Gender Identity and Sexual Orientation Use in and Impact on LGBTQIA+ Healthcare

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Abstract. The LGBTQIA+ community has unique health experiences and needs that often go unmet by both healthcare providers and current health technologies because they are not being asked about their identity nor is their care being tailored to their unique health needs as LGBTQIA+ individuals. The purpose of this qualitative study was to improve patient care for the LGBTQIA+ community by identifying, through perceptions and experiences of LGBTQIA+ individuals, the challenges and barriers they experience when seeking health information and services. We discovered that there were several technological and societal improvements that could be made that would drastically improve their health experiences and accessibility while simultaneously alleviating the identified challenges and barriers. To improve healthcare accessibility and experiences for the LGBTQIA+ community, our study points to the need to use LGBTQIA+ gender identity in healthcare settings and technologies, training to create knowledgeable providers, a rating system to identify LGBTQIA+ competent providers and an associated national directory, a LGBTQIA+ health information repository, and improvements to social media to facilitate health information sharing.

Keywords: LGBTQIA+ · sexual orientation · gender identity · accessibility

1 Introduction

The understanding of sexual orientation and gender identity has evolved significantly over the years, with increasing recognition of diverse identities beyond the traditional binary frameworks. The LGBTQIA+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual) community encompasses individuals who experience diverse sexual orientations and gender identities. The Institute of Medicine, Healthy People 2020, the Affordance Care Act, and the Joint Commission all considered the collection of sexual orientation and gender identity information in electronic health records (EMR) central to the quality assurance process [6], and highlighted the role of providers' knowledge of their patients' sexual orientation and gender identity in preventive health for improving access, quality of care, and outcomes.

Health disparities among LGBTQIA+ individuals have been well-documented. The LGBTQIA+ community constantly experiences exclusions, prejudice, and discrimination when seeking health information and services despite the gradually growing acceptance, [1, 18, 22, 26–29, 31, 35, 40]. They also experience more disparities in health than

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the general population, such as higher rates of mental health issues, sexually transmitted infections including HIV, substance abuse, and missed reproductive cancer screenings including breast, cervical, and prostate [13, 19, 20, 23, 24, 30, 34, 38, 41], as well as lower life expectancies compared with their non-LGBTQIA+ counterparts [2, 14]. LGBTQIA+ individuals face numerous barriers when seeking healthcare, including fear of discrimination, lack of culturally competent providers, concerns about confidentiality, and delayed care. Discrimination against LGBTQIA+ individuals persists within healthcare settings and is manifested in various forms such as refusal of care, verbal harassment, and differential treatment [18, 22, 27, 29, 36, 40]. The psychological and health effects of discrimination are well-documented, contributing to increased mental health issues, substance abuse, and reduced access to care [16, 31]. Despite the implementation of various legal protections and policies against LGBTQIA+ discrimination in healthcare to address these inequities, challenges persist. Delayed care due to these barriers has also contributed to adverse consequences on the health of LGBTQIA+ individuals [5, 28]. Factors contributing to the disparities in health, access to and quality of healthcare services among LGBTQIA+ individuals include providers' lack of LGBTQIA+ training and knowledge, heterosexism (assumption that everyone is heterosexual), social stigma, and structural barriers such as limited or denied insurance coverage for gender-affirming treatment and differential treatment by providers [21]. As such, the Institute of Medicine (2011) emphasized the importance of addressing these disparities to ensure the well-being of LGBTQIA+ individuals. Yet, many of these health concerns have not been addressed by providers or by current health information technology.

Given the unique health needs of the LGBTQIA+ community and concerns related to their sexual orientation and gender identity which are also largely unaddressed, many LGBTQIA+ individuals constantly struggle with the abovementioned challenges in their healthcare. The collection in EMR and use of LGBTQIA+ identity information by providers could minimize the disparities and help address their unique health concerns [4, 6, 10, 11, 15, 26, 27]. Sexual orientation and gender identity information were also found to help facilitate the monitoring of risk factors and risk behaviors that contributed to negative health outcomes among this population [4]. A prior study conducted in an emergency room found that patients generally perceived the collection of sexual orientation and gender identity data allowed providers to better recognize their individual identity and improve therapeutic relationships [22]. Policy makers can also acquire a better understanding of the impacts of social policies and other factors on LGBTQIA+ individuals' physical and mental health with the collection of sexual orientation and gender identity data [16]. Yet, sexual orientation and gender identity are not considered part of the common clinical data set so providers are not required to collect these data [5, 7]. In fact, these data were often not collected because providers felt sexual orientation and gender identity not relevant in most clinical evaluations. Undoubtedly, this gap in perspectives could hinder patient-centered healthcare, particularly among the sexual and gender minority groups [22].

Online platforms offer a sense of anonymity, which can be beneficial for LGBTQIA+ individuals who may feel hesitant or uncomfortable discussing their health concerns in person [2]. The ability to seek information privately also allows individuals to gather knowledge, address concerns, and explore healthcare options at their own pace. Thus, LGBTQIA+ individuals have increasingly turned to technology and the Internet as a resource for accessing health information that is relevant and sensitive to their unique needs [2, 7]. Online resources and social media platforms provide accessible and anonymous avenues for information-seeking [2, 5, 36, 38]. Moreover, LGBTQIA+ individuals often connect with others who share similar experiences or health concerns through online support networks. Other research has shown that LGBTQIA+ individuals are more likely to use HIT to address these gaps [5, 7, 24, 32, 34, 38, 42], even though there still remains huge gaps in the availability of online health information that exist for this vulnerable community and its subgroups [1, 12, 13, 16, 25, 33, 36, 40].

