



“It’s probably an STI because you’re gay”: a qualitative study of diagnostic error experiences in sexual and gender minority individuals

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ABSTRACT

Background There is a critical need to identify specific causes of and tailored solutions to diagnostic error in sexual and gender minority (SGM) populations.

Purpose To identify challenges to diagnosis in SGM adults, understand the impacts of patient-reported diagnostic errors on patients’ lives and elicit solutions.

Methods Qualitative study using in-depth semistructured interviews. Participants were recruited using convenience and snowball sampling. Recruitment efforts targeted 22 SGM-focused organisations, academic centres and clinics across the USA. Participants were encouraged to share study details with personal contacts. Interviews were analysed using codebook thematic analysis.

Results Interviewees (n=20) ranged from 20 to 60 years of age with diverse mental and physical health symptoms. All participants identified as sexual minorities, gender minorities or both. Thematic analysis revealed challenges to diagnosis. Provider-level challenges included pathologisation of SGM identity; dismissal of symptoms due to anti-SGM bias; communication failures due to providers being distracted by SGM identity and enforcement of cis-heteronormative assumptions. Patient-level challenges included internalised shame and stigma. Intersectional challenges included biases around factors like race and age. Patient-reported diagnostic error led to worsening relationships with providers, worsened mental and physical health and increased self-advocacy and community-activism. Solutions to reduce diagnostic disparities included SGM-specific medical education and provider training, using inclusive language, asking questions, avoiding assumptions, encouraging diagnostic coproduction, upholding high care standards and ethics, involving SGM individuals in healthcare improvement and increasing research on SGM health.

Conclusions Anti-SGM bias, queerphobia, lack of provider training and heteronormative attitudes hinder diagnostic decision-making and communication. As a result, SGM patients report significant harms. Solutions to mitigate diagnostic disparities require an intersectional approach that considers patients’ gender identity, sexual orientation, race, age, economic status and system-level changes.

INTRODUCTION

Diagnostic error is “the failure to (a) establish an accurate and timely explanation of the patient’s health problem(s)

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Sexual and gender minority (SGM) patients are more likely to experience diagnostic delays and misdiagnoses and less likely to receive necessary screenings for diseases such as cervical cancer, breast cancer and HIV.
- ⇒ Despite this, little is known about causes of diagnostic error and challenges to receiving accurate, timely and well-communicated diagnoses in SGM patients.

WHAT THIS STUDY ADDS

- ⇒ SGM patients attribute diagnostic error to provider-level challenges, personal challenges and intersectional issues. Patient-reported diagnostic error led to worsened mental and physical health outcomes and disengagement from healthcare. But for some, experiencing diagnostic error led them to become advocates for their own health and engage in activism to promote improved health outcomes for the SGM community.
- ⇒ We identify patient-recommended solutions to mitigate diagnostic error in SGM populations.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ SGM patients provide comprehensive recommendations to mitigate diagnostic disparities.
- ⇒ These recommendations can be used to increase inclusivity of healthcare practice and inform policy on medical training, patient engagement, research and insurance standards.

or (b) communicate that explanation to the patient.”¹ The incidence of diagnostic error in medicine remains unknown, but estimates suggest annual error rates of 5%–15% in adult U.S. populations alone.^{2,3} To combat harm, diagnostic excellence aims to optimise diagnosis while advancing patient-centred healthcare and alleviating diagnostic inequities for historically marginalised populations.^{4,5} Socially disadvantaged groups are often medically underserved, and, thus, at greater risk of diagnostic disparities, which are preventable differences in diagnostic excellence that result in disproportionate harms contingent on identity.^{5–10}

Diagnostic error is multifactorial in origin, ranging from systems-oriented causes to clinical reasoning error as a dominant cause, which is demonstrated in the USA and internationally.^{11–14} Systems-oriented causes include issues with organisation, procedures, technology and equipment.¹⁵ Clinical reasoning is the “complex cognitive process that is essential to evaluate and manage a patient’s medical problem.”¹⁶ Cognitive bias can unconsciously influence and disrupt clinical reasoning.¹² Cognitive biases are systematic thought patterns that can distort judgement, oversimplify patient information and potentially manifest in diagnostic errors.¹⁷ However, the potential role of both systems-related causes and cognitive bias as catalysts of diagnostic disparities remain unexplored in sexual and gender minority (SGM) patients.

