Healthcare Experiences of Men Who Have Sex with Men: Understanding Trauma, Patient-Provider Relationships, and the Lasting Impacts of the AIDS Crisis

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Abstract

Studies of patients' health outcomes and the quality of healthcare services show that the patient-provider relationship is crucial and that a patient-centred approach to care is essential for ensuring high-quality healthcare results. However, what might happen if a patient-provider relationship were undeveloped, or even hostile? Inadequate treatment of patients in medical settings is a common experience of sexual minorities, who have historically experienced greater burdens of disease and discrimination. This study explores the lived experiences of men who have sex with men (MSM) to better understand their patient-provider relationships. MSM are the population of interest because they are historically marginalised and stigmatised, especially surrounding their sexual health and sexual behaviours. In order to assess how an evolving social landscape has affected the experiences of MSM, 20 men were interviewed. Among them, 10 men were between the ages of 18 and 49, and 10 were 50 or older. Through a comparative analysis, this study assesses differences and similarities in healthcare experiences – and the resulting health-related needs and preferences – of participants, particularly with regard to social trauma, medical trauma, and their proximity to the 1980s AIDS crisis. Additionally, race, ethnicity, and language emerged during interviews with participants of colour as salient factors which impacted their healthcare experiences.

1. Introduction

Cultural competence is a necessity for professionals who work directly with other human beings, such as healthcare service providers. As societies progress, especially regarding the growing acceptance of new social identities as we have seen in recent years, it is increasingly important for medical professionals to understand how their patients’ identities affect their experiences, decisions, and attitudes towards healthcare. Providers should be knowledgeable about the social construction of health and disease as it relates to individual identity and should feel comfortable interacting with a plethora of unique patients.

As previously mentioned, wellness and disease are socially constructed; this study investigates how varying perceptions of wellness and disease can shape relationships between

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patients and their medical providers. More specifically, this study focuses on patient-provider relationships for 10 young men who have sex with men (MSM) (ages 18–49) and 10 older MSM (50 and older). This distinction was made on the basis that older MSM lived closer in time to the AIDS crisis of the late 20th century. Older MSM are more likely to have witnessed the medical stigmatisation of people living with HIV/AIDS, either personally, through the stories and deaths of their peers, or through the media portrayal of HIV/AIDS when the disease was initially called GRID (Gay-Related Immune Deficiency). This public health crisis influenced how medical practitioners interacted with their patients, more so for those who identified as MSM, the population with the highest incidence of HIV/AIDS in the 1980s.

1.1. Literature review

Studies of patients' health outcomes and the quality of healthcare services show that the patient-provider relationship is crucial, and further that a patient-centred approach to care is “essential for developing effective tools for public reporting and health-care quality results” (Theis et al., 2016: 9). But what happens when the patient-provider relationship is undeveloped, or even hostile? Marginalised populations report greater burdens of disease, increased social discrimination, and lower levels of health insurance coverage (Bulatao and Anderson, 2004). Additionally, these populations suffer from poorer treatment by healthcare providers, related to factors such as insufficient or unclear communication between parties, often due to a lack of trust or comfort (Theis et al., 2016).

According to Alizadeh and Chavan (2015), there is an association between provider cultural competence and outcomes such as patient satisfaction, patient trust, adherence to treatment and health index for patients being treated for hypertension, diabetes, and HIV. There are still debates within the medical community regarding the definition of cultural competence, but cultural awareness is operationalised by Alizadeh and Chavan (2015) to mean an awareness of one’s own views, biases, and prejudices toward other cultures, and the continued acquisition of information about other cultures. From a health perspective, this translates to the ability to make accurate physical assessments and collect health data regardless of the cultural or ethnic diversity among patients.

Stevens (1994) finds that lesbians and, more broadly, lesbian, gay, bisexual and transgender (LGBT) persons, experience challenges when navigating the healthcare system. When asked about their worst experiences, lesbian patients conveyed facelessness, as if they were not treated like human beings (Stevens, 1994). Furthermore, a common experience of LGBT patients is feeling that their bodily and emotional integrity has been violated, especially after ‘coming out’ to providers. Disclosing sexual behaviours with healthcare providers often left LGBT patients feeling vulnerable or violated. Overall, patients wanted to share worth-affirming and meaningful relationships – as opposed to insensitive or cruel interactions – with their care providers. Well-developed patient-provider relationships produced feelings of validation and comfort for patients when discussing matters of personal health (Stevens, 1994).

Eton et al. (2017: 1641) find that “the quality of the patient-provider relationship, as perceived by patients, is associated with self-management, treatment burden, psychosocial outcomes, and satisfaction with providers in people coping with MCC [multiple chronic conditions]”. Eton et al.’s (2017) finding that the patient-provider relationship is associated with health outcomes and satisfaction for MCC patients is especially pertinent to people living with HIV,
due to the “development of highly active anti-retroviral therapy (ART) [which has] transformed HIV infection from a death sentence to a chronic disease” (O’Leary, 2014: 18). In 2009, MSM “accounted for 52% of all people living with HIV infection”, and “78% of all new infections among males”, despite representing “about 4% of the male population in the United States” (O’Leary, 2014: 12). Given the nature of HIV as a chronic disease using current treatment options, there is a rationale for investigating whether Eton et al.’s (2017) findings can be extrapolated to MSM living with HIV as they age and develop additional chronic conditions.

1.2. Rationale and aims

Despite the growing literature on LGBT healthcare experience, there is a “notable lack of qualitative and longitudinal studies” which poses a challenge for “understanding shifts in perceptions and experiences over time” (Lee and Kanji, 2017: 86). For this reason, it is imperative to collect qualitative data from MSM to better understand their ideas and experiences concerning patient-provider relationships, especially given their increased burden of disease and trauma. To understand changes in perceptions over time, a qualitative investigation must allow for a comparison of experiences. Therefore, by conducting in-depth interviews with younger and older MSM, this research allows for a comparison of their experiences to assess changing trends in healthcare provision and patient-provider relationships. Furthermore, this research will begin to investigate whether patient-provider relationships are associated with health outcomes for MSM, as is found in MCC patients. This research directly addresses the previously mentioned gap in the literature and has wider implications for further longitudinal research studies and the revision of policies and procedures regarding social and cultural sensitivity training for medical professionals who provide services for LGBT patients.