This paper contributes a better understanding of the challenges encountered by LGBTQIA+ in healthcare and reveals that gender identity can help shape health experiences and needs more so than sexual orientation. It also contributes several technological and societal strategies to improve health experiences for LGBTQIA+ community.

Table 1. Participant Demographics by Gender Identity Subgroups

Gender Identity (n)	***Cis Men (12)***	Cis Women (4)	Trans Men (3)	Trans Women (6)	Non-binary (4)
Age					
Average Age	28.1	33	27.6	41.6	29.7
Age range	21-49	30-37	24-31	23-74	24-36
Race & Ethnicity					
White	17%	50%	67%	33%	50%
Black	58%	25%	33%	33%	-
Asian	8%	-	-	-	50%
Hispanic	-	25%	-	-	-
Jewish	-	-	-	33%	-
Mixed Race	8%	-	-	-	-
Native America	8%	-	-	-	-
Marital Status					
Single	92%	50%	67%	67%	75%
Married	8%	25%	33%	17%	25%
Divorced	-	25%	-	17%	-
Sexual Orientation					
Heterosexual	-	-	-	33%	-
Gay	92%	-	33%	-	-
Lesbian	-	75%	-	-	-
Bisexual	8%	25%	33%	33%	25%
Pansexual	-	-	-	17%	50%
Queer	-	-	33%	-	-
Non-monosexual	-	-	-	-	25%
Unknown	-	-	-	17%	-
Education					
High School	42%	-	33%	-	-
Associates	-	-	-	17%	-
Bachelors	58%	25%	67%	83%	50%
Masters	-	50%	-	-	-
PhD	-	25%	-	-	25%
J.D.	-	-	-	-	25%
Employment					
Full time	50%	75%	33%	-	100%
Part time	17%	25%	33%	-	-
Self employed	-	-	-	33%	-
Unemployed	8%	-	33%	50%	-
Retired	-	-	-	17%	-
Student	25%	-	-	-	-
Health Insurance Coverage					
Insured	75%	100%	100%	100%	100%
Uninsured	25%	-	-	-	-
Transportation Method					
Owned vehicle	17%	75%	67%	100%	75%
Public transport	83%	25%	33%	-	25%

2 Methodology

Participants. Our participants were 29 self-identified LGBTQIA+ individuals living in the United States, and all were over the age of 18 (Table 1). They were recruited through direct emails and digital flyers posted on websites of local, regional, and national LGBTQIA+ organizations, centers, clubs, and support groups, as well as social media platforms. Our study received exempt IRB approval.

All the participants self-identified themselves into one of five commonly recognized gender identity subgroups – cisgender men, cisgender women, trans women, trans men, and non-binary people. Cisgender refers to those whose current sex matches the sex they were assigned at birth. Trans refers to those whose current sex does not match the one they were assigned at birth. Non-binary refers to those who do not identify their sex in a binary fashion and includes those who identified as non-binary, genderqueer, demigender, and those who were still figuring out their gender. Non-binary would have also included gender fluid and two spirited people had there been any in our sample.

Data Collection. In-depth semi-structured interviews were conducted with the participants to acquire a better understanding of how LGBTQIA+ individuals used technology to seek health information and services and to interact with their providers. All the interviews were conducted virtually on Zoom. Our participants were asked how they self-identified both their gender identity and sexual orientation, how they sought health information and services, about their interactions with their providers, and their healthcare experiences such as barriers and discrimination that they encountered. Each interview lasted 30 to 90 min and was recorded using the built-in recording function in Zoom with the participants' consent. The system-generated transcript was reviewed to ensure the accuracy and to anonymize the participants' identities.

Data Analysis. The qualitative data were analyzed thematically by affinity diagramming. The first author reviewed the transcripts to get familiar with the data, then examined the data to generate affinity notes which were then organized by themes that emerged. The data were initially analyzed based on three broad categories of gender identities – cisgender, trans, and non-binary. However, further examination of these three gender identity subgroups revealed the need to split the cisgender and the transgender subgroups into respective binary gender subgroups – male and female because of their unique health experiences and needs. Thus our findings are reported in accordance to five gender identity subgroups.

3 Findings

3.1 Gender Identity Impacts Healthcare Experience

Levels of 'Out' to Society Vary across Gender Identity Subgroups. For many LGBTQIA+ individuals, the decision to come 'out' to society as a member of the LGBTQIA+ community was a difficult one due to negative societal views, forcing many to hide their identity (a.k.s. staying 'in the closet'). '*Out*' or '*out of the closet*' refers to disclosing their LGBTQIA+ identity to other people.