SGM refers to lesbian, gay, bisexual, transgender, queer, non-binary and people with other minoritised sexual orientations and gender identities.¹⁸ The SGM population is not a monolith; it encompasses a diverse array of people from various racial, ethnic, socioeconomic, religious and cultural backgrounds.¹⁹ The process by which these identities combine to create sociopolitical advantages and disadvantages is known as intersectionality.²⁰ Around 7% of adults in the USA identify as SGM,²¹ and this number is not adjusted for undercounting due to discriminatory social policy, nation-level oppression and structural stigma, phenomena observed elsewhere in the world.²² Prior research has documented disparities in healthcare accessibility and adverse health outcomes; SGM patients face significant challenges due to mistrust, discrimination, violence, and socioeconomic disadvantage.^{23–25}

SGM patients may delay seeking diagnostic care due to fears of experiencing discrimination and stigma or may receive substandard diagnostic care.^{26–28} These types of SGM diagnostic disparities have not been thoroughly investigated. Previous studies overwhelmingly focus on the diagnosis of sexual and reproductive issues including breast cancer, cervical cancer and HIV. Studies of sexual minority women found that financial roadblocks, intersectional stigma and lack of trust in providers led to delays in breast cancer diagnoses.^{29,30} Studies of transgender men and cisgender women who have sex with women found

cervical screening disparities due to physical discomfort or gender dysphoria exacerbated by the screening process.^{31,32} Transgender patients may also be more likely to experience diagnostic error due to the trans broken arm syndrome, a phenomenon where providers misattribute health concerns to patients’ transgender identity; for example, symptoms of a health condition are blamed on the transgender individual’s hormone replacement therapy (HRT) usage.^{33,34}

Prior research has not explored how and why diagnostic errors occur for a broader array of health issues. Our study aims to understand SGM patients’ experiences across all steps of the diagnostic process to generate a more holistic understanding of SGM patient experiences of engaging, non-engaging, or being betrayed by the health system,³⁵ regardless of specific diagnoses, as well as when a diagnosis is not yet established. Patient interviews are a valuable tool for learning about the patient’s diagnostic journey, and patients have been identified as credible informants in detecting diagnostic errors and in identifying their underlying causes.^{36,37} Therefore, we use in-depth, semistructured interviews with SGM individuals to (1) identify challenges to receiving accurate, timely and well-communicated diagnoses for SGM patients; (2) understand the outcomes of patient-reported diagnostic error and (3) elicit potential solutions to improve diagnosis for SGM individuals.

METHODS

Study design

Semi-structured in-depth qualitative interviews.

Reflexivity

The authors include two SGM individuals. Three authors identify as White and two as Asian. The authors primarily responsible for analysis and interpretation of the data include AAW, TS, and FZ. AAW, the first author, identifies as a White, queer transgender man. TS and FZ identify as Asian, cisgender-heterosexual women. All except one of the authors report personally experiencing diagnostic errors as patients.

The authors adopt a patient-centred approach to research and hold the belief that patients are experts in their health experiences. The authors hold the contextual constructivist view that meaning is produced through participants’ understandings, the researcher’s interpretations, the sociocultural context and the interpretations of the scientific community.³⁸ Thus, we recognise that our identities and experiences play a role in shaping our work and analysis of the data.

Recruitment

Study participants were recruited from November 2021 to April 2022 using convenience and snowball sampling.³⁹ Convenience sampling was accomplished by contacting 22 SGM-focused organisations, academic centres and clinics distributed across the

USA. Additionally, flyers were distributed through social media advertisements targeted to individuals 18 years or older who identify as LGBTQIA+. Snowball recruiting was accomplished by encouraging participants to share study details with their personal contacts to increase recruitment from SGM networks. This approach is appropriate for seldom-heard populations.⁴⁰

Study participants

All study participants were screened, and eligibility was determined based on five inclusion criteria: (1) 18 years or older, (2) English speaking, (3) self-identify as a sexual and/or gender minority, (4) self-report diagnostic error(s) of any mental or physical health problem and (5) able to provide informed consent. During screening, participants were informed that diagnostic error is defined as “the failure to (a) establish an accurate and timely explanation of the patient’s health problem(s) or b) communicate that explanation to the patient.”⁴¹

Data collection

Semi-structured interviews were conducted by three researchers (AAW, TS, FZ) using an interview guide (online supplemental file 1). Interviews were conducted via video-call software, audio-recorded with participant consent and lasted for 47–87 min. Notes were taken during each interview.

