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The Varied Experiences of Nonbinary Patients in a Healthcare Setting

By

Rosemary Leo

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Faculty Advisor: John Schneider

Preceptor: Alex Flores

Abstract

The experiences of nonbinary patients in a healthcare setting are diverse, ranging from typically affirming of their gender identity to instances of blatant discrimination or mistreatment. While a positive experience can allow nonbinary patients to trust in their healthcare provider, a negative experience may lead patients to avoid healthcare settings or be reserved in what information they are willing to share about themselves. In order to ensure that nonbinary patients receive high quality and equitable treatment, the specific needs and preferences of nonbinary individuals need to be taken into account. To achieve this, this study aims to improve the current understanding of how nonbinary people are treated in a healthcare setting, as well as identifying common concerns for nonbinary patients. Nine participants were asked in an interview about their experiences in a healthcare setting and general opinions of what changes would allow them to feel more comfortable receiving care. While responses of participants were varied based on their personal experiences and preferences, it is evident that their impressions of healthcare settings could be improved by using more gender neutral language to refer to patients, avoiding intentional or unintentionally harmful behavior such as misgendering or avoiding nonbinary patients, and having healthcare providers be better informed about treatments that might be relevant or effective for their nonbinary patients.

Introduction

There is an inequity in healthcare experienced by individuals who identify as nonbinary, or otherwise gender nonconforming, which needs to be addressed. A lack of inclusion of identities that differ from singularly male or female is apparent in previous research, despite the existence of nonbinary individuals being acknowledged by multiple disciplines. This is also seen

in the healthcare field, which often fails to provide suitable healthcare for nonbinary individuals. The goal of the current study is to contribute towards an increased awareness and understanding of the experiences of nonbinary individuals in a healthcare setting. By identifying issues and ways that healthcare environments can be improved, it will be possible to start addressing the current inequity in healthcare experienced by nonbinary individuals.

When there are barriers to communication between patients and healthcare providers or medical staff, there is an impact on the quality of healthcare that an individual receives. A patient may find it difficult to reveal crucial information that could assist healthcare providers in diagnosing a health problem or in prescribing suitable treatment for an issue. This can be seen specifically in the way many healthcare providers approach nonbinary patients, either being dismissive of their gender identity or lacking a proper understanding of how to communicate with them. A lack of understanding of what nonbinary genders are can result in nonbinary patients finding it difficult to convey their health concerns, or feeling unsafe to reveal information about themselves. Nonbinary patients experience situations such as providers not understanding how to treat them, healthcare providers making incorrect assumptions about what health concerns are relevant to them, and sometimes even experiencing outright hostility from healthcare staff while receiving treatment. Either from a lack of knowledge or lack of acceptance of nonbinary gender identities, there are obstacles that nonbinary patients have to overcome when communicating with their healthcare providers and healthcare staff members. Determining how healthcare workers can communicate more effectively and respectfully with their nonbinary patients is important to ensuring that nonbinary individuals will receive quality healthcare.

Although the existence of nonbinary genders has multidisciplinary support, the majority of studies utilize a gender binary when recording the gender of participants. There has been an

insufficient number of research studies that include nonbinary or gender nonconforming options as part of their sample, and even fewer studies focus primarily on this demographic. As a result, the issues faced specifically by nonbinary individuals are not adequately addressed. By including nonbinary and gender nonconforming individuals as a demographic option in more studies, research will be able to more accurately assess what outcomes are influenced by gender identity. If nonbinary gender identities are the focus of more research studies, it will become possible to identify issues which are specific to their experiences. In both these situations, there is a benefit for individuals who identify as nonbinary or otherwise gender nonconforming. By including genders other than male or female, research can increase both accuracy of results and awareness of nonbinary centered issues that should be addressed. Research as a field also stands to benefit from being more inclusive, since it will broaden the scope of knowledge about nonbinary individuals, who are a growing demographic whose distinct identities should be more widely acknowledged.

Previous Research

The concept that gender is not a binary structure has multidisciplinary support, which indicates that nonbinary identities should be more widely accounted for in research (Hyde, Bigler, Joel, Tate, & van Anders 2018). Using a strictly binary categorization of gender excludes individuals who do not adhere to the currently commonly applied gender binary (Eliason, Chinn, Dibble, & DeJoseph 2013; Koehler, Eyssel, & Nieder 2018). If a group of individuals is excluded from research, it becomes difficult to accurately make inferences about that demographic, or about the impact of gender on study results. Although the existence of nonbinary genders has multidisciplinary support, research has a tendency to exclude individuals

who identify outside of the gender binary (Fiani & Han 2018). The National Science Foundation regularly surveys the demographic information of students and researchers with the option of ‘male’, ‘female’ or ‘do not wish to disclose’, which does not account for individuals who have another identity that they would be open to reporting (DeHority 2021). A study of intake forms provided by mental healthcare providers found 56.9% of forms included transgender and nonbinary gender affirming language, with only 6% of forms providing a space to specify preferred pronouns (Holt, Hope, Mocarski, & Woodruff 2019). In both broad surveys and in settings which involve more direct interactions, there is a lack of awareness of nonbinary genders. Even though there is an understanding that gender identity is not binary, research is continuing to exclude nonbinary gender identities.

The lack of research including nonbinary individuals can be seen in the policies which are created, both by the government and individual organizations. There are situations where nonbinary identities are not taken into consideration where it would be appropriate to do so. Many forms of identification will not use a person’s preferred name unless it has been legally changed, and instead may use a name which a nonbinary or transgendered individual feels uncomfortable with. An incorrect name on identification can also lead to individuals being called by the wrong name, which causes discomfort for the individual being misidentified (Coombs & McCarthy 2020). There are laws which permit discrimination against transgender and nonbinary individuals and reinforce social stigmas (American Public Health Association 2016; Murib 2020). The presence of governmental or organizational policies which are hostile towards transgender and nonbinary individuals contributes towards inequitable treatment of individuals who do not identify as male or female.

In many places in society, transgender and nonbinary individuals face threats to their safety in addition to discrimination. Transgender and gender nonconforming individuals are often the victims of violence in the United States, with a high number of reports indicating that these groups are at a risk for assaults beginning at a young age and will often experience violence in response to perceived gender nonconforming behavior or appearance (Stotzer 2009). Being at a higher risk of violence, nonbinary and transgender individuals are under stress in environments which risk their safety. Transgender and nonbinary individuals may avoid seeking healthcare, either with safety or financial concerns (Kachen & Pharr 2020). Nonbinary individuals may further avoid identifying as their preferred gender in medical settings, in order to avoid potential mistreatment. There is a risk of receiving poor or improper treatment when seeking healthcare from a provider who is not accepting of transgender identities.

The prevalence of nonbinary genders is not often acknowledged in the medical field, which can be seen in healthcare research that excludes nonbinary identities as a demographic. Although surveys have been shown to have a higher predictive abilities when including nonbinary and gender nonconforming identities, healthcare studies still typically utilize a binary classification (Lett & Everhart 2022). Failing to account for nonbinary individuals results in many healthcare facilities utilizing a binary-focused treatment, which may obstruct nonbinary individuals' access to transgender specific healthcare, as well as prevent these individuals from being able to articulate their needs to healthcare providers (Koehler et al., 2018). With these obstacles present, it becomes difficult for nonbinary individuals to self-identify with their preferred gender and pronouns. With this increased difficulty in self-identifying, coupled with the potential safety risks to identifying themselves to someone who may become hostile towards

them, it becomes increasingly unlikely that nonbinary patients would be able to freely seek healthcare without encountering some type of issue.