2. Methods

2.1. Hypotheses

The overarching hypothesis of the study is that MSM who were sexually active and ‘out’ during the AIDS crisis are more likely to have experienced some form of stigmatisation, stereotyping, or discomfort when interacting with medical professionals. For men who have had negative healthcare experiences directly related to their sexual orientations or sexual behaviours, it is possible that any ensuing changes in attitude towards medical professionals have persisted, even after the AIDS crisis and the general destigmatisation of homosexuality. Similarly, younger MSM, those born after the AIDS crisis, are less likely to have had negative healthcare experiences directly related to their sexual behaviours, but that those who have experienced stigma or bias because of their sexuality might have similar attitudes toward medical professionals as older MSM with comparable experiences. One reason for generationally different perceptions of sexual health is the relatively recent introduction of PrEP (Pre-Exposure Prophylaxis) and PEP (Post-Exposure Prophylaxis) and the overall improvement of HIV medications following the AIDS crisis, which have allowed people to live normal, well-adjusted and relatively healthy lives even after being diagnosed with HIV.
A secondary hypothesis is that respondents would prefer to receive services from providers who are aware, without bias, of the elevated risk of HIV and sexually transmitted infections for MSM. This mutual understanding could either stem from a providers’ personal experiences, or from a history of providing healthcare services to a significant number of MSM patients.

2.2. Participants and procedure

Prospective participants for interviews were found primarily through snowball sampling. A snowball sample based on referrals was elected to reduce the likelihood of all participants belonging to a single social circle. Snowball sampling was also chosen for its convenience since MSM proved difficult to identify without at least a second-degree connection. It proved even more challenging to find MSM who felt comfortable speaking in detail about their health experiences with a stranger. One limitation of this method is that it does not necessarily produce a generalisable sample if the respondents are too closely related because of the referral-based recruitment process. With only ten interviews in the older and younger MSM groups respectively, any recurring thematic elements cannot be considered statistically significant or generalisable for all MSM. However, recurring themes could serve as the basis for future quantitative or mixed-methods research that could assess whether the findings of this study are generalisable for the wider MSM population.

Additionally, the study included in both age groups at least one man who identified as white, Black, Asian, and Hispanic/Latino for a more diverse and intersectional representation of narratives and more nuanced comparisons. In the 18 to 49 age group, the distribution of racial identities is: 4 white/Caucasian, 2 Hispanic/Latino, 3 Asian, and 1 Black. In the 50 and older group, the distribution of racial identities is: 4 white/Caucasian, 2 Asian, 2 Hispanic/Latino, and 2 Black. Figure 2.2.1 shows the distribution of participants by age and race/ethnicity.

Figure 2.2.1. Age and race/ethnicity of participants.
2.3. Interview method

An interview schedule of 52 questions organised into five sections was used during each interview. The five sections of the schedule were: (1) Background and Demographics; (2) Healthcare Background; (3) Most Recent Visit to the Doctor; (4) Best Experience with a Doctor; and (5) Worst Experience with a Doctor.

The first section (i.e., Background and Demographics) included questions about age, race and ethnicity, and other social identities which may be determining factors for healthcare access and perceptions of health. The Healthcare Background section was used to find out how often respondents visited the doctor, what kind of health insurance they had, and what their general attitudes were regarding healthcare. The third section (i.e., Most Recent Visit to the Doctor) was about each participant’s last visit to the doctor, which focused on specific interactions between respondents and their doctors and how the patient felt throughout the visit. The fourth (i.e., Best Experience with a Doctor) and fifth (i.e., Worst Experience with a Doctor) sections allowed participants to share details about their best and worst healthcare experiences. Interview questions were asked as openly as possible; for instance: “Tell me about a particularly bad experience you’ve had with a doctor” and “What made this the worst experience?”. These open-ended questions allowed participants to share as much as they felt comfortable. Unscripted follow-up questions (e.g., “Can you tell me more about that?”) were asked as necessary to unpack lengthy anecdotes or complex ideas.

By comparing responses for the older and younger MSM groups, the ‘Worse Experience with a Doctor’ section was key for determining whether patient-provider relationships have changed significantly for MSM over time with regard to their sexual orientation specifically since MSM are generally less stigmatised now than during the AIDS epidemic of the late 20th century.

3. Discussion

Interviews were comprehensive and varied based on the unique experiences of each respondent, but certain topics were central across conversations. Noteworthy discussion points were categorised into the following major themes: (1) trauma and health preferences (regarding Age and Race/Ethnicity); (2) the lasting impacts of the AIDS crisis; and (3) the importance of a patient-centred approach. Direct quotes have not been used from all 20 participants, but the three core themes were selected based on which experiences were most commonly discussed during all interviews.

3.1. Trauma as it relates to health preferences

After completing all 20 interviews, key quotes were coded thematically. The most prevalent theme among respondents was trauma. Furthermore, it seemed that various forms of trauma produced certain healthcare preferences. Participants’ traumatic experiences were categorised in two ways: (a) medical trauma, and (b) social trauma. Traumas were also correlated with aspects of each respondent’s identity, such as race and ethnicity, birthplace, and age; all relevant identity factors were coded for in the transcription phase of the research.
Trauma can be defined as any experience that causes stress, emotional and physical harm, unease, discomfort, or fear. According to Berger (2015: 180), “[a]pproaches to trauma can be divided broadly into two categories: the medical-clinical and the cultural-historical”. The former type of trauma refers to “an individual’s response to some overwhelming stress or injury […] that produces a sense of helplessness or extreme disorientation” (Berger, 2015: 180); the latter type of trauma concerns historical events that cause cumulative psychological or emotional harm. Throughout the discussion, traumatic experiences of study participants have been categorised more broadly as either social trauma or medical trauma. Social trauma describes events that happen outside of a medical context, for example, arguments with one’s family members, and verbal or physical abuse because of one’s social identities. Social trauma is also used here to describe historical-cultural trauma, such as the AIDS crisis which disproportionately affected the MSM population but still had a profound impact on the overall psyche of the LGBT community through secondary trauma – which is operationalised in this discussion as the experience of emotional duress through witnessing or learning about the traumas of others. Medical trauma describes events that involve serious injuries or illness, invasive procedures that were not explained thoroughly, or the witnessing of frightening events in a medical facility. Both social trauma and medical trauma are subjective experiences that can be correlated to various health-related preferences between patients, which will be discussed further in this discussion. Some participants recalled traumatic experiences that took place in a medical setting but occurred primarily because of social factors, such as the participant’s sexual orientation or race. If a traumatic experience could have conceivably been avoided if the participant’s social identities were different, then the incident has been categorised as a social trauma in this analysis, regardless of whether the trauma occurred in a medical setting.

