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Health Care Experiences of Non-Binary Patients and Recommendations for Improvement Through an Intersectional Lens

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2019

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Abstract

Health Care Experiences of Non-Binary Patients and Recommendations for Improvement Through an Intersectional Lens

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Background: Transgender and non-binary discrimination happens at all levels of the socio-ecological model, including in the healthcare industry. Compared to cisgender people, transgender people have worse health outcomes, and the health disparities of non-binary people are often under investigated. Non-binary people have largely been left out of public health literature, especially concerning their medical needs and recommendations for improving care. They are often lumped in with larger samples of binary transgender people or only make up a small proportion of the sample size. This ignores their unique health care needs and necessitates further investigation into their medical experiences. This study uses intersectionality as a theoretical frame to examine the specific social locations of participants and how their complex identities impact their care in addition to their non-binary gender identity.

Methods: This study conducted nine qualitative in-depth interviews with non-binary participants to gather and analyze data on the participants' feelings about inclusive and exclusive medical practices, their positive and negative medical experiences, and their recommendations for improving care for non-binary patients. Data were then thematically analyzed using MAXQDA software.

Results: Participants described four areas related to their experiences with medical interactions: inclusive and exclusive medical practices, their intersecting marginalizations, provider experiences from participants who are providers, and recommendations for improving non-binary care from their perspectives. It was found that medical forms often lack areas for providing pronouns and gender identities, forcing patients to out themselves or withhold this information from providers, affecting the quality of their care. All participants were structurally marginalized on at least one more level than their gender identity, and this impacted the quality of their care. The non-binary provider participants described best practices for engaging with non-binary patients based on their own experiences and their education, mentioning empathy and continued learning about the community as key factors. Participants also recommended a number of measures for improving the care of non-binary patients concerning medical staff diversity, updating educational curricula, and trust in patient-provider relationships.

Conclusions: This study describes the experiences of non-binary patients interacting with the current medical system that is often ignorant of their needs. Recommendations from participants included inclusive medical forms and records, more diversity in medical staff, better medical school and continuing education courses on the non-binary community and their health needs, and fostering patient-provider relationships built on trust through providers being open about their lack of experience, providing holistic care, and breaking down power dynamics.

Key words: Non-binary, transgender, non-binary health, transgender health, LGBTQ, LGBTQ health, queer, queer health, intersectionality, health disparities

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TABLE OF CONTENTS

CHAPTER I: Introduction.....1
  Purpose and Research Questions.....3
CHAPTER II: Literature Review.....5
  Transgender Health Experiences and Recommendations.....7
  Theoretical Framework.....9
  Conclusion.....11
CHAPTER III: Methods.....13
  Description of Sample.....13
  Sample and Recruiting.....15
  Data Collection.....16
  Coding and Analysis.....17
  Ethics.....17
CHAPTER IV: Results.....19
  Inclusive and Exclusive Practices.....19
  Intersecting Marginalizations.....25
    Race.....25
    Sexuality.....29
    Health and Disability.....29
  Provider Experiences.....31
  Participant Recommendations.....36
    Diversity of Medical Staff.....36
    Education on Non-binary Identities.....37
    Patient-Provider Trust.....39
  Conclusion.....41
CHAPTER V: Discussion, Implications, and Recommendations.....43
  Strengths and Limitations.....45
  Public Health Implications.....47
  Recommendations.....49
    Forms.....49
    Diversification of Medical Staff.....50
    Improved Medical Education.....51

Trust in Patient-Provider Relationships 52
Conclusion 53
REFERENCES 54
APPENDIX A: In-depth Interview Guide...57
APPENDIX B: Interview Reference Sheet 59

CHAPTER I: Introduction

Historically, sex and gender have been conflated as well as assumed to be a binary: female or male, woman or man. A person's sex is what they are assigned at birth based on their primary sex characteristics, such as genitalia. A person's gender identity can be explained as the internal perception of their gender and how they label themselves.[1] Gender identity exists on a continuous spectrum[2] with woman/female on one end and man/male on the other, with the spectrum in between encompassing those who do not fall exclusively into the woman/man binary, who experience aspects of multiple genders, and those who wish to not have a gender identity at all.[3] Transgender people are individuals whose gender differs from the sex they were assigned at birth and non-binary people are those who exist outside the two binary options on the gender spectrum.[4,5]

Though they are often lumped together, it should be noted that not all non-binary people identify as transgender. Most research looking at trans people does so along a binary spectrum (trans female vs. trans male),[5] allowing for the continuation of the gender binary and erasing non-binary and gender expansive people that do not exclusively fall into one of those two categories. This also results in the continuation of the assumption that transgender and non-binary people experience cisnormativity and its consequential health disparities and discrimination in essentially the same way, missing the intricacies of these identities and their specific intersections with other social categories.[6] As the participants of this study will describe, the labels "transgender" and "non-binary" can be distinct identities for many non-binary people and should not be conflated, signaling a need for non-binary-exclusive research to be expanded. For the purposes of this research, "non-binary" is understood to encompass a variety of identities along the gender spectrum that do not neatly fit into the categories of "woman/female" or "man/male" including, but not limited to:

agender, androgynous, bigender, genderfluid, gender non-conforming, genderqueer, and pangender.[6]

As mentioned, sex and gender have typically been assumed to exist in a binary. As such, non-binary people have been excluded from research literature, included those on transgender people which often still utilize a binary system of female and male.[7] Estimates of how much of the population identifies as non-binary vary, though the 2015 U.S. Transgender Survey had 35% of transgender respondents identifying as non-binary. The survey allowed for respondents to select multiple gender categories with genderqueer, gender non-conforming, and genderfluid being common non-binary identities among participants.[4] Estimation is complicated even with surveys like this though, as not all non-binary people identify as transgender and may not take surveys intended for transgender people. Additionally, as gender is on a continuous spectrum and can potentially shift day-to-day for some non-binary people, an individual's answer to a survey asking their gender identity may be different at different points in time.

Non-binary individuals are a specific population with specific health needs and healthcare experiences and often have more health needs than their cisgender counterparts.[5,8] While many health needs and outcomes of non-binary people may be the same as binary transgender people, it should also be considered that this is not always the case.[6,8] In the prescribing of gender-affirming hormone therapy, for example, assuming non-binary people have the same transition goals as binary transgender people and treating them the same may result in overtreatment, which could lead to regrets and further dysphoria.[2]

While studies have been done on transgender people's health needs and concerns in a variety of contexts, many continue to have a lack of complex understanding of the lives and identities of transgender people and non-binary people, especially. Transgender people's voices are seen as data to be interpreted rather than as a source of knowledge that should be taken on its own, and non-binary voices are often left out altogether. Further, the rights of transgender people and the contexts they exist in outside of health care interactions is rarely taken into consideration. All of this leaves research that condenses transgender and non-binary people, who have distinct experiences, into a single category to be analyzed and interpreted. Recommendations then come from the researchers rather than the participants themselves, which feel isolated in the health center rather than contextualized into the greater lived realities of the participants involved in the research. In looking at these issues as not separate from the world in which non-binary patients operate and giving voice to the participants themselves, new intersectional care guidelines can be imagined.

Purpose and Research Questions

While there is research on the experiences of transgender patients in health care settings, the majority of this research has very few non-binary participants or leaves out non-binary individuals entirely, leaving little written on how to improve the experiences of non-binary patients specifically. Thus, this study will conduct qualitative individual in-depth interviews with non-binary transgender people to answer the following research questions:

- How do current medical practices support or alienate/stigmatize non-binary people and their specific health care needs?
- What are the best practices for supporting non-binary people in healthcare based on recommendations and feedback from non-binary people themselves?

An intersectional lens will be used to understand the unique marginalized social locations participants are situated in, how these operate in the context of their health care interactions, and how to incorporate an intersectional understanding into recommendations for improving health care experiences for non-binary people.

From the collection of qualitative data from the non-binary study participants, the results of this study will provide needed information on how health care practices can be reformed and implemented by providers to best support non-binary patients using recommendations from the participants themselves.

CHAPTER II: Literature Review

Transgender discrimination takes place at all levels of the socio-ecological model: internalized transphobia taught by a transphobic society; interpersonal discrimination, harassment, and violence; discrimination in the workplace, educational institutions, and in access to resources like healthcare and safe housing; and at the societal level through discriminatory and exclusionary policies, rigid gender roles, and cisnormativity.

Compared to cisgender people, transgender people[1] are less likely to have health insurance.[9,10] They are more likely to have experienced harassment, trauma, or sexual assault,[6] experienced discrimination when looking for a job,[11] had at least one transient night in the past month,[12] to have engaged in transactional sex,[12] faced verbal attacks;[11] and experienced greater depression, anxiety, eating concerns, and other psychological distress.[6,12] When compared to cisgender men who have sex with men, transgender people are less likely to complete high school; more likely report greater depression, anxiety, and poorer health; and are 8.5 times more likely to have experienced gender-based discrimination.[12] These figures may be even more stark when compared to cisgender men who are not sexually marginalized.

While the health disparities between cisgender and non-binary people are generally clear, there is less consensus on the disparities between binary transgender and non-binary people.[4,5,9,11,13] Non-binary people have better or worse health outcomes depending on the indicators and the study. Some areas where non-binary people have better outcomes are in being less likely to have attempted suicide,[4,5] being more likely to have been screened for uterine cancer

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[1] It should be noted that research does not often differentiate between binary and non-binary trans people when comparing their health characteristics and disparities to cisgender people, if non-binary people are included at all.

among AFAB non-binary people, higher life satisfaction ratings, lower health-related risk behavior rates, and significantly higher levels of gender congruence and body satisfaction.[5]

Additionally, non-binary people report having experienced health care discrimination less often than binary transgender people and are less likely to postpone care due to fear of discrimination.[9] A possible explanation for non-binary patients reporting fewer experiences of health care discrimination includes a potential "passing privilege", i.e. the ability to hide one's identity if they choose and are not visibly gender nonconforming to "pass" as cisgender in the eyes of their provider. A patient's ability to not being open about their gender identity to their providers and thus not have their identity on their medical records allows for less conscious or unconscious bias to interrupt the health care interaction.[9] While this ability to "pass" as cisgender may allow for less discrimination in the medical interaction, it must also be considered that in "passing" the non-binary patient may experience discomfort and dysphoria from being misgendered or stereotyped based on their perceived gender.