There is a need for healthcare providers to be more widely informed of nonbinary genders in order to provide proper treatment to nonbinary patients. Forcing individuals to identify themselves on a gender binary may be misleading and cause confusion among healthcare providers when a nonbinary or trans individual is seeking gender specific healthcare (Eliason et al., 2013). Currently, there is no widespread protocol in place for how to accommodate nonbinary patients, so such a protocol should be developed in order to ensure that nonbinary individuals are receiving quality healthcare (Richards et al., 2016). The lack of accommodation for nonbinary individuals also means that there is not much known about healthcare issues which are specific to nonbinary individuals. This lack of awareness about nonbinary specific health issues has resulted in an unequal treatment for nonbinary patients. One example of the inequity faced by nonbinary individuals is that a healthcare setting may not be comfortable or safe environment as it is for individuals with a single binary gender. For some nonbinary individuals, identifying as their preferred gender can result in being mistreated or discriminated against, which can lead to them being unwilling to disclose their identity in order to ensure their own safety or comfort. Even in situations where a healthcare provider might be well intentioned, a lack of understanding of a patient's gender identity can result in a provider making assumptions or misgendering an individual. These are uncomfortable situations for nonbinary individuals, who may be less likely to seek treatment for medical issues as a result. Nonbinary individuals would benefit from being more widely recognized so that healthcare providers can better meet their needs (Eliason et al., 2013; Koehler et al., 2018; Richards et al., 2016). If there was a greater awareness of nonbinary individuals and their specific healthcare

needs, healthcare providers would be able to reduce the prevalence of intentional and unintentional mistreatment.

It is necessary to have an environment which allows healthcare providers to provide appropriate, high quality healthcare. A positive environment in a healthcare setting is able to improve patient outcomes, which includes increasing patient safety and potentially reducing healthcare costs (Stone, Hughes, & Daily 2008). In order to see those positive outcomes in practice, it is necessary to determine what would create a positive environment for all patients.

Having good communication between providers and patients is associated with positive healthcare outcomes (Schoenthaler, Knafl, Fiscella, & Ogedegbe 2017). The communication between a patient and their healthcare provider impacts the quality of healthcare that the patient receives. When a healthcare provider has good communication skills that are able to address a patient's individual needs, this can further engage a patient with their own healthcare and result in more effective and safe treatments (Reynolds 2009). A collaborative style of communication, in which healthcare providers work together with patients to come to a decision, has been found to be associated with a higher vaccine compliance rate (Moss, Gilkey, Rimer, & Brewer 2016). These results suggest that when providers actively work together with patients in the decision-making process, it can have beneficial effects. One instance of this is a study which found that focusing on biomedical issues rather than engaging with the patient and addressing socio-demographic concerns is associated with poor medication adherence among hypertensive patients (Schoenthaler et al., 2017). This suggests that providers should tailor their visits to address the needs of the specific patient, rather than focusing predominantly upon conveying only the basic medical information. Doing so may improve the degree to which patients adhere to their medication regimen. Several studies have found that when providers address the needs

and concerns of patients, those patients report higher quality of care and feelings of self-efficacy (Moreno et al., 2019; Palmer et al., 2014). One study reported that patients who are younger, more highly educated, female, have a less severe illness and who have an active coping style, are more likely to prefer taking a more active role in the decision making process (Arora & McHorney 2000). The disparity between different demographic groups suggests that different types of patients have different needs in regard to how healthcare providers communicate with them. Since effective communication is associated with higher healthcare quality, and different demographics have different needs for what style of communication is most effective, research should try to address the disparities that exist in how likely a patient is to be able to effectively communicate with their providers by examining different demographics individually.

Potential barriers to communication have been seen among various demographic identities. Several studies have found differences in effective communication between patients and healthcare providers resulting from race, with Hispanic and Asian individuals both reporting poorer patient-provider communication than white individuals (Moreno et al., 2019; Moss et al., 2016; Palmer et al., 2014). These results suggest that demographics play a role in the quality of communication between healthcare providers and patients. Considering this, there is a concern that nonbinary individuals may experience this problem, since their identity is commonly not accounted for by healthcare providers (Eliason et al., 2013). Although there is a lot of variation among those who identify as nonbinary, the lack of comprehensive knowledge about nonbinary genders may result in a similar impact as the disparities seen among other minority demographics. Gender nonconforming individuals have reported poorer health than binary transgendered individuals (Burgwal et al., 2019). In order to determine how communication with healthcare providers can be improved for nonbinary individuals specifically, it should first be

established what nonbinary individuals consider to be productive and what they consider to be detrimental to their experience when seeking healthcare.

For nonbinary individuals seeking mental health counseling, a study by Michelle Farrell in 2018 found that nonbinary individuals consistently reported how important it was to them that counselors validated their experience by expressing support. Nonbinary individuals also preferred to have autonomy and control over what issues are addressed, conduct sessions in a safe environment, and be able to trust their counselor. Particularly valuable to nonbinary individuals was having a counselor who could provide them with resources to empower themselves. Additionally, it was found that common issues for nonbinary individuals involved counselors making assumptions that the patient's experience would match a particular narrative, as well as counselors instigating unwanted discussions about the patient's gender identity (Farrell 2018). Poor mental health and stress can lead to a decline in physical health (Debora, Baba, & Gomathi 2018; Shaffer-Hudkins, Suldo, Loker, & March 2010). Where attempts are being made to improve mental healthcare for nonbinary individuals, similar strides need to be made in other fields of healthcare in order to ensure proper care in all aspects of nonbinary healthcare.

Among healthcare providers, a lack of understanding of what nonbinary genders are can result in nonbinary patients finding it difficult to convey their health concerns. Nonbinary patients may face discrimination from healthcare providers (Kattari, Bakko, Hecht & Kattari 2020). This discrimination includes misgendering them or using the incorrect name for them, as well as denying them medical care or refusing to offer the same treatments that would be offered to male or female patients. Some instances of discrimination are unintentional and could be the result of a lack of information about the experiences of nonbinary patients. Nonbinary individuals are seeking gender-related treatment with increasing frequency (Richards et al.,

2016), leading to a need to examine the ways healthcare can be improved for nonbinary patients. In order to accomplish this, it must be determined what constitutes good healthcare for nonbinary and gender nonconforming individuals. In order to accommodate nonbinary patients, their personal experiences with healthcare should be examined in more depth.

The current study seeks to gain more insight into the experiences of nonbinary patients, examining potential obstacles to open communication and instances of inequitable treatment. Since good communication is associated with better quality healthcare (Schoenthaler et al., 2017), and since there are obstacles that nonbinary individuals face when seeking healthcare (Eliason et al., 2013; Koehler et al., 2018), there is a specific need to examine the healthcare experiences of nonbinary individuals. By examining a range of topics that nonbinary individuals encounter in a healthcare setting, the current study aims to improve the experiences of nonbinary individuals, allowing healthcare workers to provide the healthcare benefits that are associated with a positive and safe environment. This will also contribute towards a broader understanding of what nonbinary individuals are experiencing when seeking medical care, as well as contributing towards the knowledge of how the language used by healthcare workers impacts nonbinary patients. This study includes both nonbinary individuals with positive and negative experiences in a healthcare setting, identifying what approaches should be used when creating a positive environment for patients.