Participants were asked to discuss their experiences with patient-reported diagnostic error. Interviewers probed participants to reflect on the impact of their SGM status and other salient factors, including race, ethnicity, age, socioeconomic status and insurance status, on their diagnostic process. Participants were asked to discuss the impact that patient-reported diagnostic error had on their lives. Finally, participants were asked to identify solutions to reduce diagnostic error for SGM patients.

Data analysis

Interviews were audio-recorded and transcribed. Transcripts were analysed using codebook thematic analysis.^{41 42} Research team members met regularly to discuss interviews and generate initial codes.⁴¹ We started with a set of deductive codes, following the structure of the interview guides, and further codes were added inductively under each major theme.⁴³ Study team members (AAW, TS, FZ) coded two transcripts and met to discuss and resolve conflicts developing a codebook. The initial coding phase was used to establish the alignment between coders on how codes were being interpreted and used. Alignment was reached after two transcripts were coded, at which point the remaining transcripts were coded. Transcripts were coded manually using Word by one researcher (AAW) and reviewed and edited by a second researcher (TS). Coded text was exported to

Excel for data storage using a Word macro.⁴⁴ Themes are presented narratively in the results.

Ethics

This study was reviewed and approved by the Johns Hopkins School of Medicine Institutional Review Board (IRB00252985). Informed consent was required to participate.

RESULTS

We enrolled 20 participants who identified as SGM. Participant characteristics are reported in [table 1](#). Forty per cent of participants identified as gay or lesbian, 15% as bisexual, 40% queer, 5% straight and 15% another identity, including polyamorous, asexual or questioning. Some participants identified with more than one sexual orientation. Thirty-five per cent of participants identified as cisgender men or women and 40% identified as transgender, non-binary, agender or gender non-conforming. Ages ranged from 20 to 60, 40% were 20–39 years old, and 45% did not disclose their age. Fifteen per cent of participants were White, 5% were Black, 5% Asian and 15% biracial, mixed race or people of colour, and 55% did not disclose their race. Primary health concerns included mental health conditions (25%) and physical health conditions (80%), with one participant reporting both. 60% of participants held an undergraduate degree or higher and 40% had health-related occupations. All remaining individuals did not disclose their educational or occupational background.

Findings are arranged into three domains aligned with the interview guide: (1) challenges to diagnosis; (2) outcomes of patient-reported diagnostic error and (3) solutions to patient-reported diagnostic error disparities.

Challenges to diagnosis

Several themes were identified related to challenges to diagnosis. Provider-level challenges include (a) pathologisation of SGM identity, (b) dismissal of symptoms due to anti-SGM bias, (c) cis-heteronormative assumptions and (d) enforcement of gender norms. Patient-level challenges include (e) internalised shame and stigma around SGM identity. Intersectional challenges (f) were also identified.

Pathologisation of SGM identity

Participants reported that providers pathologised their identities and misattributed medical symptoms to their sexual orientation, sexual behaviours or gender identity. One participant reported being misdiagnosed with bipolar disorder following a provider’s biased questions about bisexuality. These questions led them to stop interacting with the provider in a manner conducive to co-producing an accurate diagnosis:

Table 1 Participant characteristics

Participant	Gender	Sexual orientation	Race and ethnicity	Age	Primary health concern
1	Gender non-conforming	Queer	Brown	Late 20s	Oral infection
2	Cisgender man	Gay	Not disclosed	Not disclosed	Dermatological issue
3	Cisgender woman	Lesbian	White	Not disclosed	Mental health condition
4	Cisgender man	Gay	Black	Mid 30s	Chronic gastrointestinal and pneumological problems
5	Cisgender woman	Lesbian	Not disclosed	Late 50s	Cardiac issue
6	Cisgender man	Gay	Not disclosed	Not disclosed	Musculoskeletal issue
7	Non-binary	Queer	Not disclosed	Not disclosed	Chronic pain; autoimmune/connective tissue disorder
8	Transgender man	Straight	Not disclosed	Early 40s	Gynaecological condition; precancerous growth
9	Not disclosed	Queer	Biracial	Not disclosed	Tumour; autoimmune disorder
10	Agender	Polyamorous; questioning	Not disclosed	Late 30s	Gastrointestinal condition
11	Not disclosed	Gay	Not disclosed	Mid 20s	Spinal disc herniation; hormone imbalance
12	Non-binary	Queer	Biracial	Not disclosed	Chronic pain; mental health condition; heart condition
13	Cisgender woman	Lesbian	Not disclosed	Early 60s	Autoimmune disorder; inflammatory bowel disease
14	Non-binary	Queer	White	Early 20s	Inflammatory bowel disease; nose and sinus disorder
15	Cisgender woman	Queer; bisexual; polyamorous	White	Not disclosed	Gynaecological issue; Sexually transmitted infection
16	Not disclosed	Queer	Asian	Not disclosed	Behavioural health condition
17	Not disclosed	Gay	Not disclosed	Early 20s	Gynaecological anomaly; noncancerous growth
18	Non-binary	Bisexual; asexual	Mixed race, Hispanic	Early 20s	Neurodevelopmental issues
19	Non-binary	Queer	Not disclosed	Late 20s	Connective tissue disorder
20	Not disclosed	Bisexual	Not disclosed	Not disclosed	Mental health conditions

[The provider] was saying... “is there any traumatic experience with my father that turned me into a bisexual?” ... Rather than sitting here and being judged, [I decided,] let’s just keep my answers short. ... At that time, he diagnosed me with bipolar and started giving me lithium...I know that that diagnosis was incorrect because after just three days of consuming lithium... instead of becoming better, I fell into deeper depression. (Participant 20)

Respondents also reported that providers misattributed their symptoms to sexually transmitted infections (STI) after becoming aware of their sexual orientation. This was particularly common for men who have sex with men. One participant, who identifies as a queer person of colour, went to an urgent care visit with tooth pain and was told “it is probably an STI because you’re gay,” (Participant 1) despite experiencing symptoms that were not consistent with an STI. Another participant who identified as a gay man confirmed this experience as well: “he was more interested in getting me tested for STIs because I marked down [that I was] a gay sexually active male” (Participant 2).

Transgender and non-binary patients reported that their symptoms were misattributed to their transgender status and HRT. One queer, non-binary participant’s chronic pain was blamed on HRT, despite symptoms starting before they initiated HRT:

Usually what I am seeing a doctor about is chronic pain... [the provider] was like, “you are probably having pain because you are taking testosterone.” Well, no, [I’ve had] these joint issues since before puberty. (Participant 7)

Dismissal of symptoms due to anti-SGM bias

Some participants felt that their symptoms were dismissed and not taken seriously due to providers’ perceptions that gender non-conforming patients were untrustworthy and unreliable reporters of their symptoms. Young transgender and non-binary patients were particularly impacted by this:

There is a perception that younger people are not old enough to know if we are not cis[gender]...there was this idea that [because] I was confused about my gender, maybe I could be confused about my health or what medical care I needed. (Participant 12)

The same participant reported being unable to access diagnostic testing when they presented in gender non-conforming ways:

I think by dressing in a way that was gender nonconforming, that further reinforced the idea that I was not a reliable source when it came to my own body.... I went in to go see that doctor a couple more times... and I did dress in a way that was more

feminine...I was able to like actually get more testing. (Participant 12)

This was confirmed by other participants, who described altering their clothing choices and gender presentation for clinical encounters:

I wear jewelry, I have my nails painted. Sometimes I'm wearing eyeliner. I shop in the men and women's section... But...when I go to...clinical appointment, I change who I am. (Participant 1)

Communication with provider distracted by SGM identity

Diagnostic visits were sometimes derailed when providers focused on patients' SGM status rather than their medical symptoms and diagnostic needs:

Often, when queer stuff comes up, that is the only thing that the doctor wants to talk about. Those appointments do not touch on anything else...I have had providers go off script and ask inappropriate questions that are not relevant to the appointment. (Participant 7)