However, there are some indicators that show worse health outcomes for non-binary people compared to binary transgender people. Non-binary people report higher rates of feeling isolated and thinking about suicide,[6,11] engaging in self-injury,[6] having psychological health problems,[4,6,11] experiencing abusive behavior or traumatic events,[6] sexual assault,[4,6] difficulties seeking legal services,[4] and difficulties accessing hormone therapy when desired.[2] Compared to binary transgender people, non-binary people also report lower rates of feeling happy or very happy,[11] of having seen a healthcare provider in the last year, having health insurance or a primary care provider, and forgoing health care visits due to cost.[9,13]

Aparicio-García (2018) found that of cisgender, binary trans people, and non-binary people, their non-binary participants had the lowest support from their friends and family.[11] In contrast, the 2015 U.S. Transgender Survey had 32% of non-binary people experiencing family rejection due to gender identity compared to 59% of binary transgender men and women.[4] One complicating factor in this statistic is that fact that many non-binary people do not tell others they are non-binary and let them assume their gender, often due to fears that their identity will not be understood, that it's easier to not say anything, that their identity might be dismissed, or that they might face violence.[4,9] Non-binary people may also experience less rejection than binary transgender people due to the fact that they have not come out to their family or if they do not pursue physical transition, which non-binary people do at lower rates than binary transgender people.[2,4,14]

Transgender Health Experiences and Recommendations

Every health care interaction is a "dignity encounter," in which a patient's dignity may be affirmed or violated.[15] Negative experiences can affect the trust transgender and non-binary patients have in the health care system and can result in them delaying or avoiding care altogether.[1,15–19] This knowledge makes it imperative to ensure that these patients are receiving high quality, informed, and compassionate care to encourage them to continue seeking care and reduce the vast health disparities these communities experience.

Transgender people report numerous negative experiences they have encountered during their interactions with healthcare professionals. The top issues reported include having their identity challenged, invalidated, or ignored;[15,16,20] invasive questioning;[1,15,20] being pressured to choose between female or male or align themselves with narrow gender roles, including at transgender clinics;[1,15,16,20,21] having staff be visibly uncomfortable with transgender people;[15,20] providers lacking of knowledge on transgender and non-binary people and bodies;[1,9,10,15,20,21] being forced to educate providers on transgender people;[1,20] physical examinations without warning or explanation;[1,20] inaccurate documentation of gender identity in both written and electronic formats;[16,20] and long wait times for care or not receiving help finding care.[15,20] It's especially important to consider the experiences of trans and non-binary people during physical examinations and other situations in which their body may be exposed, as this can be a dysphoric experience for many and can make it difficult to preserve their gender identity.[1,22]

Recommendations for improving health care practices for binary trans people are numerous and have been discussed in many different forums. The most common recommendations cited by previous studies include using preferred names and pronouns,[15,16,20,22] using gender-neutral language,[1,15,20] validating gender identity,[1,15,16,22] learning how to properly document gender identity, names, and pronouns,[16,20] being treated with respect,[1,15] asking respectful questions and having an open dialogue about not knowing everything,[1,15,20,21] treating patients according to needs and not solely focusing on their trans experience,[15,21] providers taking it upon themselves to gain more information,[1,15] displaying sensitivity during physical examinations,[1,20] educating all health center staff on non-binary identities,[13,16,20–22] improving electronic health records and forms to more easily document non-binary people,[16,20,21] and integrating recommendations into medical curricula.[23]

An obvious issue is that many of these recommendations come from studies where a majority or all of participants are binary trans people, leaving non-binary people out of the considerations of the researchers. In addition, these recommendations often come from the researchers' interpretations of their findings rather than from the participants themselves. In one instance of patient input on recommendations for improvement, contrary to other studies, reported that some participants saw "alliance signaling" (patient-facing messaging about the clinic's gender inclusivity) as distrustful based on previous negative experiences with reported gender-inclusive providers.[16] This is seemingly in opposition to other studies where participants have requested explicitly inclusive brochures, resources, and health care environments.[1,13,20] What can be learned from this incongruence is that it cannot be assumed that inclusivity means the same to every person in the transgender and non-binary communities and that it is important for health care providers to partner with their local transgender community to develop gender-appropriate resources, support, and health care environments.[15,22,23]

Theoretical Framework

Intersectionality is the guiding theoretical framework in the development of this project and in its analysis. Kimberlé Crenshaw coined the term intersectionality in her 1991 Stanford Law Review article on interpersonal violence against women of Color.[24] In it, she considers how in discussions that involve women of Color, such as domestic violence and rape, the issues are generally seen as being split into affecting distinct identity groups (women *or* people of Color) rather than accounting for the intersecting social location of these identities possessed by women of Color and how their location does not create an additive experience of oppression, but an entirely new dimension of it. Intersectionality asks us not to consider how sexism *and* racism affect the material conditions and structural marginalization of women of Color, but how these two types of oppression combine to create a specific marginalized experience. By considering these issues simultaneously, we are able to gain better understanding from women of Color on how their lives are inherently different from both white women and men of Color, and how they exist at a specific, unique intersection of marginalization only they know.

While originally discussed in the context of women of Color's marginalization, intersectionality has become widespread in its application and is now used to examine the intersection of any and all marginalized identities, such as low-income disabled people or queer immigrants. Patricia Hill Collins (2015), in a discussion of the complexities and contradictions in defining intersectionality, provides a general definition of the term: “the critical insight that race, class, gender, sexuality, ethnicity, nation, ability, and age operate not as unitary, mutually exclusive entities, but as reciprocally constructing phenomena that in turn shape complex social inequities.”[25(p2)]

There is a need for intersectional research on the diverse population of LGBTQ+ people, especially in transgender and non-binary research, as transgender people are more likely to live at the intersection of multiple areas of marginalization. Additionally, much of the research lumps all transgender people together as experiencing the same marginalization.[9,26] Transgender people are more likely to be Black, Latinx/e, or other people of Color,[9,12] sexual minorities,[13] have no health insurance,[9,13] no usual source of health care,[9,13] and lower incomes.[13] Trans women and non-binary people assigned male at birth (AMAB) experience higher levels of social and economic marginalization, including violence, depression, and substance use.[10,27] Transgender Black, Indigenous, and people of Color (BIPOC) patients experience feeling both misgendered and racialized by providers. The racism experienced is also seen as a barrier by patients for self-advocating for their gender identity to be respected, leaving BIPOC patients to prioritize which identities are most important in a given interaction.[16] BIPOC non-binary people additionally are forced to challenge the common narratives and assumptions that non-binary identities are exclusive to white people, complicating and intensifying the discrimination against having an already marginalized gender identity.[6] Combined with the interpersonal and institutional discrimination previously discussed, living in socioeconomically strained situations, as many transgender people do, increases the likelihood of earlier morbidity and mortality, making it essential to interrogate and dismantle the structural factors that lead to the discrimination against and marginalization of transgender people.[12]

With her definition of intersectionality, Collins adds that one of its core tenets is its use in critical praxis to examine how social justice work can be done.[25] By recognizing the ways our oppressions overlap and are amplified due to our social location, we can better work together in our collective fight against oppression in all forms. Though intersectionality in public health literature is rarely used in this radical way, the guiding principle of praxis reminds us that our intersectional work is best used to impact the material realities of those we study and work with. In looking at transgender health care, we can engage in praxis by examining the unique, intersecting experiences of transgender and non-binary health care patients to assess and reimagine care guidelines that not only meet everyone's basic needs, but account for patients' experiences at the intersections of marginalization. There are some universal experiences among transgender and non-binary people, though many aspects of their marginalization are unequally distributed or entirely distinct based on the person's sex, race, ethnicity, income, or disability, to name a few. In failing to account for this, we fail to thoroughly and effectively examine the breadth of issues transgender and non-binary people face.

Conclusion

Non-binary people are a specific health population with different health needs and outcomes compared to both cisgender people and binary transgender people. In the literature reviewed, non-binary people have consistently worse health risk factors and outcomes than their cisgender counterparts, though their comparisons to binary transgender people are less clear, with some indicators being worse and others better depending on the study. Non-binary people encounter a number of barriers to receiving care and often experience discrimination or discomfort when they do receive it, in addition to being invalidated, questioned, and facing providers' lack of knowledge on their lives and bodies. Numerous recommendations on improving transgender health care have been created and implemented, though the research backing these recommendations is most often only focused on binary transgender people with non-binary people left out or as an afterthought. While they may have many of the same recommendations for improving care as binary trans people, non-binary people have largely not been asked. Ensuring that health care practices and policies are welcoming to non-binary people and invested in meeting their specific health needs is key to addressing the health disparities that have been established.

CHAPTER III: Methods

Qualitative research allows us to investigate topics in ways that access the deep knowledge held by populations in ways that are more in-depth and contextual than can be accomplished by solely quantitative methods.[28] Additionally, qualitative methods such as in-depth interviews allow the researcher to establish rapport with the participants, providing the potential for greater detail and less hesitancy to discuss sensitive topics such as, in this case, personal healthcare information and experiences.[28] The use of qualitative methods in this study, specifically the use of open-ended and semi-structured questions, allowed participants to give meaning to their experiences in their own voice and provide personal context for their beliefs and behaviors.[28] This study took place from July 2022 to April 2023 and all interviews were conducted over the video conferencing platform Zoom which gave participants the ability to share their experiences in a chosen comfortable setting.

Description of Sample

This study involved interviewing nine people who identified as falling under the non-binary umbrella. Participants held a variety of non-binary identities, including genderqueer, gender non-conforming, agender, and transgender. Three participants identified as Black and six identified as white, with one white participant identifying as ethnically Jewish. Most participants identified their sexuality as queer, with others identifying as lesbian, polyamorous, and/or bisexual. The majority of participants had one or more disabilities or chronic health conditions. Most of the sample identified as middle class. Ages of participants ranged from 22-39 with a median age of 24. All participants in the study use they/them pronouns. A full description of the sample is found below in Table 1. The descriptions were taken from participants' own answers to questions about their identities.