Methods

The current study used a qualitative interview to examine the experiences of nonbinary patients when seeking healthcare. Recruitment took place using physical and electronic flyers, which provided an email or phone number for interested participants to contact. After being

contacted by email or phone, participants were sent a pre-screening demographics questionnaire which determined their eligibility to take part in the interview. The requirements for participation was that participants needed to be over 18, identify as nonbinary or another gender aside from singularly male or female, and needed access to the internet to complete the interview.

Participants who qualified were contacted by email or phone to set up a time to conduct the interview over Zoom. After consenting to participate and to be recorded for the purpose of later transcription, participants completed the interview which was scheduled to take 30 to 45 minutes. Following the interview, participants were given \$25 as compensation for their time.

Of 10 participants who qualified to participate and were recruited, nine completed the interview in its entirety while one participant decided not to include their interview responses in the study. All participants were adults over the age of eighteen, with six included participants listing their age as 25 to 34 and three participants listing their age as under 25. The participants who completed the interview included seven nonbinary participants, one genderfluid participant, and one participant who reported being both nonbinary and genderfluid. During the interview, several participants who had identified as nonbinary on the demographics survey later reported a more complex response to being verbally asked what their gender identity was. Some participants identified with multiple genders and had multiple preferred pronouns, with two participants using both they/them and he/him pronouns with a preference towards they/them pronouns. Another participant reported that they liked to use multiple terms for their identity, including nonbinary, agender and genderqueer. A fourth participant explained in the interview that their identity was both nonbinary and gender fluid.

The demographic identities reported in the screening survey were primarily Caucasian, with one participant reporting that they were Black or African American, one reporting that they

were Hispanic or Latino, and one reporting that they were mixed race Asian or South Asian and Caucasian. Participants recruited were primarily located in the Chicago or Boston areas, although some reported during the interview that they had recently moved from various southern states. Three participants reported having a chronic illness. The education level reported by participants included four participants with a 4-year degree, three with a Master's degree, one with some college but no degree, and one with a high school diploma/GED. The relationship status of the study participants was that four participants were single, two were in a monogamous relationship, one was in an open relationship, and two were in a polyamorous relationship. The intention of the study was to include individuals with different life experiences that might potentially impact their experience when seeking out healthcare, such as having a partner's support or dealing with a chronic illness. This was to ensure that a broad range of experiences would be taken into account. The demographic information of the interview participants indicates a range of life experiences.

The target demographic of the current study was nonbinary or otherwise gender nonconforming adults. This includes individuals who identify as nonbinary, agender, genderfluid, and transgender. A nonbinary person is an individual who identifies as a gender that is not male or female, and this is often used as a generalized term for any person whose identity is outside the gender binary or male and female. An agender person is an individual who identifies as genderless or otherwise without a gender identity. A genderfluid identity indicates that an individual identifies as male or female at different times, in some cases identifying as both male and female or as neither. Being transgender indicates that an individual identifies as a gender that differs from their biological sex. In this study, transgendered individuals either identified as having multiple gender identities, such as identifying as male in addition to their nonbinary

identity, or they identified as being a nonbinary transgendered individual. Transgender is a term which can be used as an umbrella term that includes nonbinary, similar to how nonbinary can sometimes be an umbrella term which includes multiple gender identities. The term transgender can refer to having a binary gender that is opposite to one's birth sex, or it can include multiple identities which are not male or female. However, the focus of research is often on male or female transgendered individuals, rather than nonbinary transgendered individuals. In order to focus more specifically on the obstacles faced by individuals who identify outside the gender binary, the study examined only nonbinary transgendered individuals and others with identities that were not singularly male or female.

The focus of the interview was identifying common or unique issues encountered by nonbinary patients within various healthcare settings. In order to achieve this, the interview included questions about their experiences from their experiences with intake forms, healthcare staff, and healthcare providers themselves. Questions were framed as open-ended in order to allow participants to speak freely about their experiences and opinions about how they would prefer their healthcare visit to be conducted. During the interview, unscripted follow up questions were asked to prompt participants to further elaborate on their responses. All responses that patients consented to include in the study were recorded and later transcribed with identifying information redacted. After transcriptions of the interviews were complete, all recordings of the interviews were destroyed with the exception of one recording, which was sent to the affiliated participant for their personal records. Transcripts and survey information were stored on UChicago Box, a secure cloud based storage. The study was determined to be exempt from further review by the University of Chicago Social and Behavioral Sciences Institutional Review

Board. Participants gave written and verbal consent to participate in the interview prior to participating and being recorded.

Results

The interview process began by asking participants for their gender identity and preferred pronouns. These questions were included to establish the gender identity of the participants, confirming that each participant had a nonbinary gender identity. It also made it possible to determine which individuals had male or female as part of their gender identity, which would allow them to use an accurate gender identity in instances where other participants would not be able to. Of those participating, several used male or female as part of their gender identity, one used both as part of a genderfluid identity, and most used neither male nor female as part of their identity. In addition to determining the demographics of those participating in the interviews, asking for their gender identity and preferred pronouns was a way of establishing a respectful rapport between the interviewer and the participants. Some participants were not entirely certain about the best way to describe themselves, with a tentative gender identity label being expressed with a remark that it has changed recently or may change in the future. Others expressed their identity simply with little explanation beyond the terminology for their gender. All participants knew their preferred pronouns and were most able to respond to the questions straightforwardly. A couple participants responded that they were still figuring out their specific gender identity. All participants used they/them pronouns, with a couple participants using he/him, and one using he/she/they pronouns. These responses do not encompass all possible genders or pronouns, and others who were not a part of the study but who identify as nonbinary or are otherwise gender nonconforming may have different responses to these questions. Of those who participated in the

study, there was a consensus that they/them pronouns were acceptably gender neutral. Many participants expressed a desire for gender neutral pronouns to be used by default. It was expressed that doing so may mitigate the risk of misgendering patients in a healthcare setting.

Issues Experienced by Gender Nonconforming Patients

Participants were asked whether their gender identity had ever been an issue at a doctor's visit or medical setting. Some participants did not find their gender identity to have been a problem in a medical setting. One reason given for this was that some participants had recently transitioned and had not experienced many medical visits while identifying with their current gender identity. For other participants, they did not consider their identity to be the source of any issues because they would avoid revealing their gender identity in any setting where they were not confident they would be safe. In contrast to those who did not find that any issues arose as a direct result of their gender identity, several participants responded that they had experienced treatment that made them personally uncomfortable. Of those who responded this way, a common experience was being treated a certain way based on their biological sex or apparent gender. A common negative experience was being misgendered, either directly or being spoken of in a way that the participants overheard themselves being misgendered. All participants, regardless of whether they reported being misgendered, expressed that they were concerned about the prevalence of healthcare staff misgendering patients.