A few participants did not feel comfortable enough to disclose their LGBTQIA+ identity to society in fear of being judged, marginalized, and discriminated against (Table 2). Some fit into multiple categories, e.g., they were out to their family and indirectly out to everyone or out to a selected few while their family was against their identity. None of the gender identity subgroups in our study were 100% fully out. Some participants were out to everyone, a few were indirectly out, some to only a small number of those they know, and others were out to no one. *Indirectly out* refers to those who had not directly announced their LGBTQIA+ identity to others but thought others assumed they were LGBTQIA+ from their behaviors. Many had conversations with their family to ascertain if they were against those who identified as LGBTQIA+, without necessarily having to disclose their own identity to their family.

The ***cisgender men*** we interviewed expressed a feeling of a heavy shame associated with their LGBTQIA+ identity and thus none were fully out. The other subgroups did not speak about feeling ashamed of their identities like the cisgender men did. The cisgender men only disclosed their LGBTQIA+ identity to certain people, most were out to a select trusted group of people – some were only to their friends, others to their family only, some were out to both their family and friends, only one was not out at all. P5 explained, *"the reason for not being very open to my friends and relatives and the society at large is because like fearing the stigmatization or the isolation that I could face."* Some had supportive families but for some cisgender men in our study, their family members were against their sexual orientation.

Among the ***cisgender women*** participants, only half considered themselves fully out, a quarter were out to family and friends while indirectly out to everyone else and the rest were not out at all. P28 discussed her being indirectly out, *"I feel like it's if I didn't have that conversation with you, it's pretty well known just through word of mouth and because of social media posts. I wear T shirts, I have the flag in my yard so like I'm not hiding or anything but it's not like, I had the conversation with every single person that I know."*

Unlike cisgender people, all trans people were out to some degree. 4/6 of the ***trans women*** in our study considered themselves fully out, 2/6 were out to a selected few who they trusted, one was out to their family, and another was out to their friends. Like trans women, 2/3 of the ***trans men*** also considered themselves out to everyone but 1/3 was out to just their family and friends.

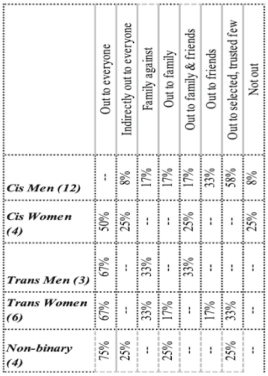
The ***trans people*** we interviewed, both men and women, had the highest percentage of families who were against their trans identities – 3/9 regardless whether they identified as male or female. A trans woman explained what happened after disclosing that she was trans to her family, "*Daddy just wanted to kill me. I had to run from home just to save myself*" (P11). Some trans men said their families were also against their LGBTQIA+ identity as P21 shared, *"My father actually disowned me. She's [Mother] not okay with me being gay, but we still communicate. My family knows that but dislikes me for that."* This showed that if disclosing to one's own family could result in such an adverse response, it would certainly make trans people hesitant to disclose to other people, such as providers.

Our ***non-binary*** participants were out with different levels of outness for sexual orientation and gender identity. One-quarter were fully out, and another quarter were indirectly out with everyone. The other 2/4 were out in terms of sexual orientation, with half of them out to their family about their gender identity and the rest only out to a few people they carefully selected and trusted.

In summary, fear of discrimination, stigma, and marginalization continued to shape how 'out' many participants in our study were. Trans and non-binary people were more likely to disclose their LGBTQIA+ identity. This may be due to the often-visual nature of their physical transformations that occurred during gender transition and not conforming to gender norms and expectations associated with the sex they were assigned at birth. Despite being one of the most fully 'out' subgroups in our study, trans people's families were the most likely to be against their identity. None of the cisgender men was fully 'out', but it seems easier for this subgroup to hide their sexual orientation as it typically does not involve name change or physical transformations. In short, despite the growing acceptance of diversity, many participants still did not feel comfortable enough to disclose their LGBTQIA+ identity to society in fear of being judged, marginalized, and discriminated against (Table 6).

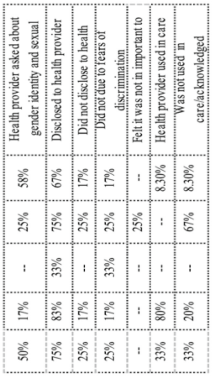
LGBTQIA+ Identities Largely Ignored in Healthcare. Many providers did not ask for LGBTQIA+ identities (Table 3), but most LGBTQIA+ participants would volunteer

Table 2. Levels of 'Out' to Society in General



	Out to everyone	Indirectly out to everyone	Family against	Out to family	Out to family & friends	Out to friends	Out to selected, trusted few	Not out
Cis Men (12)	--	8%	17%	17%	17%	33%	58%	8%
Cis Women (4)	50%	25%	--	--	25%	--	--	25%
Trans Men (3)	67%	--	33%	--	33%	--	--	--
Trans Women (6)	67%	--	33%	17%	--	17%	33%	--
Non-binary (4)	75%	25%	--	25%	--	--	25%	--

Table 3. Disclosure and (Non)Use of LGBTQIA+ Identifiers

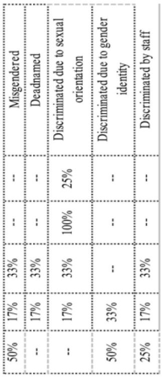


Health provider asked about gender identity and sexual	Disclosed to health provider	Did not disclose to health	Did not due to fears of discrimination	Felt it was not in important to	Health provider used in care	Was not used in care/acknowledged
58%	67%	17%	17%	--	8.30%	8.30%
25%	75%	25%	25%	25%	--	67%
--	33%	--	33%	--	--	--
17%	83%	17%	17%	--	80%	20%
50%	75%	25%	25%	--	33%	33%

to give this information to their providers because they perceived it as important to their healthcare. Yet, providers often did not embrace the gender identity information in the patients' healthcare or in their interactions. This can potentially lead to patients' perception of discrimination, which could lead to negative outcomes.