Each participant has been assigned a pseudonym to protect their identities while retaining the human aspect of their individual narratives. All names were selected via a random name generator, and any closeness to real-life persons should be considered a coincidence.

3.2. Age-related traumas and preferences

In each interview, participants were asked about their worst healthcare-related experience. As stated previously, certain participants recalled traumatic events that could be classified as both social and medical traumas, but in this analysis, their worst healthcare experiences have been categorised primarily due to one type of trauma or the other. If a traumatic event occurred primarily due to social factors – for instance, a doctor providing inadequate service due to their own biases about the participant’s identities –, this was categorised as social trauma. If a traumatic event occurred primarily because of a healthcare provider’s lack of medical knowledge, poor communication skills, medical mistakes, etc., then these experiences have been classified as medical traumas.

For participants younger than fifty years old, ten worst healthcare experiences were caused by social traumas and ten were caused by medical traumas – an even split. However, for participants older than fifty years old, medical traumas were the primary cause of the worst healthcare experiences for eight of ten participants. This finding could be explained by differences in health conditions – and treatment pathways for those conditions – as they relate to age. As males age, certain illnesses are more likely to develop, such as arthritis, cardiovascular disease, prostate cancer, and mental health disorders, such as clinical
depression (Ravi et al., 2014). As men age and develop more serious health conditions, the treatment pathways become more complex, and perhaps more likely to incur trauma in patients. Another way to interpret this finding is by thinking about the relationships that develop between healthcare providers and patients based on a patient’s age. Relatedly, it is important to consider each patients’ ability to communicate their concerns or advocate for themselves based on their age. For example, one participant, Stephen, who identifies as white and is 59 years old, recounted an unfortunate story about a medical trauma experienced by his father:

There’s always somebody there to help you bathe [at medical facilities that specialize in care for the elderly]. So [Stephen’s father] was taking a shower on Monday, and the health worker was there, and I guess they’re there and they sort of like, ya know, open the soap so you can wash your hair and all this kind of stuff, and he was used to that. And the woman who was there on Monday didn’t do any of those things. And he said she turned on the water to make sure it was the right temperature, and then she just leaned up against the wall in the bathroom, and just was on her phone. And he was saying, “she didn’t help me at all, and it was really difficult.” He couldn’t open those bottles – my father’s wheelchair-bound, and he’s relatively weak, so to go and get things – it just wasn’t happening, and he was really unhappy… My sister then followed that up and said, “what’s going on with this woman? She’s not doing her job.” They arranged for my sister to meet [the health worker] and say “listen, this is what I’m hearing from my father,” and the health worker said, “Well, my daughter was sick,” and my sister said, “listen, the concern you have for your daughter is the same I have for my father.” Unfortunately, I think, the older you get, you need someone to advocate for you. That’s what I’m realizing dealing with my father… I guess it’s kind of known that when you hit like eighty-five or something, your brain just doesn’t work as well… you start having health problems, that especially as a guy, you would never have. You have UTIs – urinary tract infections – and I don’t know if you know or not, but when you get to be old, a urinary tract infection is deadly, and, man, your brains are just like, you don’t know what you’re doing, so you need somebody around [to take care of your medical concerns and to advocate on your behalf if your health needs are not being met].

There are several possible explanations for why Stephen’s father was treated inadequately by the health worker. Perhaps, Stephen’s father was simply unable to communicate to the health worker that he needed more assistance than she had offered. On the other hand, the health worker might have treated Stephen’s father with less care than was appropriate because she was too distracted by her own family’s issues, seeing as how she replied to Stephen’s sister’s complaint with a rebuttal that her own daughter needed assistance. Regardless of the explanation for the lack of proper care in this incident, the fact remains that Stephen’s perception of ageing in care has been negatively impacted because of secondary trauma caused by his father’s medical trauma.

Furthermore, many participants indicated preferences for the gender, race/ethnicity, language spoken, and sexual orientation of their providers. Regarding gender, 8 of the 10 participants who were 50 or older indicated a preference for male primary care providers (PCPs). One participant, Glen, who is 56 years old and identifies as a white man, said “I feel more comfortable with male doctors… Just the comfort level about intimacy with another man,
I’m more comfortable with, I suppose, than a woman that I don’t know”. Another participant, Avery, who is fifty years old and identifies as Latino, told me quite explicitly:

It depends on what I need done. If they’re going to look at my asshole, I need a man, you know. I don’t want some straight girl looking at my butthole... I don’t know, because girls don’t look at my butthole ever, ya know? I don’t know, it just feels uncomfortable to me, and I feel like when you’re getting examined, you should have a man examining those private parts because they know them better.

For Avery, it seems like the comfort that he experiences with male PCPs stems from a comparable and shared understanding of the male body. Similarly, when Carl, a 50-year-old man who identifies as Black, was asked why he prefers male doctors, he said:

I’m a man. I feel like I generally relate better to men. Men, I find, are a little bit easier, or a little bit better at emotionally decoupling. I have had some female doctors, and particularly when it comes to sex and sexuality, I feel like men just sort of understand each other’s sexuality and can be a little bit less judgmental about it than women can be. Generally, I’ve always related better to men, so that’s just a personal pattern, and I have nothing against women, I just don’t relate to them as well, and in terms of the practice, women doctors that I have had – and again, this not a general statement about female doctors, it’s just the female doctors I have had – have been distracted, cynical, just not as easy to talk to, not as warm. Not that the male doctors have necessarily been warm, but the bedside manner I’ve experienced so far has not been as good [with female providers]. I’ve not felt a desire to go back. I’ve not had [a female provider] yet where I said, “wow, that was an amazing doctor.”