The threat of experiencing others misgendering them, or of receiving overly gendered treatment based on incorrectly perceived gender identity, was considered a significant occurrence among all participants. Several patients felt that this was more common outside of a healthcare setting, but also stated that they made a point to specifically seek out LGBT focused healthcare

centers, which would be more likely to be sensitive towards patients' gender identities. Those who had received care outside of such a setting, or who had identified as a nonbinary gender for a longer period of time, reported that they had experienced being misgendered frequently in a healthcare setting. The participants in this study all reported some method of trying to avoid occurrences of being misgendered. In some instances, patients would do research into potential providers to ensure that they would be more likely to be open to different genders and sexualities. Other participants reported that they would avoid going to the doctors entirely unless absolutely necessary, in order to avoid being in an uncomfortable situation. One participant explained that they would try to appear masculine in order to access care. These behaviors are a concern to ensuring quality healthcare for several reasons. Patients who have to do extra research to ensure their own comfort and safety are limited in their options of where they can receive healthcare, as well as putting on an additional amount of work on themselves whenever they need to receive care. The patients who avoid receiving healthcare entirely are much less likely to receive healthcare when they may need it, particularly in regard to preventative care that could reduce future health complications. Similar to how one patient would put on a masculine appearance and adjust their behavior to appear as a man, it was common for participants to alter their behavior in some way, either by omitting information about themselves or by acting in a way that might ensure their safety from negative or harmful responses. Although not every participant reported their gender identity being an issue, participants all reported either changes in behavior or an avoidance of healthcare settings.

Accommodations for Self-Identification

To examine the prevalence of accommodation provided for nonbinary patients, participants were asked if they were ever provided with forms that allowed them to specify their gender identity or preferred pronouns, and if so, how frequently they received such forms. Several participants reported receiving these forms, but explained that this was infrequent and typically only seen within LGBT focused healthcare centers. The majority of participants responded that they did not ever receive a form which would allow them to specify their gender identity. For those who had received such forms, it was still common to experience being misgendered in spite of what was written on the forms. The lack of proper identification, even where forms were provided that allowed participants to specify their identity, was a source of frustration and damaging to the trust participants had in their providers or healthcare staff. In response to being asked how they would respond to a form not allowing them to specify their gender identity, participants reported several different ways of addressing a lack of gender options or pronoun options on intake forms and other medical forms. In some cases, participants would put their biological sex, even if it felt inaccurate. Some participants reported that they would write in their preferred pronouns or gender identity alongside their biological sex. Several participants mentioned after being asked these questions that they preferred forms with open ended options where they could self-identify. This indicates that even where an option to identify is present, it may be best to provide room for participants to self-identify in order to ensure accurate responses about their current gender identity. If this space is not provided by a form, or is subsequently ignored, it can give the impression to patients that the facility is not welcoming or trustworthy, resulting in patients limiting the amount of information they are willing to disclose about themselves.

Following up on how willing participants were to disclose about their gender identity in a healthcare setting, participants were asked whether they typically told their doctor or medical provider their gender identity. Two participants said that they typically did tell their doctors, while the majority of participants said they would not. When following up on this question, participants who did disclose their identity elaborated that it was typically a doctor that would bring it up first. Both of these participants further explained that they may not offer their gender identity in instances where it did not feel relevant. One participant listed the dentist and optometrist as settings where they would not bring up their identity, while the other told a short anecdote about their dental hygienist who had identified that the participant was not cisgender. This participant recalled that they had a very pleasant experience and thought highly of this hygienist, having an overall better experience than they usually did. Other participants in the study also reported pleasant experiences with healthcare staff who were able to identify that they were not cisgender, although this was not universally the case. These experiences suggest that even in settings that might seem irrelevant to gender identity, such as healthcare settings which are focused on care unrelated to an individual's sex or experiences, being referred to by their proper name and being correctly gendered can contribute towards a positive experience. Of the many participants who responded that they did not report their gender identity, or who would only bring up their gender rarely when asked directly, several expressed that they would feel more comfortable bringing up their identity in an environment focused on transgender healthcare. Many of these participants also expressed that their preference would be for the healthcare provider or staff to bring up their identity first, in a straightforward or casual manner. Doing so was said by these participants to be an action which would lead them to feel more positive towards the provider or staff member, potentially improving their overall experience.

Varied Reactions to Gender Nonconforming Identities

To broadly examine the experiences of participants when interacting with healthcare providers and staff, the next interview question asked what reactions doctors and staff had towards participant's gender identity. The most common reaction reported was general confusion, such as uncertainty towards how to refer to the patient or being unsure of what treatments would be relevant for the patient. One example of this is staff at a gynecologist's office being unsure of whether the patient should be seeking treatment there, and once it was confirmed that they should be there, the staff still did not know how to approach the patient and would frequently ask the patient how to proceed. Another common experience was for doctors or healthcare staff to either ignore or be dismissive of participants' gender identities. There were even several participants who reported hostile responses to their stating their gender identity. One participant recounted receiving top surgery, with some nurses and staff being friendly and encouraging but at the same time receiving cold or hostile reactions from other staff members. They described how some nurses were sweet while others acted angry about their being there, doing things such as refusing to allow their visitors entry and generally making the experience unpleasant. This level of unprofessional behavior and discrimination was very harmful, and created a hostile environment during what should have been an exciting and positive experience. While the general policies of hospitals and healthcare clinics should discourage discriminatory behavior and mistreatment of patients, it does not always prevent it from happening. The responsibility for protecting patients is on those providing care, meaning that it is vital that hospitals take steps to try to train their staff on how to act towards nonbinary patients to avoid

causing harm. In some instances, even healthcare staff with good intentions can say or do misguided things which can make patients feel uncomfortable.

Following up on what reactions participants experienced when interacting with healthcare providers and staff, participants were asked if they had encountered healthcare providers or staff who were well intentioned but confused. The majority of participants reported encountering healthcare staff who gave the impression that they had good intentions but would still make mistakes. Participants felt that there was generally a lack of understanding of their gender which would result in an otherwise supportive individual using incorrect pronouns or otherwise creating an awkward or frustrating atmosphere. Several participants attributed this to a gap of knowledge among individuals in a particular demographic, which they felt was typical among individuals who were older, cisgender, or male healthcare providers. Other participants felt that the lack of knowledge stemmed from a lack of experience, leading to them having better experiences in settings which were more focused on providing healthcare to LGBT individuals. One participant recounted an experience with a doctor who was doing her best to be accommodating and provide care, trying to avoid “gatekeeping” since she had heard that this was something that was a bad thing to do to trans people, but ultimately needing to rely on the patient to text a friend and do research into the treatment they were seeking for themselves during their appointment. Situations such as this could be avoided by providers taking time to be informed on the treatments that a patient may be seeking from them, either staying informed of the topic themselves or being able to direct patients to relevant resources. Relying entirely on the patient to bring in the needed information is not a viable solution, even if a provider is otherwise welcoming and manages to create a good rapport with their nonbinary patients. A patient may not always have the answers a

doctor needs in order to provide suitable treatment, and this may limit how effectively a healthcare provider can treat their patients.

While there are still issues which arise where doctors are well-meaning, there are far more frequent issues resulting from providers and staff who mistreat nonbinary patients. The participants in the study reported issues such as needing to change providers or feeling blatant hostility from those they are meant to receive care from. Participants were asked about whether they had experienced microaggressions such as being talked about as though they were not present or being the target of unsolicited remarks about their gender identity. About half of participants reported being the target of microaggressions, Most commonly, this was in the form of gender stereotypes or assumptions based on their perceived gender or biological sex. Examples of these microaggressions include healthcare providers attributing all physical symptoms to their medication and being spoken about as though they were not present. One participant reported being on the receiving end of numerous microaggressions, and further explained that they tried not to think much about them and move on when they occurred.