Pseudonym	Age	Race & Ethnicity	Gender	Sexuality	Health & Disability	Class	Country of Origin
Jay	28	White	Genderqueer, Masculine	Queer	Obsessive Compulsive Disorder	Middle-class	United States
Cynthia	24	Black	Non-binary female	Bisexual	N/A	Middle-class	United States
Arden	23	White	Trans, Non-binary, Agender	Lesbian	Bipolar disorder	Middle-class	United States
Ray	39	White	Genderqueer, Genderfluid, Non-binary	Queer, Bisexual	Anxiety, ADHD	Middle-class	United States
Ricki	30	Black	Gender non-conforming, Non-binary	Queer	Albinism, Legally blind, Anxiety	Middle-class	United States
Max	24	White	Trans, Non-binary	Bisexual, Polyamorous, Queer	Mentally ill, Type II Diabetes	Working-class, paycheck-to-paycheck	United States
Seven	22	Black	Queer	Queer	N/A	Middle-class	United States
Dawn	28	White	Non-binary, Trans, Queer	Queer	Depression, Anxiety, ADD	Middle-class	Japan, U.S. Citizenship
Levi	24	White, Jewish	Genderfluid, Male presenting	Queer	N/A	Middle-class	United States

Table 1. Participants' Demographics and Identities

Sample and Recruiting

Convenience sampling was chosen as the sampling method. Convenience sampling is appropriate as transgender people, though a broad population, are hard to reach as there is not a single list or organization that could be used for other sampling strategies.[29] As a non-binary transgender person myself with many non-binary and transgender contacts, I felt I would have access to a large enough personal network to recruit a sufficient sample. Purposive sampling was not implemented as there were a limited number of potential participants who reached out for more information on the study. There were two interested participants who dropped off during the recruitment process.

Participants were asked to reach out to me through my Emory email or an Instagram account created to host information on the study to go over screening questions and answer any initial questions they had about the study. Once participants had gotten in contact with me, they went through a very simple screening process as my study population is rather broad. Participants were asked about their gender identity, if they identify as intersex, their sexuality, their race/ethnicity, their country of origin, if they have a disability or identify as disabled, if they identify as neurodivergent, and their age. Participants were included if they identified as non-binary transgender and were over the age of eighteen, though other screening questions were considered in an attempt to have a diverse sample in the categories listed. Though this didn't come up in the sampling process, participants would have been excluded if they did not identify as non-binary or were under the age of 18. Participants were not initially asked about the length of time since their last medical appointment or frequency of medical appointments as it is a common experience for transgender people to avoid medical care due to previous discrimination.[17–19]

Participants were directly recruited through three sources: digital flyers on the study's Instagram, in organizational group chats, and through emails sent by an Emory student organization. Flyers contained a one-sentence introduction to the study, eligibility criteria (identifying as non-binary transgender and being 18+), and the researcher's email. Additionally, the researcher's personal contacts shared the flyers with their own contacts through Instagram and LinkedIn.

Data Collection

The interview guide was constructed based on the data presented in previous studies referenced in the literature review, including both the ideas and themes presented by the researchers and the experiences of their participants (see Appendix A). The guide was not pilot tested, though it was reviewed by the IRB and the researcher's thesis advisor. Topics were ordered in a way that attempted to mimic how a natural conversation would flow, moving from introductory questions about identity and inclusivity, to main questions about positive and negative health care interactions and recommendations for improvement, and a closing question to give participants the option to share any information not already covered in the interview. Potential probing questions were listed for almost every question to ensure the researcher covered all aspects of the question being asked. Additionally, there was a reference listed at the end of potential health care factors to improve upon to use to prompt participants should they struggle to think of recommendations, though this was rarely used (see Appendix B).

All interviews were conducted over the video conferencing platform Zoom. They were audio recorded and transcribed verbatim, with the researcher taking additional notes during the interviews. Consent for both participating in the study and to audio recording the interview was obtained through a signed consent from prior to beginning the interview. The consent form explained the purpose of the study to participants along with the approximate length of the interview, the general themes of the interview questions, the de-identification process, and the voluntary nature of the interview, including the participant's ability to skip questions or end the interview at any time. Participants were asked if they understood all the information presented and if they had any additional questions before being asked for their signed consent.

Coding and Analysis

After being recorded, interviews were transcribed verbatim then read multiple times before being to code for key elements and themes. Though the process began with some deductive codes, most codes emerged during the analysis process. Deductive codes were developed based on the interview guide, including "Changes in Healthcare," "Interactions with Oppressive Systems," and "Provider Interactions." Inductive codes were created during the coding process and included codes such as "Avoiding Medical Care," "Insurance," and "Gender Presentation." During the coding process, I sought to create codes that were guided by what was shared by participants, with one mention being enough to create a code, even if that code was not used many times, an example being "Referral Letters," which was only mentioned once by one participant. Some codes were created further into the process, though, and required going back over previously coded transcripts to ensure every instance was noted, as was the case with "Gender Presentation." Coding was done only by the researcher, so there was no opportunity to test for inter-coder reliability. The codebook was developed after the coding process was completed due to the codes and their definitions changing throughout the coding process. The codebook includes parent and child codes, code definitions, inclusion and exclusion criteria, and example quotes.

Ethics

This study was deemed exempt from Rollins IRB approval. Participants were asked to consent to the study, informed that they would be participating voluntarily and without compensation, and that their information would be deidentified and confidential. Data was deidentified by replacing participant names with pseudonyms and removing any other information that could be used to identify the participant, such as their locations, insurance plans, or names of doctors. One participant was given the opportunity to choose a pseudonym and voluntarily chose to have their first name associated with the study, though other instances of identifiable information were removed. This request was followed as feminist research methodologists have discussed the right of the participant to choose for their name to be associated with the research they are involved in, which can be especially important for participants who are marginalized and oppressed.[30] There are power dynamics between researchers and participants inherent to the research process, but steps can be taken to lessen them. Giving the power to the participant to reject their anonymity and choose to have their name associated with research is one step in rebalancing power in the research relationship.[30]

Recordings and transcriptions were kept confidential by being stored on a secure password protected computer and by destroying audio files following the completion of transcription. It was determined that the only potential harms to participants were emotional distress or discomfort, loss of privacy, and breach of confidentiality, none of which appeared in the study. No other ethical issues emerged during the course of the study.

CHAPTER IV: Results

"I think that our healthcare is just, like, a reflection on our, like, society not being comfortable with, like, non-binary people." **Ray**

This was a qualitative study that used semi-structured in-depth interviews to gain a deeper and richer understanding of the past medical experiences of non-binary people and their recommendations for improving healthcare. Participants in this study were asked about the formation of their non-binary gender identity, their definitions of inclusion and exclusion, their past positive and negative medical experiences, and their recommendations for improving healthcare for non-binary people, including how to foster trust between patients and providers.

First, I will summarize inclusive and exclusive practices identified by participants. This includes how they define inclusion and exclusion—both in general and medical settings—and the most commonly reported and needed practice for full inclusion: the use and respect of patients' pronouns. Following, I will discuss the intricacies of privilege and marginalization expressed by participants, how their race, sexuality, ability, and class (and their intersections at the center of these marginalizations) played into the quality of the healthcare they received. Next, I will talk about the experiences of the providers who participated in this study, including their time in medical training and the practices they currently employ to ensure they are creating safe and inclusive medical spaces. Finally, I will cover the recommendations identified by participants on how to best create medical environments that are welcoming, inclusive, and supportive of non-binary patients.

Inclusive and Exclusive Practices

Participants were asked about how they define inclusion and exclusion broadly as a non-binary person at the beginning of the interview and were later asked how they define those terms in a medical setting. These questions were meant to give space to participants to share how feelings of inclusion and exclusion affect their everyday lives, with multiple participants sharing how these concepts operate in their workplace and academic settings in addition to medical ones.

One participant, Dawn, used the metaphor of the kitchen to describe inclusive environments, “make sure everyone, like, has a chair at the table and if not bring your own, one, but…make sure everyone has actual access to the kitchen.” They noted that inclusion is not just about making sure that people are included superficially, but that, additionally, everyone has access to the power of “the kitchen,” to make the decisions that affect them along with the rest of the people at the table.

Other participants, however, had a more difficult time defining inclusion and exclusion, both broadly and in their interactions in medical spaces. Specific examples were often given, but they struggled to articulate the concepts in succinct ways. This represents the multidimensional aspects of inclusion, as there are many components to inclusion beyond simply saying that certain people are welcome in a space, as Seven tells here,

> “I think inclusion or inclusivity is a hard goal to achieve because I feel like it's less about the act of, ‘we did the thing, we, like, used your pronouns or we said, you know, birthing people instead of women,’ and more about, like, [pause] I feel like it's a lot less tangible. It's like, I feel like it has a lot to do with feeling and community and, and knowing that you're safe and that you're seen, and I'm not sure I have a good answer for what that looks like or at least how to get there.” **Seven**

Seven said themself that this is a hard concept to define and that they don’t have a good answer, but they captured the idea that we must consider that inclusion cannot be accomplished by making simple gestures that someone is welcome, but that it must be all encompassing. We must instead consider the patient’s own community and create structures that ensure that they truly feel the sense that they are safe and belong. Inclusion cannot be achieved in a simple manner; it must be an effort taken on by every person involved in the medical space.

In terms of feelings of inclusivity in medical appointments and settings, participants' most common answer was on pronouns. Most medical forms only list "female" and "male" as gender options, give limited options for sexuality and partners' genders, and do not provide space to say what the patient's pronouns are. This is most often because electronic medical records (EMRs) do not give space for providers to have more checkboxes or write-ins. This exclusionary practice makes patients cautious about the medical interaction before they even enter the exam room. The absence of a wide variety of self-identification options made participants feel they could not share this information voluntarily with providers or made them wary of what a provider's reaction would be if they did disclose their gender and pronouns.

Jay noted that when given the option to disclose their pronouns, they instantly feel relieved, "but I think, I think when, when I see an intake form that's got, like, a room to put my pronouns on there that I immediately feel, like, safer and more like, 'okay, I can like, tell this doctor.'" Jay's quote shows that when patients are immediately given the option to be open about their identity, their feelings of safety increase. They instantly feel like it's more likely their pronouns will be well received by their doctor. The inclusion of pronouns on intake forms, even if they can only be noted in EMRs, is one example of creating an environment in which non-binary patients feel welcomed, respected, and like they belong in the medical space.

