgendering* and *pronouns were respected,* emerged exclusively from the data itself; other subcodes were created in relation to themes identified in the literature review. Themes regarding health care experiences and obstacles that emerged from the data include conflict about staying closeted to providers, fear or discomfort in doctors' offices, and lack of respect for identity leading to the avoidance of health care. These themes are slightly different than the themes of tough decisions, fear, and benevolent oppression that emerged from the literature review; however, in general, themes that emerged from this data corroborate and expand patterns that have been previously identified. In regards to health care solutions, this data provided new insight to existing knowledge. Whereas the literature identified societal, legal, and policy changes as beneficial solutions, the participants identified much simpler and obtainable solutions. Examples of solutions include intake forms that provide alternatives to the gender-sex binary, better education for medical professionals, and office level options to indicate preferred name and pronouns.

Findings and Discussion

Key themes regarding health care experiences that emerged from the data include feelings of fear and discomfort, tough decisions, benevolent oppression, and lack of respect for divergent gender identities. This research revealed that feelings of fear and discomfort do not originate from overt discriminatory experiences for most people. One participant remarked that they do not "openly say much about [their] gender" and "fear that [doctors] may treat [them] differently." This participant also commented that while seeing a doctor other than their primary care physician, the doctor "looked at [their] pronoun comments on the intake form and then

proceeded to ignore them." This participant's experiences highlight that first-hand experiences with overt discrimination is not the primary cause of patient fear and apprehension. Instead, negative feelings often emerge when patients try to be open about their identity and face a lack of support and respect. These experiences occur within a larger context of transgender patients being abused or refused care and are consistent with the finding that about one in five transgender people avoid seeking medical care due to fear of discrimination (*Transgender Health*, 2015). As established in the literature, avoidance of medical care has disproportionate and severe health implications for the transgender community.

Even well-meaning and open-minded doctors who try to avoid systemic discrimination can create discomfort through benevolent oppression. Benevolent oppression refers to doctors attempting to validate transgender identities in ways that the patient did not perceive as being supportive (Wagner et al., 2016). Examples of benevolent oppression include excessive questioning of a patient's gender identity and asking the patient to educate the provider about the transgender community. A trans respondent said their doctor's expectations for them to educate him about trans history and health concerns "made [them] prevent seeking care when [they were] ill…[they] couldn't imagine talking to that physician again." Despite being accepting of their identity, their doctor nevertheless caused similar feelings of apprehension and discomfort that the previous participant mentioned when their pronouns were not respected. Ultimately, the end result of that discomfort, in this case caused by benevolent oppression instead of systemic discrimination, is the same—the patient started avoiding medical care.

The feelings of fear and discomfort transgender patients experience when accessing health care are compounded when they have to decide whether or not to inform their providers about their true gender identity. For several of the participants, deciding whether or not to stay

closeted was a tough decision. If a patient decides to stay closeted, then they experience fear and discomfort about the doctor using the wrong pronouns. A closeted respondent to the survey said that because she stays closeted, she is "sometimes misgendered, and that negatively affects [her] experiences." On the other hand, if the patient decides to inform the doctor about their identity, the feelings of fear and discomfort may still exist due to open discrimination or a lack of respect for the newly revealed identity. Four participants in the survey indicated that even after revealing and reasserting preferred names and pronouns, the doctor and their offices "misgendered [them] regularly." Their doctors' refusal to use indicated names and pronouns is yet another manifestation of systemic discrimination, which often had powerful consequences. One participant indicated that after medical experiences where they were misgendered, their dysphoria and anxiety increased. This means that avoidance of medical care not only results in poor management of chronic mental health conditions like anxiety, but seeking medical care that is not affirming and supportive can in fact escalate mental health conditions that often accompany transgender lived experiences

Feelings of fear and discomfort, benevolent oppression, lack of respect, and tough decisions are the underlying factors that impact the transgender community's health outcomes. These factors contribute to the increased avoidance of health care for this community; avoidance of health care, in turn, leads to worse health outcomes and shorter life span. Due to the significant impact that health care experiences have on transgender health outcomes, it is important to implement solutions that will minimize negative experiences and foster a better relationship between the transgender and medical communities. A solution identified by four participants and supported by the literature was increased sensitivity and medical training for all medical professionals (Wagner et al., 2016). Better training would likely help decrease instances

of systemic discrimination and benevolent oppression; for example, if the primary care physician of the trans patient that asked them to educate him had been better educated prior to caring for them, the doctor could have informed and guided them instead of the other way around. Feeling confident in and supported by their doctor, the participant would likely have a better relationship with health care.

Another solution that was offered by survey participants was creating a system to indicate preferred name and pronouns. Currently, intake forms do not have sections that allow patients to passively indicate their gender identity. Instead, patients have to write in their preferences or ask their providers to make a note in their chart. One trans participant remarked that her office still "dead named [her]," even though it was "on file to call [her] by [her] preferred name." Creating a better system to normalize chosen names and pronouns would significantly improve transgender health care experiences; six of the participants mentioned respect of their identity, name, and pronouns in the positive experiences section of the survey. Participants remarked that it made them feel "amazing" and "fantastic" to have their real identities recognized by their doctors; one participant said that they "almost cried" when they were called by their chosen name. Access to gender affirming medical treatment has significant implications; as discussed in the literature, when patients receive gender conforming care, rates of suicide and smoking decrease. Using preferred names and pronouns and showing respect towards a patient's identity is an extension of gender conforming care that the survey participants indicated has a similar beneficial impact as physical gender conforming treatments. Therefore, finding solutions to educate and encourage providers to be more supportive of the transgender community is of the utmost importance.