Most participants who reported that they did not experience microaggressions attributed this to their avoidance of discussions about their gender identity, or their attempting to pass as cisgender in instances where they did not consider it important reveal their gender identity. One participant explained that they made a point to only see likeminded people who were likely to understand their gender identity, and further felt that living in a politically liberal area with a shared cultural context was the reason they did not experience microaggressions from their healthcare providers. Aside from this participant, the other participants who reported that they did not experience microaggressions also reported being misgendered or having healthcare staff make assumptions about them based on their biological sex or gender presentation. They

categorized these experiences as being different from microaggressions, several participants giving the reason that they did not believe these actions were done intentionally or with any harmful intent. Although some experiences were not reported to include microaggressions, most participants had endured being misgendered or having assumptions made about them based upon their biological sex or apparent gender expression. These experiences could still be interpreted as microaggressions by others, as was seen among the participants who were less inclined to assume good intentions from healthcare staff.

Impact of Lack of Knowledge and Understanding

To examine how nonbinary individuals might perceive their healthcare to be affected by a lack of understanding about their gender identity, participants were asked if there had been any times where a lack of knowledge about their gender identity had resulted in problems with the quality of medical care that they received. Two participants reported that they did not believe their identity resulted in problems with the healthcare they received. One participant explained that they did a considerable amount of research before any healthcare visit to ensure their safety and that they would be able to convey their own healthcare needs. The other participant stated that they felt it was inevitable that they would be in uncomfortable situations such as being misgendered or that their providers may not understand certain things about them, and so they had come to accept that these things would happen. Both these participants reported that they may feel reluctant to see certain providers, either as a result of their preemptive research or as a reaction to a bad experience. This indicates that there may still be minor issues that result from a lack of understanding of nonbinary gender identities, even among individuals who might not perceive substantial issues with their healthcare.

Among the individuals who did perceive issues with their healthcare, the most common impact that was reported was a general feeling of discomfort or anxiety. Several patients reported that they felt unsafe in a healthcare setting, which impacted what they were willing to tell healthcare providers about themselves. This prevented some participants from sharing important or useful information with their healthcare providers. One participant reported that they found that some healthcare staff did not know how to approach them and were hesitant to provide them treatment, while a different participant reported a similar reaction when trying to get lab results from their healthcare provider and being ignored. Another participant reported that they struggled during doctor visits because their identity was treated as a mental illness and all their symptoms were assumed to be the result of their medication. This indicates that a lack of knowledge from a healthcare provider can result in barriers to receiving treatment. One participant who was able to receive gender specific treatment felt that the provided treatment of a large dose of medication was not correct for them since they did not want to drastically transition their appearance. Prescribing an incorrect dosage of medication can have unwanted side effects, in addition to not being the correct treatment for an individual. The participant who experienced this felt that their provider did not understand gender beyond the existence of transgendered individuals with a binary male or female gender. With a lack of understanding, it is difficult for nonbinary patients to receive gender or sex related healthcare which is specific to them.

Further examining the potential issues that nonbinary patients might experience, participants were asked what health issues cannot be effectively addressed by providers who are not aware or respectful of nonbinary gender identities. One participant explained that they personally felt there were topics they did not feel comfortable discussing with their provider, and also believed that other patients in their position may be reluctant to share information about

traumatic events which may prevent some patients from seeking healthcare for symptoms related to their trauma. Several participants also identified mental health as a major concern for treatments that would be directly impacted by a lack of knowledge or respect for patients' identities. It was also reported by several participants that they had multiple experiences with providers who would make assumptions about their symptoms that could be impacted by hormones, with hormone treatments being treated as the source of whatever issue they were experiencing. As a result, conditions which may be triggered or exacerbated by hormone levels cannot be effectively treated by doctors who do not have an understanding of what should be attributed to hormone treatments and what should not be. Additionally, doctors who do have an understanding of hormonal treatments may be better able to find alternative solutions for patients to address their symptoms without reducing their prescribed hormone treatments. In order to allow patients to physically transition into a physical appearance they are comfortable with, stopping hormone treatments cannot be the only solution healthcare providers think to try, meaning that more knowledge is required of them to find alternative treatments. It was also remarked upon by several participants that any treatment that was related to their biological sex, such as gynecological appointments, exams for breast cancer, or other sex specific healthcare topics were likely to be impacted by their providers' understanding of their gender identity.

A lack of knowledge or acceptance of nonbinary gender identities could also result in improper treatment during health exams, or in patients not receiving the specific treatment that they are seeking. One participant described an experience where the staff at a gynecologist's office did not believe they were in the correct place and were hesitant to provide them treatment. Several participants identified reproductive health as a notable topic that could not be addressed well by providers who did not understand nonbinary gender identities. Potential issues identified

included not understanding a patient's body or making assumptions such as assuming that a nonbinary or transgender individual may want to have children even if they do not identify with their biological sex. Where a lack of knowledge was concerned, many participants felt that healthcare providers would not be able to resist making assumptions or improper diagnoses or prescribed treatments. This was concerning to them, since it could potentially mean that they would be unable to receive good or even appropriate treatment for health issues that were very important because of their gender identity. One participant explained that they did not believe they could receive holistic care when their gender identity was not taken into account. The inability to address a patient's specific needs is limiting to how effectively a healthcare provider is able to treat symptoms or issues that a patient experiences.

Preferred Methods of Gender Identification

Participants were asked how they would prefer to let a doctor know about their gender identity. The purpose of this question was to determine how a patient might want to self-identify when they felt safe doing so. Three participants responded that they would prefer to directly tell the provider or staff member at their own discretion. One of these participants felt that they might feel annoyed by having to self-identify every time, but would still do so as a preferred method. Their proposed alternative to having to do this themselves was for healthcare providers and staff to use neutral or gender nonspecific language by default. This would allow patients who wanted their identity to be recognized to self-identify, while avoiding misgendering individuals who might not feel comfortable doing so. Another one of these participants, who wanted to bring it up directly, felt that they would prefer not to have it included in their chart in order to avoid their identity being known to someone who they might prefer it not be known to. There was a

fourth participant who similarly did not want to have to bring up their identity in all circumstances, who said that while they might bring it up directly they would prefer not to self-identify at all to avoid potential conflict or threats to their safety. For this participant, they would prefer only to bring up their gender identity where absolutely necessary.

Several participants wanted to verbally acknowledge their gender identity, but they wanted the provider to be the one to bring up the topic first, either by introducing themselves with their personal pronouns or by confirming information from an inclusive intake form. Another participant wanted to identify using an inclusive intake form, but they stated that they would prefer not having to verbally identify themselves. This was similar to two other participants, one of whom preferred identifying on a form and another who wanted nametags to be used in order to create an inclusive environment. Among most participants who were inclined to share their gender identity in some way, it was expressed that there would need to be follow through from any doctor or staff member who knew their identity. Simply self-identifying would not be sufficient in addressing the common issue of being misgendered, which many participants expressed had been a negative experience that they encountered in the past. Additionally, it might not always be relevant or ideal for all staff to know their gender identity, particularly in situations where it would cause staff members or doctors to mistreat them.