For Carl, the explanation of his preference seemed simple enough: he has had three or four female PCPs in his lifetime, and his opinion is that none of them was amazing in his experience. Carl has also had about a dozen male PCPs, and overall, feels that he has created better relationships with them. Since Carl claims to build rapport with other men more naturally, it makes sense that he would be able to develop better relationships with male doctors, reaffirming his preference. Carl was asked follow-up questions to uncover why he might have a preference for males in general, and he admitted that he had a strained relationship with his adoptive mother growing up, who tried to commit him to a mental hospital when he came out to her as gay at nineteen years old. Carl’s mom, who is Black and raised in the South, also tried to convince Carl that he became gay by spending time with white people. Carl’s mom was also misinformed about HIV and automatically assumed that Carl had AIDS when he came out as gay. When Carl decided to get tested for HIV to prove to his mother that he did not have AIDS, she celebrated by telling Carl’s adoptive father and the aforementioned mental health specialist that Carl was no longer gay because he tested negative for HIV. These social traumas that stem from Carl’s relationship with his mother might have been influential in the development of Carl’s preference for building relationships with men rather than women, which could have in turn affected his relationships with healthcare providers.

Regarding gender preferences for participants younger than 50, 5 of the 10 participants indicated having a preference at all, but interestingly, three of these 5 participants had a strong preference for female doctors, while the remaining 2 participants preferred male doctors. The
3 participants who preferred female doctors were also among the youngest in the study at ages 20, 22, and 26, respectively. On the contrary, the remaining 2 participants under 50 who preferred male doctors were ages 37 and 40, respectively. When I asked Alexander, who is 22 years old and identifies as Latino, about his preference for female providers, he answered:

I feel like men who have sex with men are more likely to not be as uncomfortable, or not be as nervous about discussing their sex lives with a medical professional, if they’re just generally open about their sex life or have had more experience discussing their sex life with a medical professional. Cause like if I think about myself, I think the short amount of time I’ve been having sex with guys, and the short amount of time that I’ve had to discuss my sex life with a medical professional, and like my discreet sexual life – it’s all connected; I think they all inform each other. I think it somewhat is – maybe not [that older MSM are necessarily] sexually liberated, but just like, open with talking about their sex life, and have had a lot of experiences. Aside from maybe a health scare, they are probably just more at ease with getting tested and interacting and discussing their sex life with medical professionals [than younger MSM]… And when speaking about intimate things, I don’t want to speak to someone about sex if outside the medical context we might have sex. With male doctors, there is that possibility. It might be a hormonal explanation – younger guys are hornier.

Alexander’s reasoning would explain why participants more frequently indicated a preference for male providers as participant age increased. As MSM age and develop a stronger sense of identity, coupled with greater control of their hormones, they might generally feel more confident speaking to any doctor regardless of gender. Another explanation for this trend could be that, as men age and the chance of male-specific issues increases, they feel that it is more appropriate to receive care from a provider who shares the same anatomy, regardless of their previous gender preferences.

3.3. Race/ethnicity-related traumas and preferences

Although this study originally focused primarily on age-related experiences and preferences, many themes were evidently more related to race and ethnicity than age. There were 3 participants who identified as biracial, all of whom identified as part white. A separate ‘biracial’ category was considered, but ultimately, it did not make sense to group these three men together since their primary racial identities and ensuing experiences were significantly different. These 3 participants were filtered into the race category with which they most personally identified, which were Black, Latino, and Asian, respectively.

All the Black and Latino participants expressed that they have experienced both social and medical trauma. However, it is interesting to note that the only two participants who did not indicate medical trauma were both Asian, ages 34 and 52. It was not readily clear whether this finding was a mere coincidence or if it were related to a cultural construction of health shared by the 3 participants. After revisiting both these participant’s transcripts, it was noted that both have primary care providers who identify the same as they do ethnically, Chinese and Filipino respectively, and have been with these providers for many years. This could explain why these 2 men have been able to avoid medical trauma: they share a native language with their providers and, possibly, a similar cultural lens through which to think about health and
medicine. However, both men indicated experiencing social trauma regarding their identities as gay men. Overall, every participant reported either medical or social trauma, and 14 of the 20 participants reported both.

White men overall reported fewer social traumas in proportion to the other race categories, but still, 5 of the 8 white participants reported being treated inadequately at least once because of their sexual orientations. Interestingly, all 8 white participants reported medical trauma. First, it is important to note that 6 of the 8 white participants were at least 40 years old, and 4 of the 8 were at least 50 years old. Overall, white men were among the oldest in the current study, and as was discussed previously, there was a relationship between ageing and medical trauma within my sample. Secondly, it is possible that white participants were simply more likely to focus on their medical traumas during interviews, compared to participants of colour who often focused heavily on their social traumas.

For 2 of 3 Black participants, their worst healthcare experiences were due primarily to social traumas. Not only that, but Black participants recounted more stories overall compared to any other race category about instances in which they felt they were treated inadequately or inappropriately. Between these 3 Black participants, they provided accounts of doctors being too parental, doctors being too rough and rushing through visits, doctor barking orders instead of treating their patients with respect, and even more severe cases, including one that might be considered sexual harassment. Historically, there have been false beliefs in the medical field that Black people have a higher tolerance for pain and discomfort than white people due to inherent biological differences, which might explain why these Black participants had experienced more social and medical traumas overall (Hoffman et al., 2016).

Evan, who identifies as Black and is 26 years old, reported several of his traumas:

I remember there was a time when we were talking about STDs and HIV – [the doctor] kind of like made me feel uncomfortable, and kind of made me feel paranoid, because he was like talking to me as a father, saying “oh, you shouldn’t be doing this, because if you do this, this is what’s going to happen to you. So, you make sure you cover up because you wouldn’t want your parents to find out,” or something like that. I can’t really remember how it all transpired, but it just felt as though he was talking down towards me. It was because I didn’t use a condom one time – and I had a scare. Nothing happened, I just had a scare. This was the first time something like this had happened to me, and I was already paranoid, and he like damn-near reprimanded me – he did reprimand me – for what I did. And I guess it’s supposed to be some sort of tactic, but it kind of came on too strong. I had another doctor who I felt like he was too touchy… That was weird. I didn’t like that at all. And let’s see, going to the HIV/STD clinic, I went there, and I actually did have [an infection], and I got that taken care of, but [the provider] was absolutely rough. Like, when it came time for the culture swab – rough with the swab, aggressive, no smile, told me what I needed to do, and everything felt very fast. That was very uncomfortable for me.