Patients felt pressured to educate providers on SGM topics during diagnostic visits, wasting appointment time and limiting communication about their symptoms and diagnoses:

[The provider said] "you're nonbinary, explain that to me" ... I try to keep myself organized, and [remember] what I came to talk about... [but] I got completely distracted and off-topic. I got nervous or shut down. (Participant 19)

Cis-heteronormative assumptions hinder appropriate diagnostic communication

Several participants experienced significant diagnostic delays because of cis-heteronormative assumptions about their reproductive goals. One transgender man reported receiving a delayed diagnosis of endometriosis because providers disregarded his pain and told him it would go away once he had children:

I had severe pain every month...And on top of that, I had heavy bleeding...And the doctor [said] ... the pain can be normal. Because that sometimes happens in younger women.... And sometimes it will resolve slightly after having children. (Participant 8)

Cis-heteronormative assumptions also resulted in failures to adequately involve patients' same-gender partners in diagnostic communication. One participant, who identifies as a lesbian woman, described how providers mistook her wife for her daughter, preventing her wife from receiving diagnostic education or communication:

Everybody was addressing my wife as my daughter. And she was not really given any kind of education, she was not interacted with as a spouse. (Participant 5)

Cis-heteronormative assumptions were also built into clinic workflows. A transgender man reported difficulty accessing appointments at health clinics due to a mismatch between his gender marker and gender presentation:

My ID still said female. My insurance still said female, making it harder for me to seek diagnostic testing at testing facilities centered around women's health. (Participant 8)

Internalised shame and stigma around SGM identity limits symptom disclosure

Patients reported that internalised shame and the stigma around being SGM hindered them from openly discussing their symptoms and receiving a diagnosis. One respondent experienced shame about his sexual orientation that prevented him from disclosing information that could have aided the provider in reaching a diagnosis:

The last question of the doctor was if I ever had a sexual partner of the same sex.... And during that time, I did not accept myself as gay. I said "no, never" ...And now I think it was not really good for my diagnosis. (Participant 6)

Several participants reported modifying their diagnostic care-seeking behaviours or hiding symptoms due to fear of being outed. One participant did not feel comfortable disclosing their mental health symptoms and explained how being in the closet about their gender identity put them in 'ultimate hiding mode':

You cannot get diagnosed with something that nobody knows is happening. I did not tell anybody that I was struggling, so I did not see any mental health professionals...I was in ultimate hiding mode. (Participant 18)

Intersectional challenges

Participants reported intersectional challenges including provider bias based on factors like weight, race and age (table 2).

One participant described how weight, age and sexual orientation played a role in her perception of the biases that providers formed about her:

They see essentially a fat, middle aged, old lesbian coming in the door, you know, and you don't feel necessarily cared for. You feel more like, well, you brought this on because you're overweight. (Participant 5)

Another participant reported that providers' lack of knowledge about how symptoms present on people of colour led to challenges diagnosing their medical issue:

They suspected that I had something on my skin...he [the provider] wasn't familiar with how someone of my skin tone would present with that [medical issue]. (Participant 9)

Table 2 Intersectional challenges

Theme	Illustrative quote
Provider bias based on patient characteristics	
Age	"Another component of the diagnostic difficulty was my age; I was really young. And I didn't have a lot of autonomy over my health choices. . . most of my diagnosis was handled by them [parents] and communicated to me through them. So, at first, I didn't even know what I had." (Participant 16)
Weight	"I am of average weight I don't seem to present with like any distress, and I think that's led to a lot of just missed opportunities over the years." (Participant 10)
Race	"But the problem is, once they see you, you're young, you're Black, and you're gay. . . But getting a chance to get past that and look at the patient on [an] individual basis." (Participant 4)
Appear healthy	"They saw someone who seemed fine, who wasn't presenting with much distress visibly, who looks pretty healthy. And they just didn't think it was that much of a priority." (Participant 10)
Substance use	"In that [lung] infection case. . . [I was told] "it's because you're a smoker" . . . so that's been my one big obstacle, people making snap decisions about you immediately based on little pieces of information. They never bothered to ask questions." (Participant 4)
Mental health	"I needed to see a cardiologist. I was having quite bad heart palpitations. They were pretty frequent, and I went in the first time, and he was like: "You're fine. It's anxiety." (Participant 12)

Additional illustrative quotes are outlined in online supplemental table S1.