Although all staff should treat their patients with respect and avoid saying or doing anything to make patients feel uncomfortable, it may be the case that not all healthcare staff need to know a patient's specific gender identity. To determine this, participants were asked what kind of staff in a medical setting would ideally need to know their gender identity in order to provide them suitable care. Most participants expressed that they would want anyone who they were going to directly interact with or speak to for a prolonged period of time to know their gender

identity specifically. They expressed that it was important for healthcare providers and staff to use the correct gender pronouns, which was a view shared by most of the participants who did not feel that the specifics of their identity needed to be known by everyone. The general consensus was that correct pronouns should be known or asked for in order to avoid misgendering patients. One participant expressed otherwise, feeling that they did not want to be compelled to reveal anything about their gender identity. Instead, they felt that it should be the general practice to use gender neutral terminology and pronouns in order to avoid misgendering anyone. Several participants expressed the view that they/them pronouns should be considered the default since the terms are not tied to a specific gender identity. Aside from the participant who stated that they did not want to reveal anything about their identity, most participants felt that the doctor or provider they were specifically seeking healthcare from needed to know their specific gender identity.

It was also expressed by multiple participants that front desk staff or receptionists should know the correct pronouns to use for them and their preferred name, though only two participants felt that these staff members needed to know the specific gender identity. The participants who did not want front desk staff to know expressed a concern that they may not feel comfortable or safe to reveal their gender identity in all settings. It was expressed by one participant that front desk staff should know the correct way to approach patients who were not male or female, since this initial interaction may be impacted by how safe a patient feels to self-identify. Careful consideration should be taken towards the fact that a patient may not always reveal themselves to be nonbinary, but they may also feel uncomfortable being misgendered. In this situation, the solution proposed by another participant of avoiding using gendered pronouns may help resolve this potential issue. There was one participant who felt that

every member of staff should know all patients' gender identities, since this would create a good impression of being an open and welcoming environment, but no other participant expressed this view. This, along with the varying answers given by participants, indicates that different individuals have different levels of comfort towards who is aware of their gender identity. Since not every individual is fully out, particularly in new or unfamiliar settings, creating a positive environment may need to involve indirect approaches such as using more gender neutral language when talking to or referring to patients.

Additional Topics of Interest

To conclude the interview, all participants were asked if there was anything else related to their gender identity and healthcare that they had not been asked about. The purpose of this conclusion was to give participants a chance to draw attention to any topics that might have been overlooked when creating the interview script. Several patients responded that they could not think of anything, some reiterating things they had said previously which they felt would be important points to include in the study. One participant elaborated on their perspective that they felt resentful when the onus was placed on them to self-identify and make certain that everyone knew how to address them correctly, and instead wanted to see an overall change in healthcare environments to include gender neutral language as a default. They felt it was unfair to have to put in additional work to ensure they were treated respectfully, advocating for equitable treatment in healthcare settings. Another participant did not have much to add, explaining that they did not have much insight since they did not face discrimination, but that this was also something they were fortunate for. They further elaborated that they understood that not

everyone had a positive experience, so they were pleased that healthcare settings were being researched in this context.

Several participants suggested methods for improving how nonbinary patients are treated in a healthcare setting. It was suggested by one participant that healthcare settings might benefit from sensitivity training that includes gender identities, such as the training that is present in many workplaces to discourage harassment such as racism and sexism. Other participants brought up points which they had not had a chance to talk about earlier. One subject which was brought up was the topic of insurance coverage, which can prevent access to healthcare. It was explained by the participant who brought this up that some people seeking gender affirming care may not be able to access it if it is not covered by their insurance, or they may find that it is covered but still difficult to get insurance to pay for it. Additionally, one participant identified that healthcare providers and staff need a greater amount of cultural competency, which they explained to mean that these healthcare workers should be more conscientious of others in order to effectively connect with their patients. The participant who brought up this point further elaborated that they did not believe there was a lack of resources available, but rather a lack of intention where being aware of different genders is not prioritized or seen as necessary. This same participant felt that patients were often being treated as a source of income rather than as people, which could prevent healthcare workers from understanding what services a patient might need, thereby preventing patients from receiving healthcare.

It was brought up by one participant that transgender or gender nonconforming people had a big choice to make that not everyone would experience, which they found frustrating because there was a lower rate of nonbinary and transgender people seeking medical care despite a high rate of chronic illnesses. They explained that the reason for this was fear which prevented

these individuals from seeking healthcare in the first place. Additionally, they said that they had to make the conscious decision to wear something which would identify them as nonbinary, while others would make a similar choice or might choose to detach from their individual identity for the purpose of seeking healthcare. These choices are an added stress that not every person has to go through, which the participant felt was important to draw attention to. Another issue they addressed was that it could be difficult to find information on whether healthcare providers were accepting of nonbinary individuals, unless they were specifically centered on queer healthcare. This means that patients need to rely on external sources and word of mouth, even though it would be easier if it was made clear on the provider's website that they offered healthcare to LGBT individuals, specifically including both transgender and nonbinary individuals.

Visible steps to being more inclusive of nonbinary genders was considered by many participants to be something they would like to see more of in healthcare settings. When prompted specifically about what they might like to see in a healthcare environment, one patient stated that they would like to see posters using inclusive language, particularly in healthcare settings that are typically focused on one gender such as the gynecologist, since not everyone seeking healthcare will necessarily identify with the gender that providers assume are seeking healthcare specific to one sex. Another participant responded that they personally did not want their gender to be focused on in a healthcare visit, or to be pressed to identify themselves, but they did express that they thought it might be a welcome change for others if gender identity was considered more during healthcare visits. While they would not want to be forced into identifying themselves, they would still feel more welcomed if it was clear to them that the environment was welcoming to transgender and nonbinary individuals.

While not the focus of the study, it was reiterated by two participants that mental health has a significant impact on physical health. According to these participants, addressing disparities in the access transgender and nonbinary individuals have in mental healthcare should be mentioned as a topic of interest. These two participants explained that mental healthcare was difficult to seek out because they had trouble finding providers who were understanding and accepting of transgender gender identities. This issue mirrors what is seen in physical healthcare settings, with several study participants experiencing obstacles when seeking healthcare because of a lack of acceptance of their gender identities.

It was also brought up by several participants that stereotyping based on perceived gender identity could happen in ways that might be easily overlooked by most. For instance, assumptions that male-presenting patients will be invested in sports or action movies can result in a patient feeling misgendered even if the wrong pronouns are not used. The participant who spoke about this specific example further explained that the trust they felt towards a healthcare provider and their staff was a cumulative effect that would be influenced negatively by this type of stereotyping. Small talk such as what was described may not occur to the person speaking as something which is gendering a person, but because personal interests are often gendered as male or female, it may be necessary to choose topics of conversation more carefully to avoid indirectly misgendering an individual.

Conclusions

The needs of nonbinary and other gender nonconforming patients is something which differs between individual patients, requiring healthcare workers to be more involved and informed with these patients in order to provide suitable accommodations. Potential

accommodations which are accepted by some people may be rejected by others, which is why there needs to be research into the preferences and experiences of nonbinary patients. There is also a need to ensure that patients feel safe and accepted in a healthcare setting. The common issues which many of the participants in this study reported were experiences which elicited feelings of discomfort or made them feel unsafe. The responses given by study participants also indicated that a lack of knowledge about their gender identity resulted in poor or improper treatments being given to them. Even among well-meaning healthcare staff, there was a tendency to misgender individuals or make assumptions about them based on their perceived gender. Additionally, healthcare providers had a tendency to rely on the knowledge of their patients when prescribing hormone treatments. Similarly, some participants reported that their healthcare providers would diagnose all symptoms as resulting from changes in hormones, rather than looking more deeply into potential causes or solutions to addressing their symptoms without adjusting the hormone levels. In order to improve the healthcare environment for nonbinary patients, individual preferences for accommodation need to be taken into consideration in addition to healthcare providers taking time to learn more about healthcare treatments involved in gender presentation such as hormonal treatments or surgeries.