In Evan’s case, it is unclear exactly which factors led to his inappropriate treatment, but he concluded that it might have had to do with his physical appearance. Evan describes himself as a big Black man, standing at six feet and four inches, with an athletic build from his days of playing college basketball and a rigorous exercise plan that he has maintained since. Evan is also a young adult at 26 years old, which might explain why the first PCP whom Evan mentioned had a fatherly attitude when reprimanding Evan about having condomless sex. Because of Evan’s appearance, it is possible that the doctor who was too rough presumed that
Evan would be okay experiencing more physical assertiveness, perhaps compared to smaller patients, but Evan has been traumatised by these experiences nonetheless, and as a result, has developed a strong aversion to visiting doctor’s offices. Evan also shared his thoughts about what it is like in general to be both gay and Black:

As a gay, Black man… I think of it as double jeopardy. You know, it’s hard when you’re a gay man, it’s hard when you’re a black man, and it’s twice – four times as hard when you’re a gay, Black man. And for me, individually speaking, it’s really hard when I’m a gay, Black man who relatively just came out and is still trying to find my way – find myself... I honestly haven’t really dwelled on it enough to really think about what I truly want.

Parker, who is 50 and also identifies as Black, echoed Evan’s sentiments almost exactly:

Well, as someone that’s African American, you always [feel stigma]. It’s based on your skin color, not just a gay thing. As someone that’s gay, and you’re African American, you can feel a double whammy.

These parallel sentiments are important to consider when discussing power imbalances in patient-provider relationships, especially if the provider has more social privilege than the patient. Evan and Parker’s ideas hint as to why participants of colour seemed to have reduced confidence in advocating for themselves when certain interactions with providers made them feel unsafe or uncomfortable.

For Latino participants, the causes of the worst healthcare experiences were evenly split between social and medical trauma. Bradley, who is 22 and identifies as Hispanic/Latino, told me that his worst healthcare experience happened when he was in high school; the doctor had asked Bradley to do push-ups and very directly said to Bradley, “Yeah, you’re fat. You should lose weight”. This social trauma, stemming from a complete lack of bedside manner, was scarring for Bradley and affected his self-esteem. This is one such way in which healthcare providers can do more harm than good when their intention is to help the patient, but the actual impact of their words is traumatising. This doctor surely wanted Bradley to become healthier, but because he lacked the necessary tact, he caused Bradley to develop an aversion to seeking care.

It was a piece of shit, the dental school. At least the way they treated people, really like guinea pigs, I felt. It’s not only because you’re seen by students, with the doctor going around, but if you’re going to a specialty clinic – I went to the periodontist there – and I think they’re doing like sessions of torture. The time that I was sitting in the dentist chair, I was in pain, and what they were doing to me was extremely painful and outdated – [good dentists] don’t do that. Maybe they learn to do that, they were learning to use the tools – manual tools – but now they use the machine to do that shit. They were doing a treatment on me which was inefficient. I was there for like six months. When I moved to a different dentist, he finished the treatment in like two or three months, and I didn’t have that problem anymore. And he never did the same thing that I was being subjected to [at the dental school]… What really matters is the quality of service that you get. It’s not so much if it’s a man or a woman, old or young.
Bradley’s medical traumas were so severe that they have essentially caused him to disregard the social identity of any future providers. His focus now is almost exclusively on finding providers who offer the best quality service possible, regardless of his ability to identify with them.

Only one of the 8 white participants reported a worst healthcare experience that was due primarily to social trauma. Quentin, who is 37 and identifies as white, is one of the few participants who has not experienced medical trauma, but who was outwardly discriminated against for being gay, which he considers his worst healthcare experience:

Around 2011, I got laid off from my job, I started getting Medicaid, and I found a doctor to go see, and as soon as he found out I was gay, his demeanor changed. It was just very uncomfortable, and I never went back to him. And he would refer to ‘gay’ as ‘homosexual,’ which I guess is fine, but it just felt like very old-fashioned to me—in a negative way. I just got super uncomfortable.

Quentin was not the only white participant who mentioned feeling stigmatised because of his gay identity, but interestingly, medical traumas seemed to leave much stronger impressions on the remaining 7 white participants. Some of these medical traumas will be discussed in detail in the following sections.

Regarding race, ethnicity, and language, it is noteworthy that at least one person in the Black, Latino, and Asian race categories said that they prefer their PCP to identify the same as them racially or ethnically, or to speak their native language. Donald, who is 34 years old and Chinese, offered this thorough explanation for this preference:

Based upon assumption, that’s why I go for doctors who speak Chinese or who are Asian, just assuming commonalities in our upbringing, that they’ll understand what I say or why I believe certain things, just because of tradition or culture... I speak English, multiple languages, but when I speak Chinese, I associate that with a sense of closeness. That’s a language that you use with your family, your people, there’s a sense of intimacy with using that language – closeness that I don’t have when I speak English. But I guess in this country, English is the de facto language, so that’s what we use, but to find somebody who also speaks your same other language, the distance is narrowed, and so I think it’s that – we can have that common ground, and then, like I said before, there’s certain things I can just articulate better in Chinese, that I can’t or couldn’t before in English. To this day, I carry with me – I remember when I was younger, when I was in middle school and high school, that’s when I started having – I didn’t know what [it was] at the time – but the whole left side of my body would go limp if I suddenly went from a resting state to a sudden burst of energy state. For example, I would be standing in line for a dash, and the teacher would [say] “on your mark, get set, go,” and from not moving to moving, my whole left side would go limp. “To go limp,” there’s a way to say that in Chinese, which literally translates to “to become soft,” but at the time, my doctor was an English-speaking doctor, and I didn’t connect that that meant limp, or I didn’t have that vernacular in English at the time, so I said, “it feels weak.” They ran all these tests with me, and sent me to the urologist, and EKG, and MRI and all these things, and they couldn’t find anything wrong. It was very frustrating, and much later in my life, maybe ten years later, I found out that I have a cataplexy, which is a symptom of narcolepsy, where one or more sides goes limp, and that’s exclusively collected to narcolepsy. And I was like, dammit, if I had been able to
explain [the Chinese word for limp] as ‘limp’ at the time, I think I would have avoided a lot of these crazy things, and maybe it would have been resolved. And so that experience I’ve carried with me, to be able to articulate certain things or certain feelings.