Outcomes of patient-reported diagnostic error

Three main themes developed around outcomes of patient-reported diagnostic error: (a) worsening relationships with providers, (b) poor mental and physical health outcomes, but (c) increased patient self-advocacy and community-activism. Illustrative quotes and subthemes for each theme are presented below and in [table 3](#).

Worsened relationships with providers and healthcare systems

Patient-reported diagnostic error led to a loss of trust, withholding information and disengaging from care. One participant, who identifies as biracial and queer, expressed distrust of healthcare systems: "experiencing diagnostic difficulties has made me a lot more skeptical of the medical system" and began hiding personal information from providers: "I hide my sexuality on medical documents" (Participant 9). Several patients stopped seeing their providers: "I haven't gone back to get OB-GYN [obstetrics and gynecology] specific

Table 3 Outcomes of patient-reported diagnostic error

Theme	Illustrative quote
Worsened relationship with providers and healthcare system	
Increased mistrust	"After that I could no longer trust her to be my care provider." (Participant 4)
Non-disclosure of identity	"I was. . . more reticent to come out and to. . . dress in a way that I personally am more comfortable with." (Participant 12)
Disengagement	"the initial feeling was: I'm not gonna see this person. Then the next feeling was: I need to report them. Then the next feeling was: I don't have the energy to report them. I'm just gonna not see them." (Participant 9)
Compensation	"I try to take into account all the things that went wrong and compensate for them with the next specialist I see." (Participant 7)
Worsened mental health outcomes	
Distress	"I probably lost a decade of my life and amount of stress that I've gone through already." (Participant 1)
Frustrated	"I also came out of that conversation more frustrated, pissed off, and prone to anxiety about the intersection between medicine and patriarchy." (Participant 8)
Rumination	"There's been a lot of thought as to, you know, what if I looked differently? Would I get treated differently? Would I get treated better? And also, if I presented both as White and straight, would that cause a differential outcome?" (Participant 9)
Traumatised	"I have some trauma surrounding seeking medical care. . . every time I receive a new diagnosis, I keep thinking. . . Oh God, I don't want to go through this again." (Participant 9)
Invalidated	"It feels like you're not important enough or like things aren't bad enough to earn the attention of the medical establishment, which shouldn't be a thing that we have to earn." (Participant 10)
Worsening physical health outcomes	
Adverse outcomes	"I was barely eating anything. I developed an eating disorder because of it." (Participant 9)
Increased self-advocacy and community activism	
Self-advocacy	"It has really caused me to advocate more for myself." (Participant 13)
Community activism	"I have more capacity to make provider encounters safer for other people who don't have access to all of those things." (Participant 14)
Advocating for family members	"I'm a lot more knowledgeable of what can happen compared to my peers or. . . family members. . . I was like Dad, you're receiving care that is not. . . culturally sensitive. . . I can help you find another provider." (Participant 9)

healthcare since then. I avoided seeking health care after this happened” (Participant 17).

Worsened mental and physical health outcomes

Participants reported negative short-term and long-term mental and physical health resulting from patient-reported diagnostic error. One respondent reported undergoing an unnecessary and life-threatening procedure which led to cardiac arrest after being misdiagnosed:

He went ahead and did the procedure, and I had an adverse outcome. He ruptured the LAD [left anterior descending artery], and I ended up with cardiac arrest and ended up on the aortic balloon pump. (Participant 5)

Another participant reported mental distress which negatively impacted their ability to access further diagnostic testing:

[It] caused a significant amount of mental distress... for example, they asked me to go into the hospital for a sleep study and I couldn't do it. (Participant 9)

Increased self-advocacy and community-activism

Participants made increased efforts to advocate for themselves after experiencing diagnostic errors. Self-advocacy took varying forms, including requesting diagnostic test results, switching providers and writing letters to administration. However, sometimes patients were left with limited options to pursue diagnosis, such as being unable to find a new provider after leaving an old one:

I've become more willing to fire doctors...I usually handle it by just trying to find a provider with whom I feel comfortable...sometimes that creates diagnostic

delays because...I can't work with all providers the way [a] straight person could. (Participant 15).