In contrast, Levi, who is an AMAB genderqueer non-binary person and is often assumed to be a cisgender man, has never felt like they could talk about their gender identity with their physicians. They have not been given the option to self-identify on forms and, because of their presentation, have never been asked about their gender or pronouns. They choose not to disclose these aspects of themself to doctors because they don't feel it would be well received and because they believe doctors would make harmful assumptions about them anyway.

Similarly, Ricki has also felt that they could not disclose their gender or pronouns to providers unless explicitly asked. They are AFAB and often assumed to be a cisgender woman and, because of this, do not feel like they can advocate for themselves,

> "I like, go in, keep my head down. If you think I'm a lady, I'm a fucking lady, you know, like kind of thing. Then I'd say they've been pretty consistent because I have not been an advocate for my gender identity most of the time, unless I—again, it's on the form and they seem like they know, then I'm not gonna bring it up." **Ricki**

Like other participants, Ricki feels they are forced to hide their identity through feeling like their provider would not respond well to it unless there was a previous message that they would be accepted. By not including pronouns and gender self-identifications on intake forms and not bringing these topics up in the exam room, physicians are leaving patients to hide important aspects of their person, excluding these patients from the holistic care that they deserve. As will be discussed further later, Ricki is also Black and has albinism, making doctors often assume their race in addition to their gender. Like other Black participants, not giving space to be upfront about their pronouns puts Ricki in a bind where they must choose which identity is more important for them to be vocal about, their race or their gender, if they feel safe enough to speak up at all.

Dawn recounted their experience of getting tubal ligation and having their identity completely disrespected by medical staff. While the procedure itself went well, they were never asked their pronouns and, as a result, were misgendered throughout the process. They explained, "[I was] literally getting my tubes removed so I don't have to be, like, a reproductive member of society," but there was no consideration of the possible gender-related reasoning for them undergoing the procedure. After they got out of the operation and were on anesthesia, they told one of the staff that they are non-binary and use they/them pronouns. They also told the health care worker to call them by their name if it was too difficult to use their pronouns. The staff person then asked what non-binary meant and Dawn then had to explain while, again, still under the effects of anesthesia. They then said,

> "And then like, obviously, when I came to later, it didn't hit me until like, yeah, it hit me like 24 hours later, nobody respected my pronouns, nobody acknowledged it except that, like, one lady and I had to educate her on [being] non-binary. I was like, the fuck people?" **Dawn**

Dawn's experience was one of many shared by AFAB participants of being disrespected or having their identity ignored in OBGYN spaces. OBGYN offices were repeatedly brought up as sites that feel exclusionary through marketing and language that implies that these spaces are only for cisgender women. Multiple participants were made to take pregnancy tests even after disclosing the anatomy of their sexual partners or explicitly refusing the tests. All participants who reported these experiences commented that they and other transgender and non-binary people need reproductive healthcare too, and that these messages made them want to avoid medical settings that did not explicitly state that they are inclusive of transgender and non-binary patients.

For some participants, like Jay, these feelings of not belonging in a medical environment started when they were young. In discussing how they came into their non-binary identity, Jay talked about their experiences as a child going to pediatricians as they were just starting puberty,

> "…like, all the doctors I had when I was, like, 'going through puberty' and like, 'becoming a woman,' like, they talked to me in ways that, looking back now, I understand why they felt wrong at the time, but at the time, I couldn't be like, 'oh, the way you're talking to me about me getting my period for the first time is like, giving me dysphoria.' You know? Like, I couldn't know at the time, I was just like, this is icky and weird and I don't like it. But now looking back like, yeah, I was seeing doctors who were trained to train me on how to be a woman." **Jay**

For participants like Jay, feeling like they were excluded from medical settings began before they identified as non-binary, though they couldn't articulate why at the time. This experience shows that even when patients are not out as transgender or non-binary, and even if they are children, physicians should be taking care to ask about gender and pronouns and their comfortability with talking about their bodies, especially around puberty. Their comment that they were seeing doctors "who were trained to train me on how to be a woman," shows their acknowledgement that many pediatricians are trained on how to talk to children about puberty without taking into account how they feel about it and that there may be underlying feelings surrounding their gender. Some children may not be able to explain their gender or feelings around their body in detail, but many can, and a provider knowing that they feel "icky" or "weird" when talking about the changes their body is going through may better inform the provider about how to care for their patient.

As said previously, inclusion is hard for participants to define and can be difficult to tackle. While multiple participants stated that they felt included through symbols like flags, this was the bare minimum for some participants. Dawn said that these displays can be performative and often "doesn't mean shit." For them, providers being competent on pronouns, non-binary identities and bodies, and not requiring patients to explain these concepts to them was much more important. Levi had a similar perspective, saying that many cisgender people,

> "…don't have a framework to understand it. And so, it's like, I can talk to you about being queer, but [they] don't understand it, [they] don't really understand what you're telling [them]. [They] might, you know, [they] can regurgitate it back to you. But I think that that's where like, a lot of the misgendering was, you know, especially around pronouns and stuff like that, where people are like, okay, they go by they/them, but then they'll just automatically default to he/she because they can, they truly only can think in the binary." **Levi**

Levi described that it can be difficult for cisgender providers to step out of the societal frameworks that center cisgender people and their experiences and that this is a detriment to the health of their transgender and non-binary patients. They might be able to understand the very basics of pronouns, but until they do deeper learning, self-reflection, and tear down the cisnormative structures in their minds, they won't be serving transgender and non-binary patients to the best of their ability.

Defining inclusion and exclusion beyond specific examples was difficult to describe for many participants, with multiple participants calling it a "feeling" they have about the space and providers they interact with. These terms can't be easily defined for most participants, though pronouns were especially important to feeling like they belonged in a space. As mentioned by participants, having a provider give space to talk about pronouns—both in forms and in person—immediately made most participants feel at ease in the interaction. Beyond that, though, it was about abstract feelings of safety and community that make them feel like they belonged.

Intersecting Marginalizations

All participants, and all patients for that matter, enter the medical space at the intersection of a variety of identities and these are often marginalized. Participants in this study were asked how they identify on a number of factors, including their age, race, ethnicity, gender, sexuality, health and disability, class, and country of origin. This section will mainly focus on race, sexuality, health and disability, and class. It's important for providers to consider the social locations of their patients because they need to be seen as whole people and, as participants will describe, when their full range of identities are not taken into account, they feel they are not receiving the care they desire and deserve.

Race

Before diving into the participants who are marginalized in terms of race, all of whom in this study are Black, it's important to note that all white participants said at some point in their interview that they recognize the racial privilege that they hold and many also acknowledged that it is their role as white people to use their privilege to help those that are marginalized,

> "And it's very unfortunate that our own entities where we can just be in live, have become such a political thing, but you know I reflect on that that I am a white person and people of Color, their whole identity has always been political. Like they're, you know, they've always had to be conscientious and so I think it is just a snippet

> or sneak peek of like, what their life experience is. And so, I think you, you have to use your own privilege and aspect to help others." **Dawn**

As Dawn expressed, having a non-binary identity brings its own challenges, especially in the current political climate that seeks to limit the rights of both trans youth and adults, including banning gender affirming care, removing medical transition expenses from Medicaid coverage, and the right-wing demonization of the LGBTQ+ community at large. Participants discussed that the transgender and gender expansive community has always been in a political battle for the right to exist, though not in the same ways people of Color, especially Black people, have been marginalized in the U.S. and abroad. As described by participants, it is important for white transgender people to recognize that their struggles are not the same and that Black transgender people, especially Black transgender women, experience the brunt of the marginalization, dehumanization, and refusal of medical, housing, economic, and other resources. As Dawn acknowledged, this recognition must also come with a duty to use the privilege you have to advocate for those who are more marginalized.

For Black participants, they all felt that there was a tension between their racial and gender identities, often resulting in them hiding or downplaying their gender or race depending on the situation. Ricki has albinism and because of that, has always had others make assumptions about their race, often assuming them to be a white person, making it difficult for them to take on another marginalized identity others may not understand,

> "I just still didn't want to identify as non-binary, because, *because* I knew that my racial identity was already too confusing for people…. And so, I really just, kinda to people-please, you know, I didn't want to identify as non-binary because, I was like, 'well, it's just already confusing.'" **Ricki**

Ricki felt their racial identity was "confusing" for others and didn't come out as non-binary for a while because of this, even though their life is "very queer", and they had dated multiple transgender and non-binary people. Ricki described the tension between their race and gender that is also mentioned by other participants, though their experience is unique due to their medical condition. Ricki said later in their interview that they have been assumed to be white by multiple doctors even when their race is listed on their chart. With these racial assumptions by physicians, Ricki is put in a bind of choosing to correct them on their race, share their gender identity, or choose to be quiet about both.

Black participants also shared that they must also choose whether to be upfront about their gender identity within their own racial community, as they may not be accepted unless they are around other queer Black people,

> "…sometimes when I'm engaging with some parts of my identity I have to sometimes hide or like suppress some other parts. So, like, hanging around um, other Black folks that may not be queer like, having to like, sort of prove my femininity or having to like, sort of play cisgender sort of how people assume you are, um, because it may not be as much accepted within your racial community..."
> **Cynthia**

Like choosing to not be open about their gender identity in medical settings, Black participants must also choose when to be open with other Black people. Cynthia felt they had to "prove their femininity" and "play cisgender" in order to be accepted and, because Black community was so important for participants, this often left them to suppress their gender for fear of being rejected or facing misunderstanding.

As Ricki so well said, "medical racism is real, it's still very alive and real." This was on the minds of all Black participants when entering the medical space, as there is a long, traumatic history of structural medical racism in addition to their own individual experiences of being racialized and marginalized when seeking medical care. Seven shared their own traumatic experience at an OBGYN,

> "Something else comes to mind, but it was a really bad experience, um. So, I'm trying to think of ways to express what I feel in a way that's not visceral or graphic words, um. With the doctor that I went to mistakenly, um, I just, I had to get like, swabbed for a test and it was like, very clear that I was physically uncomfortable.