Interestingly, none of the 8 white participants indicated this sort of preference for race, ethnicity, or language. Based on what Donald described, this finding makes sense; the majority of services in the United States are already catered to English-speaking people, so white people who are born in the United States and learn English as their first language are unlikely to face the same type of cultural or language barriers that people of colour and immigrants experience.

Of the 8 white participants, 7 indicated preferences for providers of a specific sex or gender, and six preferred providers of a specific sexual orientation, compared to considerably lower rates for participants of colour. A possible interpretation of this finding is that white men have an increased capacity to search for providers who share similar identities and experiences based on their sex and sexual orientation since they are not preoccupied with finding providers who share their cultural understanding of health, or the same language to describe symptoms, as did many the participants of colour. For participants like Donald, his lesser English-language ability throughout his youth was possibly the cause of ten years of stress, since his doctors were unable to diagnose his cataplexy until he had developed the proper vocabulary to describe his symptoms in English. Because white, English-speaking men are not experiencing these sorts of trauma, they can effectively put more time and energy into finding LGBT-friendly doctors, or male doctors with whom they feel more comfortable discussing their health.

The key distinction between the aforementioned preferences, however, is that race and language preferences were more often founded on traumas that had explicit health implications for participants, whereas sex, gender, and sexual orientation preferences did not necessitate health implications. However, if any of the latter preferences are not met, this may at the very least cause undue stress to patient-provider relationships. Since a patient’s comfort level is a key factor that determines the perceived quality of care, any unmet preference could potentially affect health outcomes. Further research could determine if this finding is applicable to people of all identities and experiences. However, it could be argued that there is a gradience in the severity of preferences and health implications based on identity: that heterosexual white men have more privilege than white MSM in medical contexts (the distinction being that straight men are less likely to have a preference for their PCP’s sexual orientation), and white MSM have more privilege than MSM of colour. Further, it is worth considering that MSM of colour have greater privilege still than queer women of colour or transgender/gender non-conforming people of colour.

3.4. The lasting impacts of the AIDS crisis on attitudes toward health and sexual behaviours

In the previous analysis section, it was reported that 16 of 20 participants indicated social traumas that influence their perceptions of health. One common cause of secondary social trauma that was almost exclusively discussed in the conversations with men 50 or older was the AIDS crisis. The interview schedule that was used for data collection did not have any questions built in that asked about the AIDS crisis, but at some point or another, the majority
of participants would introduce the topic themselves, as it was relevant for their identity-formation as adolescents, and has directly influenced their sexual behaviours, both during and after the AIDS Crisis. Glen, who is 56 years old and white, told his story about living in New York during the AIDS Crisis:

"Things are a lot better now, because when I was your age (laughs) – I came to New York in 1979, it was pre-AIDS, and everybody was, you know, out of their minds, you know, just sleeping with everybody, and if you got an STD, you’d get a shot, and it was not all about safe sex, or consciousness to any of that. So, I lived through all that, and then I lived through when all of a sudden – suddenly my friends start dying. No, it was like a war. I mean literally, can you imagine all the people around, and all of a sudden, you’re at three memorial services every week. And people died – classmates, even people I’d dated or had slept with – all of a sudden… And I was very, very lucky. Nobody knew anything about what was going on, so that was a very scary time. As I say, the fact that I’m alive and negative now is a miracle, you know, that’s proof that there’s a God, because we didn’t know anything… It was a wild, wild time, but nobody was thinking about anything, so I guess going through all that, it was the best of times and then the worst of times. Suddenly you’re afraid, you don’t know why everyone’s getting sick, and then you’re afraid to have sex with anybody. So, for me, when I think about as far as having safe sex, when the doctor talks to patients about that, the fact that I have an appreciation for [safer sex options] is because I had friends and lovers die, and I’m amazed at how many people in your generation can even say that – nobody. You go, you get shots, there’s something you can do to take care of it, but to have that feeling, how serious it is, that informs my decision whether or not to have safe sex, to protect myself. Why I’m on PrEP, why I’m gonna’ do whatever is going to protect me, because I know what [the AIDS Crisis] look[ed] like… because I lived through that. You can’t know that, you can’t appreciate it, really, [even though] someone could tell you. The fact that the doctor never had a discussion with me about that, about how to protect myself, that is something that I think is very important. It’s really been through my own initiative that I’ve protected myself. My doctor didn’t suggest PrEP, didn’t have that conversation, and as a gay man going to the doctor, I think it’s important.

Glen’s likening of the AIDS Crisis to war depicts how tragic and traumatising it must have been for MSM, especially at the start of the crisis when there was no scientific explanation for a disease that seemed almost exclusively to target gay men. It is also notable how Glen points out that the younger generation of MSM have so many more treatment and prevention options for HIV and STIs than his generation did, so he feels that PrEP is absolutely necessary for maintaining his health.

Brian, a 50-year-old white man who was a medical student in the 1990s, cared for 20 AIDS patients and watched every single one of them pass away – he described it as “horrific – a slow-motion death where your body disintegrated”. Because of this trauma, Brian now has mixed feelings about PrEP. While he is glad that younger men do not have to worry about dying from HIV, he is also concerned with the public health implications of the relatively new drug, which, when taken once a day, can protect the body from being infected by HIV if an exposure were to occur. As Brian reported, “until we have a cure or permanent vaccine [for HIV], we shouldn’t be so blasé about it”. Many other men shared this same sentiment, regardless of age, which I found to be interesting. Many participants were concerned that
MSM are inadvertently transmitting STIs to one another by having condomless sex, focusing only on HIV instead of protecting themselves completely.

Furthermore, many participants said that they know a lot of gay men, especially younger gay men, who are having unadulterated, condomless sex, because they are on PrEP. Among the sample, however, very few participants said that they have chosen to have condomless sex unless they were in committed relationships, and those who were on PrEP were still very conscientious of their health overall and try to practice safe sex as much as possible. Even some of the youngest participants were also wary of PrEP, such as Alexander, age 22 and Latino, who first wrote off PrEP as an excuse to be ‘slutty’. After learning more about PrEP, Alexander said that he realised it could be used to have unprotected sex with just one partner and that taking PrEP should not be associated with sexual promiscuity. Regardless, when asked by providers if he is interested in PrEP, Alexander’s stance is still a firm no, but his reasons have changed; he no longer associates the drug with ‘slutty’ behaviour but feels that he is already extremely risk-averse when it comes to sexual behaviours, and personally does not feel that having to take a pill every day is worth the benefit.