Nonbinary individuals are not a monolith in their identities, experiences, or preferences. Accommodating their specific needs as a demographic will involve taking their differences into consideration. The goal for some nonbinary individuals is to be able to be open with their healthcare providers about their gender identity, and for them it would be necessary to offer opportunities for them to self-identify, or create an environment where they feel comfortable doing so. For other nonbinary individuals, they might prefer not having to self-identify or would prefer not to draw attention to their gender. The results of this study indicate that even these

individuals feel uncomfortable being misgendered or stereotyped. Some will try to avoid having the expectation of having their gender accepted by healthcare workers, while others may suffer internally rather than risk confrontation. Regardless of how a patient responds to mistreatment, it is the responsibility of healthcare providers and staff to ensure that patients feel comfortable and safe. To achieve this, there should be a default gender neutral language used to refer to patients unless specifically instructed otherwise. While some nonbinary patients may welcome the opportunity to self-identify, those in this study who did not were not always open to the idea. However, there was a general consensus that gender neutral language would be a step in the right direction, since it would avoid making patients feel that they were being incorrectly gendered.

Among nonbinary individuals who are more readily willing to share their experiences, there is an opportunity for providers to inquire further about what accommodations they might like to see in their specific practices. Doctors can introduce the topic of preferred pronouns by introducing themselves with their preferred pronouns, setting a precedent for an open dialogue that does not put the responsibility of introducing the topic on the patient. Several patients reported feeling frustrated or angry about having to be the one to ensure that they were correctly identified, which indicates that it might reduce their stress if providers began introductions by identifying themselves. Additionally, it was mentioned several times that while it was good to have inclusive intake forms, not all doctors would review them, causing the participants to be misgendered even when the information was readily available. Inclusive intake forms were broadly seen as a positive thing, but it would disappoint participants when doctors or staff would not follow through on using correct pronouns for them. The trust that patients have in their providers can be easily shaken by mistakes or a lack of follow through, so there needs to be an increased conscientiousness of nonbinary patients and their preferences.

There was a mixed response among nonbinary patients in response to the majority of the questions asked during the interview. While there was a general agreement that some changes would be beneficial, such as increasing the use of open responses on intake forms which ask for their gender identity or using more gender neutral language when referring to patients who have not specifically identified themselves as male or female, not all participants felt the same level of comfort about self-identifying their gender. While all participants in the study wanted their gender identity to be respected, some were more hesitant towards changes that would draw more attention to their gender identity. There was also a variance in the types of experiences participants had encountered in healthcare settings. While some had largely positive experiences, many had negative experiences that caused them to be more reserved or avoid receiving healthcare. The tendency for nonbinary patients to respond differently indicates that there is not a single shared experience or a specific change that will improve the healthcare environment for everyone who identifies as nonbinary. However, the negative impression that some participants had of healthcare environments indicates that there is still a need to improve the healthcare environment to provide suitable care to nonbinary patients.

Future research should continue to gather information from nonbinary and gender nonconforming individuals from other geographic regions. It might also be beneficial to understanding the diverse experiences of nonbinary patients by focusing future studies on people with specific racial identities, particularly in Native American populations which were not included in the current study. This will ensure that a broader range of individuals are accounted for. In future, research should also investigate how identifying as nonbinary impacts access to health insurance, since one participant indicated insurance as a significant hurdle to receiving healthcare as a direct result of their gender identity. Mental healthcare was also a concern raised

by multiple participants, who felt that there was a lack of mental healthcare providers who would accept their gender identity, making it difficult to receive care. Sex specific healthcare settings is another specialization which may need to become more aware of nonbinary gender identities in order to accommodate patients who identify as nonbinary but who still need healthcare related to their biological sex. The questions asked in the study interview were broad, so more specificity in future may increase insight into where improvements can be made.

There needs to be a focus on improving the healthcare setting for nonbinary patients by addressing their concerns for respect and safety. One method to create a positive environment for nonbinary patients may be to improve communication between healthcare providers and their nonbinary patients. Avoiding situations such as using the incorrect name or pronouns is crucial to ensuring that a nonbinary patient feels safe and comfortable. Since nonbinary patients may not always be willing to self-identify, it may also be necessary to use gender neutral language for any patient who has not specifically offered a gendered alternative. This could help ensure that nonbinary patients feel secure and be able to trust their healthcare provider not to make assumptions about them and their specific health needs. Creating a good healthcare experience for nonbinary patients also requires presenting the option to self-identify without forcing patients to do so when they do not feel comfortable. Improving communication and avoiding misgendering or mistreating individuals are all important steps that should be taken to ensure that patients are treated equitably and have positive health outcomes.

Individual healthcare practices may want to utilize a similar methodology of interviewing their nonbinary patients to understand the needs of the community they serve. However, it may be difficult for some individuals, who may feel wary of reporting information to their healthcare providers. Other methods such as surveys of patients, or surveys of healthcare staff themselves,

could provide valuable information and require less of a time and trust commitment on the part of participants. It would also benefit healthcare providers to share information with each other, such as what practices their patients are receptive towards. Changes that might be beneficial to implement include increasing the use of intake forms which allow patients to self-identify their gender, using more gender neutral language by default in order to avoid misgendering an individual, and having a healthcare provider introduce themselves with their pronouns to give the opportunity to the patients to verbally identify their preferred gender or pronouns without pressuring them to do so. If healthcare providers can put more consideration into how they are treating their nonbinary patients, it may serve to improve their experiences in healthcare settings, which could result in better health outcomes.

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Appendices

Prescreening Survey Consent Form

You are invited to participate in a research study on nonbinary patient-provider communication in healthcare settings. Please read this information carefully. Make sure that you understand it to your complete satisfaction before signing your name at the end. Please ask questions if you do not understand any of the information, or if you have any questions or concerns related to the study. To do so, contact the researcher by email at rleo@uchicago.edu for clarification.

This research study will be conducted by Rosemary Leo, a student at the University of Chicago, under the supervision of Dr. John Schneider.

The study aims to answer the question of how patient-provider communication can be improved for nonbinary patients. This work will contribute towards broadening our understanding of the healthcare provided to nonbinary individuals, as well as contributing towards better understanding of the general impact of patient-provider communication on the quality of healthcare. Participating in this study involves completing the following prescreening survey to determine if you are eligible to participate, followed by either a survey or video interview depending on your eligibility.

To participate in the study, you must be over the age of 18 and identify as nonbinary or as another gender identity outside of a singular binary gender.

After you sign this form, your demographic details (age, race, etc.) will be recorded in the following demographics screening survey to determine if you meet the qualifications for inclusion in this study. If you are eligible to participate in this study, further instructions will be provided to you at the end of the survey.

All information recorded in the survey will be recorded in a way that is anonymous, and will be saved in a password protected computer for additional assurance that the information will remain confidential. Any potentially identifiable information that comes up over the course of this study, such as names or email addresses, will be redacted from the data that is collected.