> And [pause] what words do I use? [pause] Instead of recognizing that I was uncomfortable for a reason and like, giving me like, time or space or like, inquiring, there was like—it was my natural reaction to resist and it was her response to like, keep going…. And like, I don't know, I'm feeling like [pause] I don't know what it has to do with, I don't know if it was just like, an unfortunate turn of events or if you know, I was also wondering when I left like if it had to do with like, my being Black. Like I can't prove that, I don't know that, like, she didn't say anything to me that would indicate that, but I feel like there is the clear lineage of dehumanization of Black people in, in medical settings and so, I, I really don't know." **Seven**

Though Seven acknowledges that they can't exactly say that what happened to them was because of medical racism, they are exactly right on the "clear lineage of dehumanization of Black people in medical settings." Practitioners have been taught that Black patients have higher pain tolerances, thicker skin, and do not require pain medication to the same degree white patients do. Even if their physician had none of this in mind at the time, it is undoubtable that they had at least some unconscious bias toward Black patients, and this may have influenced their decision to ignore Seven's clear discomfort.

Cynthia had an experience also linked to medical racism where they visited a neurologist and had their concerns ignored because of their race,

> "I did have one experience with a neurologist who, sort of—I threw out a possible diagnose-diagnosis for some things I was experiencing, and they dismissed it because they're like that doesn't happen with your race…. And I was like, they're like, 'oh, it doesn't really happen to Black people like, you know, it only happens to those who are white,' and, you know, etcetera, etcetera. And I was like, I mean, I guess-I guess it's, maybe it's not common in my race but that doesn't mean you should throw the diagnosis out the window." **Cynthia**

Cynthia came to their appointment with their experience and a potential diagnosis and was immediately shut down by their doctor because of their race. As they said, the condition may not be common in Black people, but that doesn't make it impossible. Luckily, they found a new neurologist who has helped them figure out what's going on, but they could have easily had a diagnosis sooner if their first physician had listened to their concerns and investigated possible causes, even if they were unlikely.

Sexuality

As a teenager, Levi identified as gay and went to their pediatrician for a pre-exposure prophylaxis (PrEP) prescription to protect them from HIV infection. Instead of being compassionate towards a young gay person's health concerns, Levi's doctor instead refused treatment,

> "So, with my old pediatrician, I, when I, I was like 17. At first, I was like, I know I'm at an increased risk for HIV. I knew about PrEP. So, like, at this point, I was a very well-educated 17-year-old. And when I went in for my physical, I was like, I am like, she didn't ask, first of all, she just like, blew past everything. And at the end of the appointment, I have to be like, I am gay, I know I'm at an increased risk for HIV, I know there's a medication called PrEP to prevent me from getting it, like, how do I get a prescription for it? And she just, like, looked me dead in the eye and said, 'I don't know, Google it,' and walked out of the room…. And I was just, I sat there for like, a good like, 5, 10 minutes, where I was just like, I don't know what to do with that. And then I just kind of like, walked out. I didn't tell anybody." **Levi**

Levi's physician completely disregarded their concerns for their sexual health due to her stigma against their sexuality. As a pediatrician, she should have admired a young person trying to take control of their sexual health and protect themselves against an infectious disease, instead refusing to even listen to them or direct them to resources. Levi is one of the practitioners in this study and discussed later in their interview that it is also the responsibility of physicians to direct patients to other doctors who can meet their needs if they have religious or moral bias against proving care. This experience left Levi without the compassionate health care and consultation they were seeking and with the shame of asking a simple question of their provider and being denied resources, leaving them without the words to share their experience.

Health and Disability

At the time of their interview, Max was very recently diagnosed with type 2 diabetes and has since had a complicated relationship with their diagnoses based on their size and health history. Max describes their body as fat and is aware of the rampant fatphobia in the medical community and in larger society. As a result, they haven't "told a fucking soul" about their diabetes "because what if they're fatphobic about it?" They explain, "it ain't worth it." They were afraid that their diabetes diagnosis was rooted in fatphobia and were at first reluctant to listen to their doctor until she explained the diagnosis and its presentation in-depth and in a way Max could understand. Additionally, Max had only recently gained insurance coverage through their job, something they didn't have as a child. In combination with their working-class status, their lack of insurance made it so Max had very limited contact with doctors until recently. Their experience of not having healthcare of most of their life added another dimension to their new diagnosis,

> "What if [my diabetes] was bad my whole life and no one—I never knew? But also like, even if it was bad my whole life, we were poor, so if it was bad—I'm almost glad I wasn't on meds because if I went off them, who know what the fuck would've happened to me." **Max**

Max's lack of access to health care due to financial constraints means that even if they knew about their diagnosis before, there would have been little they could do to manage it. Though Max now has a doctor they trust and has the ability to manage their diabetes, their past and present class status make them nervous that they won't be able to receive the care they need and deserve if they lose their employment and coinciding health insurance.

Ricki is another participant who has a physical disability. They are legally blind and have had a difficult time with optometrists for most of their life, with one previously calling them "complicated." Once they tried on their friend's glasses and could see so well, they took the glasses into their optometrist to find out the prescription to use for themselves. The doctor refused to give them the prescription, saying it was private medical information. Ricki instead found a new doctor who provided more compassionate care. In reference to optometry equipment, their new doctor said,

> "'fuck the machines and everything like that, like, go outside and walk around with these and tell me what you can and cannot see,' and I think there's just a metaphor

> there of like, ‘what is this like in practice for you, versus, like, how I've been trained.’” **Ricki**

Ricki appreciated the doctor stepping out of their strictly clinical role to give them the opportunity to see how they navigated the world around them with a new prescription and the metaphor of “walk around and see how this works for you.” By deciding to not rely on purely clinical equipment and instead listen to Ricki’s life experience, Ricki’s provider was able to give more informed care that centered them and made them feel like they were being treated holistically. Providers stepping out of their clinical role to best serve their patients will be further examined in a later section.

Provider Experiences

Three participants in the sample had received medical training, with two currently enrolled in a physician’s assistant program. These interviewees who were also providers were asked about their medical experiences as both patients and practitioners to gain an inside perspective on their preferred practices to create inclusive, welcoming, and holistic medical spaces.

Participants recognized that there was an issue with how non-binary patients were treated in the medical system. They were aware of the transgender community’s higher rate of risk factors in regards to their physical and mental health and the need to meet these patients where they are to best address their needs. As non-binary patients themselves, they also had medical experiences, some previously discussed, that informed their perspective of how patients should be treated and respected in the medical setting. Levi, like the other participants, acknowledged the common experience of transgender people being reduced to their hormones and trans bodies which prevented them from receiving comprehensive health care for other medical issues. They explained,

> “But like, you know, like if there's the joke of like, oh, a trans person shows up to the emergency room with a broken arm and they say, ‘oh, it’s your hormones.’ Like, it's always, it's always blamed on the hormones, when it's like, no, they have a broken arm, like, fix the broken arm. So, like, I think a lot of areas of medicine can

> just, you know, fix the broken arm. And that's fine. And just kind of…blind to the transness of the person. But I think until we as an entire field of just like, service providers, we agree that trans and non-binary people exist, and that we need to talk about it and incorporate it into the care to give it a more holistic approach. That's what I think." **Levi**

The "oh, it's your hormones" joke described by Levi is often repeated in discussions about transgender healthcare and reflects the idea that many medical providers do not believe they've dealt with transgender patients before, don't understand hormone replacement therapy, and don't have the appropriate competency on transgender health to properly serve their patients, even if their hormone history is completely unrelated to the problem at hand. Lack of competency prevents health care workers from providing inclusive healthcare to transgender individuals and similar confusion occurs with non-binary patients who are not on hormones.

Participants had a lot to share on their perspectives as practitioners and medical students in regards to what makes an inclusive medical experience and how to develop trust between patients and providers. Dawn detailed many different aspects that health care workers can use to create of creating inclusive, informed, and competent care for patients. They began with approaching the patient with easy-to-understand language and using a "teach back" method,

> "And so, the things you do is you sit down at eye level with your patient and you use, like, simple adjectives like, simple terms. So, like, wherever their education is, you just kind of bring it down. You do a teach back method. So you tell them and you go, just make sure I got this right, and I shared it with you, can you tell me like, what we're gonna do and change?" **Dawn**

Dawn acknowledged that it is important for the patient to feel like a contributing member of the conversation and that their understanding of the information and the next steps to be taken in their care are key.

Next, Dawn said that there should be a limited number of changes in the patient's care, that the provider should meet them at eye-level and away from the computer, actively listen to the patient when they describe their experiences, and respond with validation,

> "And you only do like, two to three, absolute max, different changes to your patient, so like, if they can have a lot of things going on, you just minimize it, like, you do this. You show a genuine sense of care…. You know, you put your computer to the side, and you can listen to them, where you let them like, 'hey, I'm going to be listening. Like, I'm gonna listen to you, I just might have to look over my computer just to document things,' but you just make sure your computer's not your barrier. You know, you show active engagement. You can repeat things back and you validate things, like, I can see that you're really frustrated, or I feel you're really sad…." **Dawn**

Again, Dawn spoke about the importance of making sure the patient feels comfortable in the space, that they feel truly listened to, and that they are actively involved in making decisions about their care.

Finally, Dawn described the importance of the provider being accountable in the setting and acknowledge the inherent power dynamics of the situation,

> "And then again just like, the accountability. Like if you see like I see that, you know, you might be uncomfortable, did I like, overstep or something? You want to make sure that your patient feels like they're the one that has the power, not you. So, they even tell us, you know, don't bring in your white coat one, because they bring in germs everywhere, but also because it's like a power dynamic. You don't, they're going to listen and do whatever you say, right? And so, you want to break that down, but that's why you sit down, and you listen, and you provide contact, and yeah, you just validate their feelings" **Dawn**

Dawn also shared the importance of eye contact, a non-judgmental tone, open body language, and talking to non-English speaking patients directly rather than to their interpreter. Their many examples show that they have thought deeply about this issue and value the importance of the patient-provider relationship. They are cognizant of the power dynamics present in the exam room and are taking active steps in their own methods to decrease the difference between patient and provider. They, along with the other practitioner participants, saw the patient as the one who should hold the power in the medical space and that it was their job to be competent on the issues affecting the patient and the identities they hold.