3.5. A ‘tug of war’ of trust: the importance of a patient-centred approach

The last major theme that will be considered in this discussion is the key distinction between what most participants considered ‘good’ and ‘bad’ providers: patient-centred care. Many participants recounted multiple stories of all the bad providers they had to encounter until they found good providers with whom they felt comfortable and capable of developing a healthy and productive relationship. For example, one participant, a white 37-year-old named Quentin, said this about his primary care provider:

I get the feeling that he’s looking out for me. Makes me feel comfortable, at ease – maybe fatherly? I have sensed that he’s looking out for me, for my best intentions – that he genuinely cares. He definitely takes time when examining anything.

The value of time and patience was suggested by many participants. Participants noted that if a provider took their time with patients and did not make them feel rushed, they were more likely to describe the interaction as genuine. Similarly, Evan (26, Black) said:

I don’t like visits where I’m rushing in and out. It kind of puts me off when [providers] don’t feel so invested, giving you whatever they think will make you feel better. I prefer doctors who will crack a joke a smile.

This preference for a caring personality seemed to transcend age as well. Older participants felt the same, and Avery (50, Hispanic/Latino) said that the only reason he would switch providers is “because [he] doesn’t want to feel like a number, or [if] they’re not straightforward with [him]”.

In attempting to understand why providers might rush through care with their patients, some participants said that their doctors have grown increasingly busy as their practices have grown, so they simply have less time with each patient. Another participant introduced the concept of physician burnout, which basically implies that most medical professionals start
out their careers genuinely wanting to help people, but after some time, eventually become jaded and less excited about caring for their patients. In the United States, working in the medical profession is generally quite lucrative compared to many other professions. Realistically, there must be some providers who chose their careers primarily for financial security before their desire to help people live healthier lives; from a financial perspective, increased patient flow produces more money for providers, which might explain the tendency to rush patients in and out. A more optimistic theory is that providers want to deliver services for as many patients as possible, even when they are aware that the perceived integrity of services may decline in the process.

Brian (50, white) is a radiologist and physician, and even still, has faced incredible challenges as a patient. He offered this story from 2003 to explain provider perspectives:

I think once a provider knows that I’m a doctor, sort of the language changes, because as a provider – I don’t call it dumbing down – but I try not to use a lot of big medical words when I’m talking to patients, and I might take longer to explain something to a non-medical patient. So once a provider knows that I’m a physician, we can talk in medical terms, and usually the conversation is quicker and more to the point, because we know what each other is talking about. And I don’t know how it makes them feel when they have me as a patient… I used to sort of hide the fact that I was a physician when I went to providers, but I don’t know, because – it was a bad experience, and a bad outcome anyways. I think establishing myself as a physician makes them probably a little more careful with me… So, I was a radiologist in a relatively small town in California, and I had a broken finger. A pretty minor injury, and I had it pinned, an operation to fix the fracture on a Friday evening, and it quickly became infected and was extraordinarily painful all weekend, just one or two days after the surgery. And I called the surgeon’s answering service multiple times over that weekend and they knew who I was, or I assume they knew who I was, but I deferred to what they recommended, which was basically don’t do anything [about the finger]. So long story short, I finally go and four days later and my finger is so infected that it almost needed to be amputated, and it ended up being an eleven-week antibiotic which almost literally killed me, because [the infection] went to my heart, and could have been – and would have been – potentially fatal, if I was younger, a lot older, or feeble, or whatever. And part of that sort of lesson that I learned is – what a lot of patients learn – is that you have to advocate for yourself, and if you’re not getting the response that you want and need from a provider, then you have to be more forceful. So, to try to avoid getting to that position again, I make it fairly clear [with providers] that I’m a physician, and I think that makes them a little more careful with me.

Even as a highly educated, white, masculine-presenting physician, Brian had difficulty advocating for himself. Continuing his story, Brian reported how his identity as a closeted gay man was also called into question:

I had a surgeon that did the surgery on Friday evening. The person that I spoke to on Sunday evening was not my surgeon but was his partner who was covering for my surgeon, and he didn’t seem to take what I was saying seriously. I don’t think he believed how much pain I was in, and I don’t think he believed all the measures I was taking to relieve the pain. And he should’ve had me come in, even though it was the middle of the night, and two days later on Tuesday, which was only four days after the surgery, I went in and he unwrapped my finger for the first time since surgery, and it literally exploded in
puss, and my whole skin slipped off like a snake skin, because it had been under so much pressure, and from Tuesday to Friday, so four days in the hospital, he thought to cure the infection with just antibiotics. And so, I suffered in the hospital for four days with the worst pain that I’ve ever felt in my life – just extraordinary pain. And he finally, on Friday – a week after the original surgery – he took the pins out, and within twenty-four hours, I was afebrile and my finger felt way better, and I went home literally twenty-four hours after they took the pins out. There are stories about surgeons having god-complexes, or having all this hubris, and I sort of experienced that, because he thought that he could fix this, even though it was too far gone to be fixed from the beginning. He should have recognized that, and instead I suffered extraordinary pain in the hospital... I’ve never been in so much pain where that’s all I could think about. I would have literally cut off my head if that would have made me not feel the pain – or cut off my hand to not feel the pain. It was that much pain. I guess it’s hard to get that point across to a doctor, how much pain you’re in, but a doctor’s automatic reflect response is, ‘oh, it can’t be that bad,’ or ‘you’re just looking to get high on pain pills,’ or ‘I’m afraid you’re going to get addicted if I give you too many pain pills...’ That whole experience was the worst experience of my life. One of the main reasons that I left that part of the country... A period of time later, I actually hired a lawyer to consider suing [the surgeon] for malpractice, which [the surgeon] clearly did, and eventually it was dropped, but I went through the deposition with his lawyer. I was not out when I was living in this town. I don’t think that I behaved in any particular way for anybody to think that I was gay, but one of his lawyer’s series of questions was insinuating that perhaps my quote-unquote lifestyle is what got my finger infected, and not the surgery. I was still closeted at this time, and I had already moved to Denver at this point – I was going back to California to pursue legal action against them, and I don’t know if that’s the point that he was trying to make, but that’s the point that I heard... Two of the bacteria that they found in my bone and in my blood were fecal bacteria, that I probably got from the lakes and the rivers I had been in, but because they were fecal bacteria, I think that’s why his lawyer was suggesting that for some reason my lifestyle put me at risk for a fecal bacteria that goes to my heart, which none of my providers, the cardiologist, my infectious disease doctor, had ever even heard of in their entire years of practice. So even though I was closeted, I kind of look on that as my first time of ever being discriminated against for being gay.