Limitations and Future Directions

Through an online survey, this research was able to reach nine transgender participants with trans, non-binary, and gender non-conforming identities. Although the data collected from the participants corroborated with and expanded existing data from other literature, this study nevertheless has some limitations. One of the biggest limitations is the small number of participants. However, it seems that this survey data was close to saturation; very few new themes were revealed as more participants responded. Another limitation is that most of the participants identified as white university students; the nature of the survey format and the personal contacts who were recruited to respond to the survey likely influenced this. In future studies, more diverse methods of recruitment could be used, such as through a local LGBT+ resource center.

Although this data has some limitations, it is valuable because it supplements the research that features transgender stories and perspectives. A small proportion of the literature contains personal anecdotes or perspectives from members of the transgender community. Creating more research that contains transgender perspectives is important because even though health professionals are able to suggest changes to the health care system, they do not have to live with those changes. By recruiting transgender perspectives, new and innovative solutions—such as the implementing of a name and pronoun recognition system—can be discovered.

Future studies can build upon this research by including more experiences and recommendations from the transgender community beyond the white and educated; perspectives from transgender people of color would be especially valuable considering that racial and gender identity both affect health care access, experiences, and health outcomes. In addition, future studies should aim to recruit more participants, as current qualitative research with the

transgender community has small sample sizes. Ultimately, the goal of future studies examining transgender healthcare inequality should not be solely to reassert that inequality exists and has consequences. Rather, research should be focused on discovering transgender community suggested solutions and improvements to make health care equality more attainable for the transgender community.

Conclusions

Through this research, new solutions to health care obstacles faced by transgender people were identified. These solutions include intake forms that provide alternatives to the gender-sex binary, better education of medical professionals, and office level options to indicate preferred name and pronouns. Unlike solutions proposed by previous research, these solutions can be implemented on an individual basis without changes to national health care policy. Although larger changes are necessary and are important for achieving health care equity, it may be effective to start on a smaller scale so that obstacles facing local transgender communities can start to be eliminated. This research also provides the valuable insight that the transgender community has feasible solutions to the obstacles they are personally facing. Since members of the transgender community face obstacles when accessing care, they often move between providers until they find one that respects their identity. Unlike doctors who likely only have experience with their own offices, transgender individuals can provide information about different office policies that serve them the best and policies that do not. For example, one participant drew their idea about the creation of alternative intake forms from forms they had seen at Planned Parenthood. Other members of the transgender community would likely have similar, beneficial insights to share with the medical community if they were included in health care equality discussions.

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Appendix A: Survey Code Book

Category	Code	Frequency	Participant Number
Age	**1**		
18-24	1a	9	1 through 9
Location	**2**		
West Michigan	2a	5	1, 2, 3, 4, 5
East Michigan	2b	4	6, 7, 8, 9
Gender Identity	**3**		
Transgender	3a	3	2, 4, 5
Non-Binary	3b	4	1, 3, 6, 7
Gender Non-Conforming/Other	3c	2	8, 9
Race Identity	**4**		
White	4a	7	1-4, 6-8
Not White	4b	2	5, 9
Recommended Changes to Health Care System	**5**		
Better/more education on LGBT+ issues	5a	4	1, 2, 3, 7
Open doctor-patient communication	5b	2	1, 3
Insurance coverage for gender services	5c	1	4
Less mental health involvement (gender conforming care)	5d	1	4
Intake forms that differentiate gender/sex	5e	2	1, 2
Options to establish preferred name/pronouns	5f	2	5, 6
Consistency with preferred name/pronoun use	5g	2	5, 6
Nature of Intake Forms	**6**		
Alternatives to gender/sex binary	6a	3	1, 4, 6,
No alternative encountered	6b	4	2, 3, 5, 7
Forced to use legal name	6c	1	2
"Other" for sex (for intersex)	6d	2	1, 6
Pronoun option	6e	1	6
Negative Experiences and Emotions	**7**		
Dysphoria after misgendering	7a	4	3, 4, 6, 7
Consistent misgendering	7b	4	3, 4, 5, 6
Internal conflict about outing/staying closeted	7c	3	1, 3, 7
Fear for safety, discomfort in doctor’s offices	7d	4	1, 2, 3, 4
Avoid seeking medical care	7e	3	1, 2, 6
Asked to educate the doctor	7f	1	2
Misgendering in preventative care procedures (pap smear)	7g	1	2
Financial/physical/numerical accessibility lacking	7h	1	1
Positive Experiences and Emotions	**8**		
Respect of name/pronouns	8a	5	2, 3, 4, 5, 6
Allowed to change identity/express true self	8b	2	2, 3
Transparency and respect	8c	2	1, 4