Practitioners also spoke about the importance of diverse representation in medical school training. Having transgender practitioners share their experience and expertise was seen as invaluable; to have information coming from not just a professional background, but one that is rooted in the community that is trying to be served. For example, Dawn explained,

> "And then having just like that diverse like, making sure like not having like a token trans person but if you have the opportunity to have that diversity and representation, you should take it and have an opportunity for feedback from your own trans community, like, what are we doing right? What are we doing wrong? The biggest way you impact a community is asking it, what do they want? That's like, public health 101, right? Like why are you gonna do something for someone and they're like, we never wanted that?" **Dawn**

Dawn made the point that diversity is not the only important factor, but that diversity must be coming from the community directly and that community members should be involved in shaping the medical practices students are learning. It's "public health 101" to include the target population in the consideration of their care issues and that they should be included to provide feedback on the program's and practitioners' performance. As the transgender and non-binary communities are constantly evolving, it's especially important to routinely receive feedback and make corrections and additions to medical training and continuing education programs to best serve transgender and non-binary patients.

For the two medical students in a physician's assistant program, Levi and Dawn, they had both taken on advocacy roles in the classroom for transgender and non-binary patients. Their choice to be outspoken about these issues came from their own need for inclusion, as well as that of their fellow transgender students who were less likely to speak up for themselves. Dawn shared with me an email they wrote to their entire PA program where they said they were transitioning their pronouns from she/they to they/them and gave reasons for why they were making the change, including that they had begun to feel more distant from she/her pronouns. They also gave the reasoning that it was important for them to share this information as advocacy for other students and patients, making it known that competency on this issue isn't just polite, it's required to respect the basic needs of every patient who enters a health center.

Advocacy is not easy for these students, however. As Levi shared, the brunt of the work on educating on these issues is mostly given to the transgender and non-binary students themselves. They explained,

> "And I think that the education of my peers on these topics are largely given to the other students who are queer and non-binary, to educate, you know, the other people. And like, I feel like again, being part of a marginalized identity, like, you have to be the one to constantly advocate for yourself and educate other people. And I definitely, like, took on that role. And like, I want, I want to do that as part of my career. So, I don't mind doing that. But it does get exhausting to have to be like, you know, the authority on like, my identities." **Levi**

As stated, this advocacy work can be exhausting, as it takes not just the time to educate fellow students, but the emotional work of detailing their personal and community experiences, many of which may not be positive. Levi pointed out that this isn't limited to queer, transgender, and non-binary people, but that it comes along with every marginalized identity to be the expert on your community. Existing at the intersection of marginalization puts further stress on the individual to be an expert on a variety of issues, which is especially straining as a student trying to learn with the rest of their peers. Still, participants shared that they don't mind taking on this extra work, even if it is tiring, as they recognized that it is not just for their benefit, but for the benefit of fellow students, patients, and the wider community.

Participant providers shared a number of experiences working with patients and, for Dawn and Levi, their experiences currently being in medical training. What was most important to these participants was the patient-provider relationship where they seek to maintain trust, diminish power dynamics, and remain competent on the issues their patients face and the identities they hold. Not all providers have this perspective on the transgender and non-binary communities and patients though, at best feeling it is competent enough to treat them as they would any other patient and dismissing the unique medial issues that these communities face. Levi made the observation that this is not enough and that efforts to really know your patient take patient care "to another level." They explained,

> "Like, I feel like there's, there's a lot of depth, definitely, there's a lot of areas of medicine where, like, you can get away with really not bringing it [gender identity] up, and it's not a big deal. But it might also just inform your care to another level that might, you might be able to provide extra, you know, some kind of extra support or being able to connect certain dots that you weren't able to before or what have you." **Levi**

It's their perspective that any additional information that can be learned about a patient gives the provider better insight into the medical issues the patient is facing. If nothing else, giving the patient emotional understanding of their situation and demonstrating that you are knowledgeable about their community can build a stronger patient-provider relationship and create a better patient experience. As shown in the previously discussed participant experiences, though, creating medical spaces inclusive of non-binary patients necessitates an understanding of identity, feedback from the community, and continuing education on these evolving issues.

Participant Recommendations

One of the main focuses of interviews was asking participants what they felt would create more inclusive medical environments for non-binary people. Participants focused on three areas: diversity of medical staff, education on non-binary identities, and creating patient-provider relationships built on trust.

Diversity of Medical Staff

Participants repeatedly requested a more diverse medical workforce in terms of race, gender, and sexuality. They immediately felt better having a practitioner that was a person of Color or was visibly queer and felt they would receive a better quality of care,

> "I think I feel more comfortable generally around doctors who are women and doctors of Color. And so like, white dude doctors I'm like, 'bruh, I don't even think

> you'd listen to me about my medical issues, much less like, how I feel myself, so just give me this prescription so I can get the hell out of here,' you know..." **Ricki**

Like others, Ricki felt apprehensive having a white cisgender male doctor, feeling that they were less likely to be listened to, experience empathy, and receive respect. For Ricki, the gender of their provider was at times even more important than race, as they'd had negative experiences with male doctors of Color as well. Another participant, Ray, has received care at a queer-centered clinic and felt they had a much better experience having a practitioner who was visibly transgender, finding it very affirming. Having a white cisgender male doctor left participants feeling like they had to treat their appointments as purely transactional, hoping to get in and out as soon as possible with the bare minimum to meet their concerns.

Additionally, it was common for participants to rely on recommendations from other queer or Black friends on which practitioners they should go to for their concerns. Ray has a friend who will screen offices before going to see if they are inclusive of patients who are queer and sex workers and has taken their screenings to inform their own choice of providers. Because participants have had such negative experiences with white/cisgender/male doctors, it has become the burden of participants to find medical spaces that are diverse and inclusive of them, rather than knowing that they would receive quality care no matter where they went.

It's not impossible for white cisgender male doctors to create inclusive environments in their practices and many examples above were given by participants on how to create this space. Still, in the current state of the political climate, participants were much more anxious that they wouldn't receive quality, inclusive care when their doctor didn't share their identities.

Education on Non-binary Identities

The most common request from participants was that practitioners gain a better education on non-binary identities, bodies, and experiences. They felt that the topic of transgender and non-binary people should be included throughout a medical professional's training and career, evolving as the community and its needs change. The current state of provider education on the transgender and non-binary communities was seen as lacking, especially in the area of challenging current structures and frameworks that negatively affect non-binary patients,

> "I think we're starting to talk about biases and how to, like, see them. But we're not really actually talking about why those biases are there, and how to deconstruct them, and how to actually move forward in building a better system, or just building a better framework in your own head on how you're going to talk to people. You can be aware that trans people get discriminated against, good for you. But like, you don't understand how you're actively participating in that system, it's not, you're not doing anything." **Levi**

Levi identified that it is not enough for current and future practitioners to simply know about their conscious and unconscious biases, but that they also need to be taught how these biases are influenced by larger societal structures, how they participate in the continuation of them, and how they impact every aspect of their patients' lives. Additionally, knowing about structures is only half of the issue, they must also be taught how these structures can be dismantled and reformed to create better, more holistic, and more inclusive healthcare spaces.

Participants wanted to see education on non-binary people be present throughout medical training and continuing education. For example, they explained there should not only be one or two classes offered on transgender and non-binary health and they should not be electives. These issues should be integrated throughout the entirety of medical education and specialty classes should be mandatory. Participants suggested that these classes should also be taught by transgender and non-binary people themselves, or at least by experts in the field. They felt that many providers didn't even realize they have transgender patients and that they should be taught that any of their patients could be transgender or non-binary and should, therefore, ask all patients the same questions that are meant to be inclusive of transgender people, including preferred names, pronouns, and using gender neutral language when discussing bodies.

Patient-Provider Trust

One of the areas focused on when asking for participants' recommendations for improving healthcare was on establishing better relationships between patients and providers built on trust. It is common for transgender and non-binary people to avoid medical care after negative experiences where their identities and bodies were disrespected or their experiences were not believed. One of the most common experiences described by the interviewees was providers refusing to ignore the gaps in their knowledge regarding transgender and non-binary patients,

> "I think doctors really need to be honest about their gaps in their knowledge, honestly.... I would even take, 'I don't know about trans people, but I'm open to learning,' like, 'I was never exposed to trans people, I was from a small town, I'm from somewhere where I didn't know any [trans people].' Just be honest about— you can tell me about yourself, you know. As long as you're open to that then I'm okay with that, honestly." **Max**

Like other participants, Max wanted their practitioners to be open about their lack of experience with transgender patients and, therefore, believe their patients when they talk about their medical experiences. Like other medically transitioned transgender and non-binary people, Max felt that their doctors dismissed their knowledge of their own medical history, stating that they did research on testosterone for two years before deciding to start hormone replacement therapy, giving them an idea of the expected changes, medication dosages, and levels that their hormones should be at. Instead of seeing their knowledge and life experience as a resource, however, Max felt doctors would frequently dismiss them, even if they had a gap in their education on these issues. Max and other participants wanted their practitioners to instead be open to learning from patients and to trust them when they came informed on their medical history.

Multiple participants felt that their negative experiences often revolved around not receiving holistic care that took their entire selves into account. They wanted doctors to talk to them in a way they can understand and see their patients as whole humans, complexities and all,

> "People sometimes don't know how this works and you just gotta like, talk to people. You just gotta really see your whole patient like, as a person, and you don't have to care about everything in their life but like, the patient's a complex person. Like, I have all these things about me, I'm mentally ill, I'm fat like, I'm trans…."
> **Max**

Max's quote reflects what was felt by other participants, that their physicians did not take the time to get to know them as people and were instead focused on getting them in and out the door as quickly as possible. They were aware of the constraints many doctors must work under, like having more patients than they have time for and thus needing to be time-conscious, but it still left them feeling like they were receiving subpar care. To build trust with their patients, participants wanted providers to take as much time as possible to get to know their patients as whole people, listen to them when they talk about their lives, and be interested in knowing more about their patient than just their medical history.