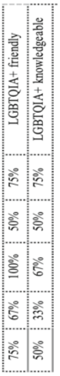
When interacting with their providers, 7 ***cisgender men*** were asked about their sexual orientation and gender identity. Even when not asked, 8 volunteered their sexual orientation information to their provider. Yet, only 1 of those cisgender men who disclosed their sexual orientation said the information was used or acknowledged in their healthcare encounters. Fears of discrimination kept 2 of the cisgender men from disclosing their sexual orientation to their providers. Cisgender men were the second least likely to disclose their identity to their provider, second to trans men (Table 3).

Table 4. Discrimination Experienced in Health Setting



Misgendered	Deadnamed	Discriminated due to sexual orientation	Discriminated due to gender identity	Discriminated by staff
--	--	25%	--	--
--	--	100%	--	--
33%	33%	33%	--	33%
17%	17%	17%	33%	17%
50%	--	--	50%	25%

Table 5. LGBTQIA+ Friendly vs. Knowledgeable Primary Care Providers



LGBTQIA+ friendly	LGBTQIA+ knowledgeable
75%	75%
50%	50%
100%	67%
67%	33%
75%	50%

Table 6. Health Information Sources Used by LGBTQIA+

100%	67%	67%	100%	58%	Health Professionals
50%	0%	50%	25%	14%	Only if serious aliment
100%	67%	67%	100%	83%	Internet
25%	17%	--	--	25%	Due to privacy concerns
75%	67%	--	25%	25%	Social media
67%	50%	--	100%	17%	Enjoy social aspect

Of the 4 ***cisgender women***, only 1 was asked about their sexual orientation and gender identity by providers, whereas the other 3 disclosed their sexual orientation to their provider either after being asked or by volunteering. Yet, 2/3 said it was never used or acknowledged in their care in any way. Such lack of use of LGBTQIA+ identifiers could have detrimental consequences like what happened to P29 in a very important moment when their spouse and the non-gestational parent were not being treated as such during the delivery of their second child. *"They didn't let [spouse's name] hold the baby, they didn't let her make decisions for the baby, she said, because she went over expecting to hold the baby and they said, oh no we give her to the mother first. So, for her it was a much different experience that second time and part of that's on us because we could have said hey this is my wife. She's the baby's other parent, you know, but I didn't know I needed to say those things until I had the experience, where they didn't know and I didn't say anything."*

Being afraid of discrimination made some of the cisgender women to not disclose their sexual orientation to their provider. P28 described her unpleasant experience after she disclosed that she was sexually active with both sexes: *"It got awkward and I don't know if that was just the nurse herself, or like the first person she's met that has answers like that or something. But suddenly it seemed like I was wrong or like I should feel ashamed and then, like all these questions followed that almost seemed like judgmental."* One cisgender woman felt disclosing gender identity to the provider was important but sexual orientation was not important for shaping health care.

Only 1 of the 6 ***trans women*** in our study had providers ask them about their sexual orientation and gender identity, while the others volunteered this information to their provider – more than any other subgroup. Many trans women described the medical importance of disclosing. For example, P1 explained: "[I am] *what any other 75-year-old woman would be except I have a prostate and the doctor needs to know that to properly diagnose me, to properly treat me.*" For some trans women in the study, explicitly stating their gender identity was the only way to signify their trans status to the provider because they did not physically present themselves as the gender they identified as. However, fear of discrimination has kept one trans women from disclosing their identity to providers, which could have adverse impact on the healthcare received.

Of the 5 trans women who had disclosed their LGBTQIA+ identity to their providers, 4 said it was used in their care and they felt the information was important for facilitating their health care. Their heavy use of health care services was the highest among all the subgroups. This was likely due to the medical treatments, like hormone replacement therapy and gender affirming procedures, needed by trans women to physically present themselves as and transition to female.

Providers did not ask any of our 3 ***trans men*** participants about their sexual orientation or gender identity which could explain why only 1 disclosed their gender identity and sexual orientation to their providers. They were the least likely of all subgroups to disclose this information. The reason that 2 did not disclose was again due to fear of discrimination. They worried that the LGBTQIA+ identity information collected by providers could be used to discriminate against them in attitude and/or care received. None of the trans men interviewed felt their provider used their LGBTQIA+ identity information to tailor the health care plans for their specific needs.

Two ***non-binary*** participants were asked about their sexual orientation and gender identity by their providers, the second most frequently asked of all the subgroups. Of the 2 who were not asked, 1 volunteered to disclose their LGBTQIA+ identity whereas the other withheld the information because they assumed the provider was not LGBTQIA+ friendly or knowledgeable, and feared discriminated.