Signing this document does not obligate you to complete the demographic screening survey if you choose not to do so. It also does not obligate you to participate in the subsequent study if you decide you do not want to participate.

By signing this document, I consent to the data recorded in this survey being used as a part of this research study. I understand that in the event I am not selected for inclusion in the study, I will not receive any compensation for study participation.

Sign and Date: _____

Prescreening Demographics Survey

Demographics Preliminary Survey (Collected in a self administered, online survey prior to selecting participants for initial interview to determine eligibility, as well as part of the healthcare provider AIM survey)

What is your preferred gender identity?

- Male*
- Female*
- Nonbinary
- Agender
- Genderfluid
- Other (please specify) _____

* Those who select Male/Female will be directed to a follow up question:

Do you have another gender identity besides male/female?

- Yes (please specify) _____
- No

(A selection of “yes” may indicate an individual who may have multiple identities but currently prefers using one binary gender. A selection of “no” may indicate that the individual is either cisgender or a binary transman/transwoman. In this event, the individual is not in the target population for the interview portion of the study. Patients with this criteria do not have to complete the rest of the survey and should be skipped to the end. Healthcare providers will be given this survey in its entirety.)

How old are you?

_____ (Selected from a dropdown)

What race do you identify as? (select all that apply)

- White/Caucasian
- Hispanic or Latino
- Black or African American
- American Indian or Alaskan Native
- Middle Eastern or North African
- Other (please specify) _____

What is your marital status?

- Never Married
- Previously Married
- Currently Married
- Other (please specify) _____

What is your current relationship status?

Single

In an Open Relationship

In a Committed Relationship

Other (please specify) _____

What is the highest level of education have you completed?

Less Than High School

High School Degree/GED

Some College, but no degree

Associate's Degree (2 year college degree)

Bachelor's Degree (4 year college degree)

Master's Degree

Doctorate Degree

Other (please specify) _____

Have you ever been diagnosed with a chronic illness?

Yes

No

Interview Consent Form

You are invited to participate in a research study on nonbinary patient-provider communication in healthcare settings. Please read this information carefully. Make sure that you understand it to your complete satisfaction before signing your name at the end. Participation in this study involves completing a 30-45 minute, one on one interview through a video call using Skype or Zoom. Please ask questions if you do not understand any of the information, or if you have any questions or concerns related to the study. To do so, contact the researcher by email at rleo@uchicago.edu for clarification.

This research study will be conducted by Rosemary Leo, a student at the University of Chicago, under the supervision of Dr. John Schneider.

The study aims to answer the question of how patient-provider communication can be improved for nonbinary patients. This work will contribute towards broadening our understanding of the healthcare provided to nonbinary individuals, as well as contributing towards better understanding of the general impact of patient-provider communication on the quality of healthcare

To participate in the study, you must be over the age of 18 and identify as nonbinary or as another gender identity outside of a singular binary gender. You also must have completed the previous demographic information survey and have been determined to be eligible to participate in the interview portion of this study.

Upon signing this document, you will be directed to contact the investigator by email or phone to schedule a time to complete the interview portion of the study. This interview will include questions about your experiences with healthcare providers and within healthcare settings, with a focus on your experiences related to your gender identity. This includes questions which are potentially sensitive or distressing, and which may ask you to recall unpleasant events that you might have experienced. A list of available support resources will be sent to you to access if you experience discomfort or feel upset by the questions. If you have any concerns, please utilize these resources or bring up your concerns to the investigator of the study.

An audio recording of this interview will be saved on a password protected computer to ensure it remains confidential, and will only be accessible to the student conducting the interview and the supervising professor. It will be saved until the completion of the study, after which the original recordings and any potentially identifiable information will be destroyed. A full or partial transcript may be recorded as a part of the results of the study, in which any identifiable information will be redacted. This transcript will be used to identify common or major events experienced by those participating in the study, and will be the basis of a written report and a thesis presentation at the University of Chicago.

Signing this document does not obligate you to complete the entire interview. You may choose not to answer some questions, and you can withdraw your consent to participate in this study at any point. Upon wholly or partially completing the interview, you will receive a compensation of \$25 as an incentive for

participation. This will be distributed electronically using PayPal, or upon request a physical check can be mailed to an address you specify.

By signing this document, I consent to the data recorded during the interview being used as a part of this research study. I understand that in the event I do not participate in the interview, I will not receive any compensation for study participation.

Sign and Date: _____

In Person Interview

(Initial interview to determine questions to ask in a broader survey)

What is your gender identity?

What are your preferred pronouns?

I am interested in learning more about nonbinary people's experiences communicating and interacting with doctors and medical staff. Has your gender identity ever been an issue at a doctor's visit or in a medical setting?

- If yes - can you tell me more about that?

Have you ever filled out a medical form that provided room for reporting your gender identity and/or your preferred pronouns? What do you do if a form does not provide a space?

- If yes - How often are these forms provided? Did that change or affect anything in your visit with the doctor? How so? Did it change or affect anything about your interactions with nursing, clerical or support staff? Tell me about that.

Do you usually offer your gender identity when you see a doctor or medical provider? Have you ever? Have you ever not?

- Do you bring up the subject of gender identity first? How do you go about doing that?
- Can you talk to me a little about situations in which you do and situations in which you do not bring up your gender identity?
- Has a doctor or provider ever brought the topic up first? Tell me about that.

Now I'd like to learn more about how doctors and healthcare providers have reacted to your gender identity. Could you give me some examples of this?

What about any times doctors or staff seemed well intentioned, but confused? Can you walk me through some examples?

Have healthcare workers ever made unsolicited remarks about your gender identity or talked about it in front of you as if you were not there? Are there instances of microaggressions which you have experienced in a healthcare setting?

Are there any times when lack of knowledge about your gender identity resulted in problems in the quality of medical care you got? Tell me about that.

What are the kinds of health issues that cannot be effectively addressed by providers who are not aware of or respectful of your gender identity?

What would be your preferred way of letting a doctor know about your gender identity?

Which kinds of staff in a medical setting would ideally need to know about your gender identity in order to provide you with suitable care? Do you want all staff to know your gender identity or just those responsible for providing healthcare?

Is there anything else related to gender identity and medical care I haven't asked about that you can tell me?

Thank you for your time

Recruitment Email

SUBJ: Recruitment for Thesis Study on Nonbinary Healthcare

My name is Rosemary Leo, a graduate student at the University of Chicago. I am conducting a study focused on the quality of communication between nonbinary patients and healthcare providers. The aim of the study is to identify how healthcare providers can better communicate with their nonbinary patients in order to provide more effective healthcare.

This study involves answering a brief qualifying survey and participating in a virtual interview, the audio of which will be recorded for the purpose of transcribing your responses. All responses will be made anonymous and recorded in a way that preserves confidentiality. After completing the interview, you will receive a compensation of \$25 for your participation in the study.

The study will be conducted during the fall of 2021 through the summer of 2022, with interviews taking place in the evenings on weekdays and throughout the day during the weekends. You will need a device with internet access to participate in the study.

If you are interested in participating, please complete the screening survey to determine if you qualify to participate in this study.

[LINK]

If you have any questions about this study, please contact me at rleo@uchicago.edu.

Thank you for your interest,
Rosemary Leo