Similarly, participants commented on the fact that they often didn't feel like practitioners were empathetic to their patients and their conditions. Like Ricki being called "complicated" by an optometrist and Seven's traumatic experience at an OBGYN, participants felt like their doctors often lacked empathy. Max stated,

> "I feel like you lose the empathy when you become a doctor and it makes no sense because your whole job is to take care of people. It's, like, backwards, like, what? You know? Like, if you care about the person, why wouldn't you want to listen to them if they're telling you something's wrong?" **Max**

Again, participants wanted to be treated as whole people, for their physicians to listen to their lived experiences and complaints, and to receive care that was affirming of their identities and conditions. They saw trust as being essential to the patient-provider relationship, and they did not feel trust could be established if they didn’t feel wholly supported and that their doctor had empathy for their lived experiences. They wanted to feel a real sense of care in their medical appointments and often felt that was not a priority of their physicians.

Multiple participants also felt that their physicians consistently maintained power dynamics while working with patients, making it clear that they held the knowledge in the situation and that it was the patient’s job to listen and take their advice without much input. Many had positive experiences where this was not the case, but their negative experiences were full of instances of disparities in power. Participants wanted practitioners to be better trained in how to break down those power dynamics, engage their patients in dialogue, and believe their patients when they talked about their experiences and health history. In short, they were seeking a more holistic experience with their providers. Participants felt that this should also be key in medical training and continuing education, recommending more educational interactions with patients where they simply listen and learn and be given suggestions in how to establish a better, more balanced patient-provider relationship.

Conclusion

Participants shared their positive and negative experiences and how they affected them at the intersectional level, including how they view inclusive and exclusive practices, provider perceptions on creating holistic health spaces, and what they would do to improve healthcare settings for non-binary people. Their recommendations were numerous, like having expanded gender options and pronouns on forms and EMRs, developing a diverse medical workforce, expanding medical education to be inclusive of the transgender and non-binary communities, and building trust between patients and providers through acknowledging their gaps in knowledge, practicing holistic care, practicing empathy, and diminishing power dynamics in the medical space.

The implications of these findings, along with the limitations of this study and further recommendations, will be found in the next chapter.

CHAPTER V: Discussion, Implications, and Recommendations

This study investigated the positive and negative medical experiences of non-binary people and explored their recommendations for improving health care. The study included nine participants whose gender identity falls somewhere under the non-binary umbrella. Participants were asked about what makes inclusive or exclusive medical interactions and environments, their past positive and negative medical experiences, and their recommendations for improving care for non-binary patients. Due to limited research on the health care needs of non-binary patients, the results from this study hold important implications for improving the health care disparities faced by the transgender and non-binary communities.

This study found four key themes in the data: descriptions of inclusive and exclusive practices, the importance of intersections of marginalization, knowledge from the experiences from participants who are providers, and recommendations for improving care for non-binary patients. I will detail the first three key findings here and recommendations from participants will be discussed in the recommendations section.

First, participants shared their perspectives about inclusive and exclusive medical environments and interactions. It was largely difficult for participants to define what inclusion and exclusion meant, as their descriptions were often based on feelings of comfortability, community, and safety. Even with their self-described difficulty in defining these terms, though, participants were able to articulate some important points. This included making sure everyone not only "has a seat at the table," but also "has access to the kitchen," as Dawn described, meaning that non-binary people are not only included superficially, but have the power to make decisions about their medical care. Along with other participants, Seven spoke about the importance of understanding the larger community and its needs and making sure that structures were created to ensure non-binary patients feel safe and like they belong in the medical space. It was very important for participants that their pronouns and bodies be respected. Some participants spoke about the importance of displays like representation in advertising or rainbow and non-binary flags, but others saw these as performative. More important for participants like Levi was for providers to have an understanding of societal structures that goes deeper than just respecting pronouns.

The second finding was that all participants, like all people, exist at the intersection of multiple aspects of privilege and marginalization which impact the quality of their care. Black participants frequently experienced being racialized and experiencing medical racism in addition to marginalization based on their gender identity. Seven had a traumatic experience at an OBGYN in which their discomfort with a medical procedure was then ignored. Their experience is reprehensible, very likely linked to the history of dehumanization of Black patients, and not something any patient should have to endure. Cynthia had a neurologist dismiss a possible diagnosis based solely on their race, something no provider should do, even if unlikely. It is the physician's responsibility to take their patient's concerns seriously and to not exclude a diagnosis simply because of the patient's race. To do so otherwise is to continue the medical dehumanization of Black people. As a gay teenager, Levi was denied a PrEP prescription by a provider, being told to "Google it" when they inquired about the medication, leaving them without the sexual health care they needed. Max's identity as a fat person makes them extremely anxious that they will be the victim of medical fatphobia and their class status makes them unsure they will be able to afford needed maintenance care for their diabetes if they lose their insurance. While their non-binary identities were still very relevant, all participants had concerns about how they would be treated in medical interactions that resulted from more than just their non-binary identity, and many had negative experiences that influenced these concerns. With these intersections in mind, it is important for providers to consider the social locations of their patients and work to meet their needs in a way that takes into account and affirms all aspects of their identity.

Finally, three of the participants in the study had or were currently receiving medical training. They recognized the specific issues the transgender and non-binary communities face and had many practices intended to create more inclusive and holistic health care interactions. As non-binary people themselves, they also had insider knowledge on what best practices should be when treating these individuals. These providers shared a wealth of information on creating better health care environments for non-binary patients, and many of their recommendations can be found further in the recommendations section. Some specific recommendations included showing empathy to the patient and their experiences and breaking down power dynamics in medical interactions. In addition to recommendations for best practices, they shared the stress that comes with educating peers and professors on the needs of their own communities. It was tiring for them to be the experts on all issues surrounding the non-binary community, though they continued in their education of others not just for their own sake and comfortability, but of that for fellow non-binary students and future patients.

Strengths and Limitations

The major strength of this study is that it is filling a gap in the literature on best practices for non-binary health with recommendations coming from participants themselves. As has been repeatedly discussed in this study, most research examining transgender patients' needs focus solely on binary transgender people, or only include a handful of non-binary people in a much larger sample size.[1,12,20,22] Additionally, recommendations from these studies often come from the researchers interpreting the words of their participants, rather than taking their actual shared experience into account. By focusing solely on non-binary people and making recommendations using their words, this research contributes to a body of literature that currently only contains a small handful of studies.

Another strength of the study was the ability to recruit multiple participants who had or were currently receiving medical training. This was not a goal of the study in the recruitment process and happened organically and these participants added rich information. By being able to include participants who are practitioners, the study was able to gain inside information on how providers are trained on treating transgender and gender expansive patients, as well as best practices from providers who are non-binary themselves. I have only found one study that includes the perspectives of providers who identify as non-binary, making this an important addition to the literature.[31]

One of the major limitations of this study is a lack of diversity in a few of the examined areas. Only three participants identified as Black out of the nine participants, and there were no participants of Latinx/e, Asian, Native, Middle Eastern, or Pacific Islander descent. This is significant as conceptions of gender, gender roles, and what it means to be transgender or non-binary vary across culture and race, even in a U.S. context. There were attempts to gather as racially diverse a sample as possible, but this was not fully accomplished. Having three Black participants is still important however, as Black patients experience intense medical discrimination and racism and often have some of the worst health outcomes in the U.S. Additionally, there was little diversity in socioeconomic status as well as a lack of diversity of physical disabilities. It is important to consider these intersections as these populations experience extreme difficulties in finding care that is financially accessible, in addition to providers that listen to their experiences and take them seriously. Again, attempts were made to create a more diverse sample in these categories, but with the limited number of interested people reaching out to participate, this was not accomplished.

Should the study have had a longer time frame and resources to advertise more widely, these limitations in diversity may not have been an issue.

Public Health Implications

Stigma against the LGBTQ+ community is still rampant in the medical community, as it has been historically. While not necessarily on the physician's mind, the most recent example of the HIV/AIDS crisis has shown that doctor's stigmatize men who have sex with men and, at the time, refused to even touch them for fear of being infected with HIV. There have undoubtedly been improvements, but similar stigma against the LGBTQ+ community continues with many physicians today. Physicians, especially mental health providers, who are not familiar with transgender or non-binary identity will often try to link a patient's gender identity and dysphoria to the root of their medical issues rather than recognizing the larger structural biases or oppression that causes negative health outcomes. If a transgender or non-binary patient has depression or anxiety, it's because their gender dysphoria is the issue, rather than the transphobia that they experience and internalize. This again reflects a misunderstanding of the real physical and mental medical issues the transgender and non-binary communities face, of which there are many.

It must be mentioned that the current political climate is extremely hostile toward the transgender and non-binary communities. Currently 44 states have proposed a combined 382 bills targeting transgender and non-binary people, especially minors, in the areas of gender-affirming care, schools, and youth athletics, among others.[32] Many bills also concern the performance art of drag in public spaces, where language is often vague and could be interpreted to include transgender people with terms like "female impersonators." At the Conservative Political Action Conference on March 4, 2023, far right-wing commentator Michael Knowles said that "transgenderism must be eradicated from public life entirely" to a crowd of uproarious applause.

It is the opinion of this researcher and some online that this is a call for transgender genocide.[33] To call for the "eradication" of "transgenderism" is to call for the extermination of an entire community of people and their ways of life. This hostile political climate must be examined as it is well known in public health that policy has the potential to uplift or discriminate against structurally marginalized people and, in this case, policy has the potential to legislate a community of people out of existence.

Similar themes to the ones found in this study have been discussed in other publications. The most common ones cited include using preferred names and pronouns along with gender-neutral language;[1,15,16,20,22] properly documenting gender identities, names, and pronouns on forms and EMRs;[16,20,21] providers having open dialogue about the gaps in their knowledge;[1,15,20,21] providers taking it upon themselves to learn more information;[1,15] and integrating information on transgender and non-binary health into medical curricula and continuing education.[23] All of these studies included feedback from binary transgender people and some included recommendations from non-binary people as well.[15,16,20,21] These similarities in recommendations from these communities shows that, if implemented, these changes would result in both communities feeling more included in medical settings, receiving higher quality and more holistic care, and having their individual health concerns and community needs and disparities be better met.