Several participants became engaged in community activism to support other SGM individuals experiencing similar issues:

I got more involved...and very vocal in the community, very vocal in the hospital, very vocal with the cardiologists, very vocal and supportive of people who have false negative stress tests... And I would demand for their care...because somebody has to advocate for people. (Participant 5)

Solutions to patient-reported diagnostic error disparities

Solutions proposed by participants to reduce diagnostic disparities included improved patient-provider communication through the use of inclusive language, asking questions and avoiding assumptions; increased medical education and provider training on SGM topics; attention to dynamics of diagnostic coproduction with SGM individuals; involving SGM individuals in healthcare improvement efforts and research; insurance changes and increasing patient autonomy over diagnostic decision-making. Solutions suggested by participants are presented below and illustrative quotes are presented in [table 4](#).

Improve patient-provider communication through more inclusive language

Participants recommended several ways to improve patient-provider communication, including using SGM-inclusive language, asking questions and avoiding assumptions.

Participants recommended the use of inclusive language and suggested providers ask for patients'

Table 4 Patient-proposed solutions to diagnostic error

Theme	Illustrative quote
Increased medical education and provider training on SGM topics	"I think there are a lot of providers out there that want to be allies, that want to give good medical care. And it doesn't matter if your heart is in the right place if you don't have any education." (Participant 7)
Improve patient-provider communication through inclusive language	"Using more generic terms in terms of spouse, acknowledging people's pronouns." (Participant 5)
Encourage diagnostic coproduction	"What is really helpful [is] providers asking what you need and taking that seriously. Really sharing power and really (being) willing to genuinely [perform] patient centered care... and figure out a collaborative plan with a patient." (Participant 15)
Uphold high care standards and a strong sense of medical ethics	"I should be no different than anybody else that comes to the door... I don't care if they're Black, White, purple, green, heterosexual, homosexual, LGBTQIA. I don't care. This is a sacred human in front of me." (Participant 5)
Hire more SGM individuals in healthcare	"I think knowing that my provider was queer definitely made me feel more inclined to come out and believe that I would still get the same standard, or close to the same standard, of care. And I did." (Participant 12)
More research and data on diagnostic error in SGM populations	"Investment in data infrastructure. Data alone will not reduce health disparities, but they help. They're one key part. You can't reduce health disparities if you don't know what the problem is and you're not tracking the problem." (Participant 1)
Structural changes	"If anything could prevent this from happening again, [it would] probably be giving primary care providers more time to talk to their patients." (Participant 8)
SGM, sexual and gender minority.	

pronouns and preferred name and use non-gendered language such as partner(s) or spouse to refer to patients' significant other(s).

He asked my pronouns and gave his pronouns, and that immediately...established a pretty welcoming environment. (Participant 12)

Participants recommended that providers ask more questions and avoid making assumptions about patients' medical symptoms, sexual orientation and gender identity. Further, one participant recommended a question providers could ask to identify whether patients were living with an undiagnosed or misdiagnosed condition: "Have you ever felt like you're living with something that no one's addressed?" (Participant 19)

Encourage diagnostic coproduction

Participants advocated for diagnostic coproduction between themselves and their providers. One participant defined this as:

When you are co-constructing that [diagnosis] with a provider who you really do feel safe with. (Participant 1)

Several participants recommended providers verbalise their clinical reasoning. Participants felt more comfortable disclosing personal information such as their sexual orientation after providers explained why that information was relevant to their care:

Asking about "what is your sexual orientation? What is your gender identity? I want to know this, so that I make sure that you feel safe and supported. When I mentioned your partners or when I think about what clinical tests I might need to run, I just want to be aware of potential risk, that's why I'm asking for it. (Participant 1)

Involve SGM people in healthcare improvement efforts and compensate them

Participants argued that SGM individuals should be centred and compensated for their healthcare improvement efforts and work in research, medical practice and patient advocacy. Several participants described seeking out SGM-identifying or affirming providers and struggling to find them.