Unfortunately, as we saw with the other subgroups, despite 3/4 disclosing their non-binary identity to their provider, only 1 of them said their non-binary identity was acknowledged and used in their care. P23 commented, "*It matters in a health professional yeah even if you're not talking specifically about LGBT related health issues, it's still matters that the person who's becoming very intimate with your body respects your pronouns and your identities and all of that and understands how it could affect the way that you're feeling about the language that they use with you and things like that*."

Although many participants were not asked, they still volunteered to disclose their LGBTQIA+ identity to providers with the hopes that it would be used in their care. Unfortunately, it was largely not used to improve care or interpersonal interactions. Trans women were the subgroup that their gender identity was used the most often during their care while the other participants often felt ignored, marginalized, and discriminated against when providers assumed the patients fit in a generic binary and heteronormative classification.

Discrimination Against LGBTQIA+ Individuals Prevalent. Discrimination was widely experienced by many participants in healthcare settings and society in general. The percentage who had experienced discrimination was deeply impacted by their gender identity and sexual orientation, as shown in Table 4.

Three of the 12 ***cisgender men*** had experienced discrimination by a provider, which represented the lowest percentage among all the gender identity subgroups. This low number may be because only 1/12 of cisgender men's providers did not acknowledge their identity, possibly making them less likely to be discriminated. Of the cisgender men, 2/12 had not disclosed their sexual orientation to providers due to fears of discrimination.

All the ***cisgender women*** in our study had experienced discrimination from a provider in their life due to their sexual orientation. P29 explained: "*Like the whole you're not* *on birth control, how are you so certain you're not pregnant and then you can just tell that the person receiving the information is not comfortable with the information you've just shared and then the room gets awkward and you're alone in a room with this person. And it's a four-by-four room so it's more been I guess those kinds of exchanges and interactions more than outward something that's been said or done, if that makes sense?".*

Some cisgender women in our study thought it was out-and-out discrimination; others felt they were unintentional, awkward examples of the person's heteronormative biases. As P9 described, *"[It] didn't even cross their mind that could have been the reason why I wasn't using birth control, because it wasn't necessary.*" Unfortunately, this was a very common experience for our cisgender women participants and one that led many to seek out LGBTQIA+ competent providers with the hope to avoid these scenarios.

One of the 3 ***trans men*** had been discriminated against by their providers and another one by the staff of a 'LGBTQIA friendly' provider. P15, a trans man, had been deadnamed (called by name associated with previous gender) and misgendered (identified as wrong gender) resulting in insurance coverage issues. Deadnaming and misgendering incidents have led to health care accessibility issues, lengthy battles with insurance companies, care denials, and additional costs for the patients.

Many ***trans women*** in our study received healthcare services for their identity. Yet, 2/6 of them was discriminated against due to their gender identity, 1/6 because of their sexual orientation, 1/6 had been misgendered, and 1/6 had been deadnamed. One trans woman (P19) was both deadnamed and misgendered by the hospital staff and anesthesiologist while undergoing gender reassignment surgery. P19 detailed her experience, "*As a trans person, it's basically like these are the things and the injustices and violations that you have to deal with in order to get the care that other people would get and it, you know, it sucks.*" Such experience illustrated how the lack of inclusion and respect for these diverse identities can seriously impact their healthcare.

The gender identity information provided by ***non-binary*** people in our study was often disregarded or even used against them, as 2/4 had been misgendered and the other 2/4 had providers discriminate against them because of their gender identity. Even at specialized LGBTQIA+ health facilities, genders and pronouns were assumed according to the conventional binary gender identities, instead of using the ones in the medical records, thus resulting in misgendering. In fact, those who did not experience discrimination was because they had not disclosed their identity.

It is thus very unfortunate that discrimination against LGBTQIA+ individuals remains common in healthcare settings and society at large. In our study, all the cisgender women, 2/4 of the non-binary participants, 3/9 of trans people and 3/12 of cisgender men had been discriminated against. These adverse experiences LGBTQIA+ individuals encounter in society and in healthcare settings can have a significant impact on their interpersonal interactions, the quality of healthcare they receive, and their experiences in other settings such as schools, social clubs, and community at large.

LGBTQIA+ Friendly vs. LGBTQIA+ Knowledgeable. Many cisgender people in our study felt their primary care provider was both LGBTQIA+ friendly and knowledgeable. Yet trans and non-binary participants feel differently. They explained that being

LGBTQIA+ friendly did not necessarily mean the provider was LGBTQIA+ knowledgeable and knew how to interact with or provide health care to LGBTQIA+ people (Table 5).

Most cisgender men and half of cisgender women felt that their primary care providers were both LGBTQIA+ friendly and knowledgeable even though their providers did not inquire about or used proper LGBTQIA+ identifiers in the care plan. All trans men in our study felt their primary care provider was LGBTQIA+ friendly but only 2/3 perceived them being knowledgeable about their LGBTQIA+ health needs.

Four of 6 trans women felt that their primary care provider was LGBTQIA+ friendly and 3/6 thought they were knowledgeable. Unfortunately, 2/6 of the trans women interviewed felt they had to educate their health provider, as P2 commented, "*about what being trans is and where I fit within the spectrum of LGBT*" and how their trans identity related to their needed health care.