This study sought to investigate the lived experiences of non-binary patients trying to receive care in a system that is largely ignorant of their needs and a society that is increasingly hostile to them. One finding that was previously discussed was that all participants exist at the center of a complicated web of intersecting identities with most participants being structurally disadvantaged on more than one level. It is the responsibility of public health professionals and public health as an institution to work to improve the health of our citizens and, with an increasing focus on the social determinants of health, we recognize that all aspects of a person's life will impact their health and the health care they are able to receive. We must continue to look at the ways in which a person's location in society has a health impact and, with an increasingly hostile political environment, how policy can cause irreparable harm to the communities we are trying to protect. This study is an attempt to direct this conversation onto the lives and lived experiences of the non-binary community which have, until very recently, been ignored in public health research.

Recommendations

Recommendations came from participants in four main areas: forms, diversification of medical staff, improved medical education, and improved patient-provider relationships built on trust. Participants were asked explicitly about their own ideas for improving care for non-binary patients as previous research has largely failed to do so. The recommendations listed below are taken from the participants themselves.

Forms

Participants repeatedly spoke about the importance of inclusive forms. As stated, many forms only offer the gender options "female" and "male" and have limited options for sexuality and do not provide space for pronouns, which is often due to limited options in EMRs. Participants found forms without the proper self-identification options isolating and invalidating, being forced to choose an option that did not align with their identity. They were then forced to either disclose their true identity to providers, which only some rarely did, or to hide their identity and be denied the holistic care they deserve. Participants were confused as to why their pronouns and gender identities could not be or were not added as comments to their EMRs and why these were not respected even after comments had been added. The suggestion multiple participants gave was to allow for write-in options for gender, partner's gender/sex, and sexuality, even if these could only be added as comments to their medical records. If all else fails, participants like Dawn requested that patients simply be referred to by their name and to avoid gendering patients and their bodies, as has been recommended in other studies.[1,15,20,34]

Diversification of Medical Staff

Mentioned by multiple participants was the need for a more diverse medical practitioner workforce. When asked about their most positive past medical interactions, participants spoke about the presence of women, and BIPOC and queer providers giving them a better quality of care and feeling more like they could be open about their identities. Ricki, like other participants, spoke about instantly being uncomfortable when their provider was a cisgender white man because of personal past negative experiences, the experiences of those they knew, and the larger societal structures that privilege cisgender white men and influence them to continue perpetuating disparities of power in patient-provider relationships.

This isn't to say that it's impossible for cisgender (white male) practitioners to be inclusive and welcoming of non-binary patients, but that they often have a set framework in their mind influenced by societal ideas of cisnormativity, transphobia, and strict gender roles. For these participants, it's not enough to simply ask for pronouns; there is a need to be educated on the significance of them and the impact they can have on a patient, both when they are and are not respected. It is the job of practitioners to become competent on these issues and to adjust the framework in their mind to decenter cisgender people, expand their conceptions of gender, and reimagine structures to create a true sense of belonging for non-binary patients. Other studies have had participants ask that providers be competent on transgender issues and societal structures that perpetuate transphobia, that they take it upon themselves to find this information, and ensure that all health center staff are educated on these issues.[13,16,20–22]

Improved Medical Education

It was mentioned repeatedly by participants that they felt medical education was lacking in helping future and current providers learn about non-binary patients and their medical needs. They wanted to see education that focused solely on the needs of transgender and non-binary people as well as including them in the rest of medical school training and continuing education. Many schools may have courses that focus on these populations, but they are often not mandatory and, as a result, a limited number of students have access to this medical education. In addition, information on transgender and non-binary people are often left out of regular courses, even though they experience healthcare needs that are the same as cisgender patients. Dawn shared the story of their hematology lab lacking information on the average hormone blood levels for people undergoing hormone replacement therapy. Once they shared the information with the professor, he promised to include it in future curricula and were apologetic that the information had not been there before. The professor also promised to have it included in a video training series that goes out to other physician assistant programs throughout the country. This is a great stride in creating inclusive education and will now be seen by a large number of students, but took the effort of a non-binary student seeking the information themselves and is currently only limited to hematology courses in physician assistant programs. Efforts must be made to ensure that information on transgender and non-binary health are included throughout medical training and continuing education in addition to devoting time solely to these populations' health needs, as every provider will have a transgender or non-binary patient at some point in their career.

In addition to medical training on non-binary patients, there were calls from participants like Levi for providers to be taught about the societal structures that influence their biases and understand how to dismantle them. Knowing that biases exist is only half the issue; providers must also take steps to understand how these biases are constructed based on societal ideals that center cisgender people and that they need to deconstruct these ideals in their own minds. It was the feeling of participants that information on societal structures of marginalization and how to dismantle them should be included throughout medical training and continuing education. This has previously been discussed in other studies which have further recommendations on integrating information on transgender and non-binary identities into medical education.[23]

Another related area is the potential differences in binary transgender and non-binary care. Most participants felt like there wouldn't be differences in their care if they were binary transgender, though some felt they would receive better treatment if their identity was easier to understand. Most of the differences proposed would be a need for deeper understanding of gender and how to work with non-binary and gender-expansive people. There was widespread recognition that many non-binary people may desire medical transition care and that there must be greater understanding of their desires to not look binary and may require different care or hormone dosages. Participants largely felt like, even if the identities didn't overlap for an individual, that transgender and non-binary identities were under the same umbrella and both fighting for the goal of challenging the cultural definition of what gender identity is.

Trust in Patient-Provider Relationships

As has been discussed in other studies, there is a need to examine the role of trust in the patient-provider relationship.[16] Participants largely felt like their relationships with medical providers were lacking a sense of trust. As previously noted, many transgender and non-binary people may avoid medical care for fear of being discriminated against because of previous negative experiences.[1,15–19] In addition, the lack of education on non-binary bodies and health and some providers unwillingness to listen to patients result in patients lacking a sense of trust that they will receive high standard and compassionate care. To improve patient-provider trust, participants recommended providers be upfront about the gaps in their knowledge, listen to patients' life experiences, and providers taking the time to get to know patients as full people, practicing active listening and empathy, and working to diminish power dynamics inherent to the patient-provider relationship. Many of these "soft skills" can be developed during medical school and continuing education through courses that focus solely on fostering patient-provider relationships. Since participants who were practitioners and involved in this study were able to articulate the need for this care to be present in medical interactions, it is clear that some educational programs are working to address patient trust issues. Still, there are undoubtedly many current providers did not receive this "soft skills" training and would benefit from these being covered in mandatory continuing education.

Conclusion

This study sought to understand the medical experiences of non-binary patients and ask for their recommendations for improving their care. The study included nine participants who have a non-binary identity and investigated their descriptions of inclusive and exclusive practices; found that they exist at the intersection of multiple marginalized identities, all of which impacted their care; and included recommendations from participants for improving their care that included more inclusive forms, diversification of medical staff, expanded medical education, and forming patient-provider relationships built on trust. This study is an important step in ensuring non-binary patients and their medical needs are represented in public health literature.

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APPENDIX A: In-depth Interview Guide

Background and Demographic Questions:

1. What words do you use to describe yourself and your identities?
   a. Race/ethnicity
   b. Gender identity
   c. Sexuality
   d. Health/disability
   e. Class
   f. Location
   g. Anything else?
2. Can you talk about your gender identity in more detail?
   a. Can you share more about your journey with your gender identity? How did you come into the identity you have today?
3. How does your gender identity relate to your other identities?
   a. Repeat back previously mentioned identities.

Opening Questions:

4. As a non-binary person, what does inclusivity mean to you?
   a. In general, when do you feel included?
   b. When do you feel excluded?
5. So, moving into talking about your health care experiences, when have you felt included in a health care setting? When have you not?
6. Have you come out in a health care setting before?
   a. If so, how did you navigate that? How did it go? Looking back, would you do it again?
   b. If not, why not? What did you think would happen if you did come out? Looking back now, would you still not come out?
7. In a medical setting, when do you think it's most appropriate to come out/when do you feel most comfortable coming out?
   a. (Should you have to come out at all?)
   b. What aspects of your identity, if any, do you feel comfortable talking about with health professionals?
   c. What aspects of your identity, if any, do you not feel comfortable talking about?

Key Questions:

8. Can you describe a previous negative experience in a health care setting?
   a. What made the experience negative?
   b. Do you think this experience was tied to assumptions about your gender? Do you think there are other assumptions about you that could have attributed to your negative treatment experience (racism, ableism, fatphobia, homophobia, etc.)?

    c. Have negative experiences kept you from going back to certain health centers? From getting medical care in general?
    d. If you have never had a negative experience, why do you think that is?
        i. Have you heard of positive experiences from other non-binary people? Why do you think their experience is different from yours?
9. Can you describe a previous positive experience in a health care setting?
    a. What made the experience positive?
    b. If you have never had a positive experience, why do you think that is?
        i. Have you heard of negative experiences from other non-binary people? Why do you think their experience is different from yours?
10. How do your experiences vary based on the type of health care interaction? (Mental health, primary care, sexual health, endocrinology, surgery, emergency care, etc.)
11. Are there specific things about being non-binary that make your medical needs different from binary trans people, including social interactions?
    a. Do you think your experiences would be different if you were a binary trans person?
12. Based on your own experiences, how would you improve health care settings and interactions with health professionals for non-binary people?
    a. How would you make the physical health center more inclusive?
        i. *See reference for suggested areas if participant struggles to think of any*.
    b. How would you improve your negative medical experience(s)?
    c. What would you keep from your positive medical experience(s)?
    d. Are there specific things providers should pay attention to for non-binary patients?
13. How can providers help create a more trusting relationship with patients?

Closing Question:

14. Is there anything you’d like to share that we didn’t talk about today?

APPENDIX B: Interview Reference Sheet

Potential Health Care Factors to Improve Upon

- Physical Setting
  - Physical room set-up
  - Brochures
  - Promotional materials
  - Images/videos in room
- Check-in Process
  - Staff
  - Documentation
    - Name/preferred name
    - Pronouns
    - Sex/gender
    - Inclusivity of queer relationships (asking about wife/husband vs. partner)
- Intake Process
  - Intake questions
  - Taking vitals
- Main Health Care Interaction
  - Provider's tone
  - Provider's prior knowledge of transgender/non-binary health
  - Participant's ability and comfortability with asking questions
  - Provider's engagement with active listening and answering questions
  - Provider's receptivity to new information from patient
  - Clinical terms or preferred names for body parts
  - Necessary physical touch or clothing removal