It is unclear whether the surgeon’s lawyer was insinuating that Brian’s secret gay lifestyle is what caused the infection, but the fact remains that Brian interpreted the claim as anti-gay discrimination or scapegoating. Because Brian was not out at the time, he felt unable to defend himself without confirming or denying that he was gay. Through Brian’s intense traumas and his experience as a physician and radiologist, he was able to summarise very articulately the perspective that providers should have in order to provide good quality care for their patients:

I guess this is a tug of war of trust [emphasis mine], because you’re with a physician who knows more than you, who is more experienced than you, and you put a lot of trust in that provider, but at the same time, you have to be aware that if things don’t seem to be going the way you think they should be going, that you need to stand up for yourself more and demand more attention, or demand more investigation, or change providers... They may be the specialized person, but it’s still your body, and you have to advocate for yourself and make sure that you’re getting the attention and care that you need – and I try to keep that in mind with my own patients, but it’s not always easy... Your day to day challenges and issues, with being overwhelmed, with what you have to do, having to deal with difficult patients, having to deal with staff that isn’t doing perhaps what they should be
doing, just being in a bad mood generally – you know, everyone goes through human emotions. But I try to remind myself that every x-ray that I look at deserves exactly the attention that I would give my mother, or anybody else that matters to me, and that I find interacting with the patient, either verbally or during a procedure, that they deserve my full attention, and if I don’t feel like [working], or even if I’m tired, or thinking about the weekend or whatever, I still need to continually focus on that person. That person doesn’t care about anything else in my life, they care about what’s in their lives, and I consistently have to remind myself, going into work, or half-way through a long day, or half-way through a long week, or whatever, that the patient deserves my full attention, whether its eight in the morning or four-thirty in the afternoon.

Brian’s awareness of his own limitations as a provider are extremely valuable; he re-emphasises that healthcare should always be patient-centred, even when he is tired or distracted at work. Because he has been on the receiving end of unacceptably poor care and possible discrimination, he understands that the primary concern of providers should always be to make their patients feel heard and fully attended to. To reiterate Eton et al.’s (2017) finding, patients need to feel like they have amicable relationships with their providers to achieve ideal health outcomes.

4. Limitations and prospective research

The small sample of narratives represented in this discussion limits the generalisability of its findings. If the study were continued to include more MSM, then, themes could be analysed statistically to produce more convincing arguments. Moreover, all 20 participants identified as gay or bisexual; during recruitment of participants, the term ‘men who have sex with men’ was used to include men who are not out, or men who identify as heterosexual but have sex with men for reasons other than romantic or sexual interest, such as paid sex work. Further studies would benefit from the inclusion of perspectives of men who identify as heterosexual but engage in the same sexual behaviours as gay and bisexual men.

Regarding gender, this study did not include the perspectives of transgender men who have sex with men. The healthcare experiences of cismen and transgender men would not necessarily be comparable given differences in physical anatomy and resulting differences in health concerns associated with the body. To effectively understand the healthcare experiences of trans men, an entire interview-based study focused exclusively on the transmasculine population should be considered. The same can be said for lesbian, transfeminine, and gender non-conforming populations.

Regarding race and ethnicity, Caucasians had the highest representation. There were only three Black MSM in the study, and only one of them was under 50 years old; his experiences are valid but cannot at all be considered generalisable for other young Black MSM. More representation from MSM of colour overall would elucidate the validity and generalisability of preliminary findings in this study.

This research addresses a gap of multigenerational qualitative research on the topic of LGBT health, but longitudinal studies are still critical for understanding how perceptions of healthcare change over time on an individual level. The older MSM interviewed for this study provided a necessary perspective on the long-term effects of historical trauma on a community. However, it remains to be seen whether the younger participants’ perspectives
will eventually reflect those of the prior generation, as the younger LGBT generation has not experienced a historical event as cumulatively traumatising as the 1980s AIDS crisis – although attacks on the LGBT community have persisted, such as Pulse nightclub shooting of 2016.

5. Conclusion and reflections

MSM patients have specific needs of their providers, both from a medical and social perspective. MSM bring vastly different experiences and traumas with them into healthcare spaces, and medical providers need to be cognisant of these factors. Participants in this study reported extremely high rates of both social and medical trauma, and even traumas that occur outside of a medical context have implications on patients’ ability to form connections with their providers and advocate for themselves if their care is uncomfortable or inadequate. This relationship between lived experiences, trauma, and self-advocacy was stronger for participants of colour than for white participants, which suggests there is a gradience of privilege with regard to treatment by healthcare professionals. One suggestion is for further research that explores the narratives, traumas, and ensuing preferences of other marginalised identities to see if the findings presented here are generalisable and statistically significant.

Medical providers contribute a necessary service to society – and it is certainly no easy task – but if done ineffectively, it can have potentially detrimental implications on the individual patient-level, as well as on a system-wide public health level. Another consideration for further research is to interview more healthcare providers to discern what they consider the most effective, high-quality service provision, given that this study ultimately only presents one aspect of a much greater narrative, with the exception of Brian’s contributions to the investigation as both a gay man and a physician.

Finally, this research supports the concept of intersectionality – or the idea that multiple identities can interplay and shape a person’s experience. One suggestion for healthcare professionals is to engage in more cultural competency training with a focus on identifying and understanding one’s own biases and privilege, as well as enhanced efforts to listen to the narratives of every individual patient. Understanding one’s own position in relation to those around them is crucial for empathy and is necessary for a patient-centred approach to healthcare. Medical professionals provide an essential service to their patients and society overall, but as long as there are health inequities related to race, sexual orientation, gender, or any other social identities – whether visible or invisible – further research, advocacy, and reform remain vital for the advancement of healthcare.

Keywords:
health; medicine; HIV; AIDS crisis; LGBT; trauma; narratives; gay/bisexual men

Reference list