On the other hand, non-binary people thought that their primary care providers were LGBTQIA+ friendly but fell short in being knowledgeable about individual LGBTQIA+ subgroups and their respective health needs. Some discussed the struggle they faced in finding providers who were knowledgeable about the health needs of less common LGBTQIA+ identities. For example, P20 desired for providers who were *"savvy with trans folks especially who are not just trans women and trans man or like even with any kind of other sexual orientations, bisexuality, pansexuality, the asexual aromantic spectrum."*

It thus appears that providers who are LGBTQIA+ friendly are not necessarily knowledgeable about how to interact with and provide adequate care to the LGBTQIA+ community and the various, unique subgroups. This lack of knowledge may explain some of the (un)intended discrimination experienced by many of our participants as discussed in the previous subsection. This lack of knowledge also requires some to not only take an active role in advocating for their own health needs but also to educate their provider about their specific needs so that they can get the care that they need.

Gaps between Health Insurance Coverage and LGBTQIA+ Healthcare Needs. All of our participants, except 3 cisgender men, had health insurance (Table 1). Yet, many participants found it difficult to seek LGBTQIA+ knowledgeable providers who were covered by their insurance plan. As such, some participants had to pay out of their pocket to ensure they could see a LGBTQIA+ knowledgeable provider. Many also discussed the struggles of having to cover the healthcare costs, with or without insurance coverage and being employed full-time.

Cisgender men were the least insured subgroup in our study with only 9/12 insured. The lack of insurance may be due to cisgender men's lower employment rate (Table 1). In fact, 6/12 of the cisgender men found it challenging to cover healthcare cost in recent years. Hence some avoided care altogether or had family members help cover the cost.

All the ***cisgender women*** in the study discussed how the costs had made accessing care difficult, even with health insurance. P28 explained that cost was always a key consideration that determined whether healthcare was sought or not. *"I don't like going to the doctor in person, a lot, because I get a big fat bill. I have insurance, but it's not great and so, if it's something that I can just kind of overlook or get over, then I will I'll choose to do that."*

Half of the ***trans women*** subgroup considered health care cost prohibitive. The other half had to borrow money to cover copays. Trans women typically had to engage in long battles with insurance companies to have gender affirming procedures and therapies covered, and often still had to pay considerable amount out of pocket or they had to forego care altogether. P1 described her experience in appealing for insurance coverage for the medical procedures she needed, "*Fighting against the fact that Medicare would not provide gynecological procedures to me because my gender status at the time was not female. The codes existed. They had the procedures documented for women. But not for transgender individuals.*" P2 was also denied voice therapy to feminize her voice because "*coverage only is if you've lost your voice completely or if your voice is damaged from surgery*".

Some ***trans*** people in our study explained how insurance limited which providers were covered and sometimes those were not qualified providers for their specific LGBTQIA+ needs. For some, the only accessible surgeons on their insurance plans had higher revision rates for gender affirming surgeries, like vaginoplasty and phalloplasty, requiring the patient to have additional surgeries to repair the work that was previously done. This would undoubtedly impact how and when they were able to transition successfully. As a result, some who were desperate for their body to match their identity had to take higher risks with subpar or inexperienced surgeons, which undoubtedly increased the odds of additional revision surgeries or postponed care until they could access more qualified LGBTQIA+ healthcare professionals. Others discussed the red tape that referrals were often needed for each step of the transitioning, thus prolonging the time the process took and increasing the costs. Some in our study had insurance plans that would not cover gender transitioning. In order to receive the healthcare they needed, they had to pay out of their pocket for the gender affirming care, including masculinizing or feminizing chest surgeries, genital reconstruction surgeries, facial reconstructive surgeries, voice surgery and voice therapy, leading to substantial financial burden.

One-third of ***trans men*** in the study had been deadnamed and misgendered, for some it caused health care accessibility issues, lengthy battles with insurance companies, care denials, and additional costs for patients. P15 described how this complicated things for him: *"The fact that legal name and preferred name are different than the whole insurance situation gets twisted in and thrown and I'm fighting a whole big like mess with medicine and everything right now, because the clinic I was at has me listed as female and insurance doesn't want to provide testosterone."* Many trans and non-binary people also discussed how their insurance plans often did not cover the LGBTQIA+ knowledgeable providers they had found, leaving them to pay out of pocket to receive safe and quality care from a knowledgeable provider.

Non-binary participants were the second most frequently affected by cost; 3/4 cited cost as a challenge to accessing care. Some explained how they considered if the health issue was worth the financial burden it might impose on them before seeking care. *"There's always this like question where I'm like I don't know how much this is going to cost and I don't really want to like undergo this, even if it's like 10 min to only get a surprise bill for like several hundred dollars" (P20).* Some had to forgo needed care due to cost constraints despite their full-time employment, insurance coverage, and higher education level, as most were still living paycheck to paycheck and healthcare costs could have long term impacts on their economic status. Others went into debt when getting the care they needed, *"I did, for the most part, get the care that I needed it was just it just it came at a cost of having to pay back some money that I didn't have at the time (P24)."* Unexpectedly, some participants said they had been charged extra fees by their providers for asking LGBTQIA+ health information questions during routine exams, making them refrain from asking these questions during appointments in fear of being charged additional fees.