All steps of everything [should involve] more queer people, more sexual and gender minorities. At every step of research, in practice, and training. (Participant 3)

DISCUSSION

We generated an overarching understanding of SGM patient experiences with patient-reported diagnostic error across a range of medical issues. This study begins to fill an important gap in the literature by including diverse mental and physical health conditions. We

identified multiple factors that participants associated with diagnostic error and subsequent harm. Patient-reported diagnostic error was tied to queerphobia, transphobia and cis-heteronormative values present at the individual provider-level and health system-level. Failures in diagnostic decision making, communication and testing emerged because of pathologisation, shame, stigma and dismissal of patients due to anti-SGM bias and lack of provider education and training.

Our study linked provider anti-SGM bias, SGM pathologisation, cis-heteronormative assumptions and lack of provider trust to decreased healthcare engagement by patients in symptom disclosure and diagnostic decision making. This finding that has been supported by others.^{30 45} Previous studies confirm that sexual minorities are less likely to trust providers that centre heteronormativity and are less likely to pursue diagnostic screening with providers they do not trust.^{30 45} Further, this issue is not isolated to SGM individuals; diagnostic disparities also exist along racial and ethnic lines.⁴⁶ Our findings challenge previous work suggesting that patient disclosure of SGM identity leads to more appropriate diagnostic care⁴⁷ by demonstrating that providers may be overattributing SGM patients' symptoms to sexually transmitted diseases. Instead, our findings suggest that provider training is needed to adequately respond to patient disclosure of sexual orientation and gender identity.

We identified patient-recommended solutions to mitigate diagnostic disparities. Participants felt more capable and motivated to advocate for their diagnostic needs and the needs of their families, friends and communities, highlighting their resiliency and lived expertise. However, participants emphasised that the burden of diagnostic safety improvement should not be exclusively shouldered by patients. They expressed the need for more attention to empowering SGM patients through diagnostic coproduction,^{48 49} improved provider communication to encourage authentic patient engagement and highlighted medical education as a way to address patient-reported diagnostic errors highlighted in this study. Providers are encouraged to remain mindful of whether any of the challenges identified in our work appear in their own practice and whether there are opportunities to integrate solutions suggested by our participants, such as both the use of more inclusive language in patient communication and increased provider training on SGM topics.

Our study begins to demonstrate how patients who do not adhere to cis-heteronormative standards may be pathologised and blamed for their symptoms and face larger structural barriers, leading to diagnostic failures. SGM patients have unique diagnostic needs and treatment goals. Based on what we learnt, we urge patient safety interventions that facilitate patient-centred and patient-led interventions to reduce patient-reported diagnostic error and mitigate the

psychological, medical and financial harms caused by patient-reported diagnostic error in SGM patients.

Limitations

Our sample size was small and consisted largely of participants who had a high level of education and medical literacy. Although non-probability convenience and snowball sampling may be used to recruit seldom-heard populations, these approaches may also limit sample diversity.⁴⁰ Studies that use recruitment efforts targeted towards individuals with lower educational attainment and health literacy levels, as well as uninsured patients, may uncover additional challenges to diagnosis. Diagnostic errors in this study were exclusively self-reported by patients and were not reviewed through methods such as chart review or provider interviews. Further studies are needed to explore the themes identified in this work in larger, more diverse samples. Finally, 55% of participants chose not to disclose their race or ethnicity and 45% chose not to disclose their age, limiting our ability to analyse the data in the context of these factors.

CONCLUSION

SGM patients experience patient-reported diagnostic errors due to cis-heteronormative beliefs and practices upheld by healthcare providers and medical institutions. Anti-SGM bias, queerphobia, lack of provider education and heteronormative attitudes negatively impact diagnostic decision-making and communication. SGM patients suggested actionable solutions that could potentially mitigate diagnostic disparities, emphasising the growing need for intersectional and systemic changes. We present these findings in the pursuit of diagnostic excellence for SGM individuals.

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Contributors AAW conceptualised the study, designed data collection tools, designed and implemented recruitment approaches, conducted and monitored data collection, analysed the data, drafted and edited the manuscript, managed references, and is the guarantor for this work. TS implemented recruitment approaches, conducted data collection, analysed the data and drafted and edited the manuscript. FZ acquired funding, implemented recruitment approaches, conducted data collection, analysed the data and edited the manuscript. NMT analysed the data and drafted and edited the manuscript. VD conceptualised the study, designed the study protocol, designed data collection tools and edited the manuscript. KM conceptualised and supervised the study, acquired funding, oversaw project development and edited the manuscript.

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