In short, most participants struggled with healthcare costs, even with insurance coverage and full-time employment. Many weighed the cost and benefits of receiving care for their health concerns prior to getting care. Thus, many had to forego the needed care while some went into debt or had to borrow money to cover the costs. Some trans participants had to resort to substandard providers for their gender affirming care they desperately needed. Some were willing to pay out of their pocket to see LGBTQIA+ friendly and knowledgeable providers even though the services were not covered by their health insurance.

3.2 LGBTQIA+ Health Information Seeking

Given their unique needs, LGBTQIA+ individuals use different resources to seek relevant health information and they encountered a variety of challenges in the course of seeking relevant health information.

Online Health Information Caused Anxiety. As with the general population, another common issue experienced was the amount of information and the alarming results returned, leaving many participants to question the trustworthiness of the results. A few cisgender men mentioned that they often struggled to decide what health information was accurate and what was not. One-third of cisgender men desired a seal of accuracy that could be used to authenticate the LGBTQIA+ health information they found online. Half the cisgender women and half the non-binary participants felt that online information often returned alarming, sometimes even fatal, health diagnoses even for mild symptoms, leaving them to question the information's credibility. As such, many had to change their search behaviors, as P27 described, *"I had to switch when I was younger. I would get myself into some anxious moments or something like that happen. I would just look up a sentence and weird stuff will come back, and I would drive myself crazy."* Only 1/3 of trans women have encountered scary or weird results while searching for health information online.

Health Literacy and Jargon Complicated Health Information Seeking. Non-binary participants were the only subgroup that mentioned how health jargon and literacy further complicated the process of finding health information. P27 explained, *"One of the big issues with online health information is probably just health literacy. People don't have the language to understand what they're reading, which is where some of the more verified sources can lose people. It's jargon."* Moreover, a few non-binary participants had trouble finding the correct terms to identify one's own identity. *"Looking back at my childhood like that makes so much sense now that I have these words to explain with what I've been feeling my whole life" (P23).* Without proper identity language, many had no idea how to express their feelings or experiences, as P20 explained, *"I didn't* *know there was a missing puzzle piece, but then when I found it, I was like okay, a lot of things make sense."*

Fragmented LGBTQIA+ Health Information. Half of the trans women, half of the cisgender women and a few cisgender men in our study struggled with the amount of health information available online, but in different ways. P1 commented that *"one of the rare instances where more is not better"* whereas P12, a cisgender man, explained, *"compared to other health topics, before you finish typing, suggestions are already there, but for our community, it's not that easy [to find LGBTQIA+ health information]".* Meanwhile, a few non-binary participants found health information too scattered and not centralized but unlike the other subgroups, none mentioned too much information to sort through.

Evidence-Based Subgroup-Specified Health Information Needed. Many people in the study (5/12 of cisgender men, 3/4 of cisgender women, 1/6 of trans women, and 2/4 of non-binary people) desired for a LGBTQIA+ health information repository similar to the popular WebMD and Mayo Clinic websites to improve access to credible health information. In addition, many of our participants (1/3 of cisgender men, 2/4 of cisgender women, 1/6 of trans women, 1/3 of trans men, and 4/4 of non-binary participants) would like access to evidence-based, niche health information for LGBTQIA+ individuals. Half of non-binary participants also wanted the health information to be easy to understand. P24 desired *"to have the information be displayed in a way that is easy to read and doesn't require like previous medical knowledge."* P5's statement *"each group of people have different matters"* helped explain why 2/4 of the non-binary people and 2/12 of cisgender men participants both wanted health information specific to their respective gender identity subgroups instead of having only generic LGBTQIA+ health information.

LGBTQIA+ Competent Providers in Dire Need

Directory of LGBTQIA+ Knowledgeable Provider. Our participants found it difficult to identify LGBTQIA+ competent providers. All our non-binary and 3/4 of the cisgender women participants discussed the need for a national directory of LGBTQIA+ friendly and/or knowledgeable providers. P20 had even tried to create one of their own, *"[I] wanted to work on making a more thorough queer and trans people of color health provider directory that could also include alternative or holistic medical providers because there wasn't really anything like that that exists."*

Training LGBTQIA+ Competent Providers. Half of the cisgender female participants wanted additional training for providers to improve their ability to interact with and care for the LGBTQIA+ community. One trans woman wanted providers to be trained better on how to care for and interact with trans individuals specifically. P19 explained, *"I do have a different physiology and things have happened to me and my body that would not happen to a cisgendered woman and that's important for your health care provider to know but they should be educated on how to handle that properly, and what that means, and to not treat us as if we're like some other."*

Increase Awareness of LGBTQIA+ Competency. Several cisgender women suggested the creation of a universal symbol for LGBTQIA+ inclusive health facilities and professionals to make navigating health care not only easier but also safer for the community. The iconography and medical information a health facility or professional displayed in their space, both in-person and virtual, and the organizations they were associated with has helped 2/4 of cisgender women determine how LGBTQIA+ friendly and knowledgeable the providers or facilities were. As pointed out by P28, *"If you have a sign basically that says that you are welcome and we're not going to judge you, it just feels so much better. It makes all the difference" and "There were rainbows on the bulletin board and workers had rainbow pins, I felt instantly welcomed."*

Overall, all sexual orientations were represented in the study. Sexual orientation played a large part in the health experience of cisgender people, while gender identity, rather than their sexual orientation, was key to shaping trans and non-binary participants' experiences.

4 Discussion

Foster Use of LGBTQIA+ Identity Information. Our research found that patients desired nuanced LGBTQIA+ identifiers to be collected and used in healthcare settings to improve patient care. Providing a more robust choice list and fill-in options for gender identity (and sexual orientation) would make the electronic health records more inclusive for LGBTQIA+ individuals. However, simply collecting gender identity information would not improve patient care. This information needs to be used by providers and institutions with their patients to shape care plans and provide holistic, inclusive care. Given the prevalent non-collection and/or non-use of the identifiers, research should be conducted with health care providers to better understand the underlying reasons and the challenges they encountered when interacting with and addressing LGBTQIA+ patients. This improved understanding can help policy makers to promote the use of LGBTQIA+ identifiers, which may facilitate access to health information and services specific to LGBTQIA+ subgroups.

Develop LGBTQIA+ Provider Competency Classification and Directory. To achieve inclusive medicine, it is important to start from the ground up by integrating LGBTQIA+ knowledge in medical education. Moreover, we believe it would be useful to design and develop a LGBTQIA+ competency classification system using inputs from LGBTQIA+ community and providers with regard to qualities a competent LGBTQIA+ provider should possess. With the proposed competency classification system, we further recommend the development of a national directory of LGBTQIA+ knowledgeable health care providers. With the growing acceptance and use of recommender systems, we further recommend a LGBTQIA+ knowledge rating system to allow patients to quickly share the perceived experience and knowledge level of their provider. Collectively, these enhancements can potentially help LGBTQIA+ individuals access providers who could provide them with the needed care and help minimize discriminatory encounters while seeking healthcare.

Create LGBTQIA+ Health Information Repository and Interactive Website. Many of our participants discussed the need for a centralized repository with credible health information for different subgroups of the LGBTQIA+ community to facilitate easy access to needed, often unique, health information. Many participants suggested that a user-friendly, trustworthy, and easily accessible LGBTQIA+ focused health website, similar to WedMD or Mayo Clinic Online designed for the general population would greatly benefit the unique LGBTQIA+ community.

Scaffolding Social Media to Facilitate Sharing and Retrieval of Health Information. Our participants frequently used social media to seek and share specific and potentially sensitive health information but the design of existing social media falls short in supporting the sharing of often personal and at times sensitive health information. We thus suggest that current social media tools should be scaffolded with enhanced features for sharing private and sensitive health information, for example, by using stronger encryption algorithms and efficient search and sorting mechanisms to facilitate data retrieval amidst the large volume of social data accumulated over time.

Limitations. This study was limited by its small sample size which became more apparent when the participants were classified into five gender identity subgroups. Moreover, the sampling method used was not truly random, thus resulting in considerable demographic differences between our sample and the US general population in terms of race, ethnicity, age, and education attainment level. Our study sample was very young, well-educated, had higher rates of insurance coverage, and represented higher rates of people of color when compared to the Unites States national averages. These demographic skews were likely due to our use of digital media for recruitment and for conducting the interviews.

5 Conclusion

Healthcare providers' and technology designers' not collecting and/or using gender identity information has huge impacts on the LGBTQIA+ subgroups' experience with health care, as revealed by our participants. Finding health information specific to individual subgroups as well as more broadly, the LGBTQIA+ community is challenging because many do not know where to find accurate LGBTQIA+ health information. Additionally, LGBTQIA+ individuals generally perceive the healthcare setting as an unwelcoming or unsafe space for their health needs and much research is needed prior to seeing a provider or facility to minimize negative experiences. Discrimination in healthcare settings is still commonly experienced by the LGBTQIA+ community, either by providers, their staff, and/or other patients. Even when asked, many LGBTQIA+ individuals choose not to disclose their LGBTQIA+ identity to providers in fear of being discriminated against. Not being able to openly discuss LGBTQIA+ health issues with their provider leaves many unanswered health questions, and likely unresolved issues as well.

The lack of use of gender identity and sexual orientation by providers normalizes and perpetuates exclusion from healthcare settings and broader mainstream culture. Thus, many LGBTQIA+ individuals feel that providers consider heterosexual and cisgender being the norm. Oftentimes, they must note their gender identity and/or sexual orientation in the margins, because of the lack of appropriate identity options on health forms. The fear of bias and discrimination as well as personal feelings of shame and worries of stigma associated with their own identity cause many to not disclose to providers even when asked, which may negatively impact their healthcare.

Finding a knowledgeable LGBTQIA+ provider is difficult, even more so to find one covered by their insurance. Our participants found many providers uneducated on LGBTQIA+ terminology other than gay, lesbian, bisexual, and trans. Many providers have trouble navigating the clinical trajectory for LGBTQIA+ patients including birth control, hormone replacement therapies, and gender affirming surgeries. Instead of reaching out to peer providers, many turn to their patients for education during appointments such as to define and explain identity terms and respective health needs. Thus, the patients are essentially providing their own care in relation to their LGBTQIA+ identity. Hence, both technology designers and health care practitioners and institutions should work together to provide LGBTQIA+ individuals better access to health information and care.

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