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Health Experiences in the LGBTQ+ Community: An Ethnographic Analysis with Recommendations

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Abstract

This article aims to share and raise awareness of LGBTQ+ realities in healthcare. It explores the reality of discrimination and disparities in healthcare faced by LGBTQ+ people and recommendations to work towards a system that recognizes the unique challenges and circumstances LGBTQ+ people face that are influenced by social and environmental factors. This article uses Amartya Sen’s Capability Approach (1979), as well as Martha Nussbaum’s revisions to that approach (2011), and Urie Bronfenbrenner’s Ecological Systems Theory (1979) to analyze the experiences of participants who are LGBTQ and healthcare professionals. This article also uses Glynos and Howarth’s model of practices and regimes (2008) and Kimberle Crenshaw’s intersectional theory (1989). Lastly, this article offers recommendations suggested by interviewees and informed by research.

Acknowledgments

I would like to sincerely thank Dr. Diana Fox, who has guided me throughout this project. Thank you for offering your insight and expertise at every stage of this study, your courses have inspired me and helped me grow as a researcher and as a human. Thank you for this opportunity. I would also like to thank everyone who participated and shared so genuinely with me their truths and experiences. I would not have been able to do it without all of you. Thank you.

Introduction

Healthcare is vital to all of us yet so many people suffer under a system that historically has not accounted for the lived experiences of marginalized people and communities. This article aims to explore experiences in healthcare and elevate voices within the LGBTQ+ community that often go unheard. I will also share the perspectives of professionals in healthcare who advocate for more training, representation, and interventions. By the end, I hope to demonstrate how vital it is that we address and understand how LGBTQ+ people navigate healthcare.

The framework for this study draws from Urie Bronfenbrenner’s Ecological Systems Theory, which recognizes environmental and social factors that affect every aspect of a person’s life. This framework, when applied to LGBTQ+ health disparities reveals the various barriers on a multitude of societal and environmental levels affecting LGBTQ+ people’s ability/ inability to receive proper care and meet their needs. The wider cultural context of stigma and discrimination, based on the values and beliefs of the culture at the macrosystem level, impacts individual health care experiences, whereby individual needs may not be met. Stigma and discrimination co-exist with changes in the chronosystem—societal changes in attitudes over time (Aleshire 2019 173-174). I have also drawn from Amartya Sen’s Capability approach (1979) and Martha Nussbaum’s Partial Capability Theory of Justice (2011) as moral frameworks that determine an individual’s capacity and freedom to choose between systems of value to affect well-being. These choices are dependent on social systemic factors outside of the individual’s control. Similarly, the Ecological Systems theory, when applied to this study, proposes that the capability of LGBTQ+ people to meet their needs and achieve well-being is impacted by and dependent on their positionality or social location within a social system, dependent on a wide array of conditions and factors outside of their control such as sociocultural race, nationality, and sexuality. The idea of “capability” is tied to freedom: ideally, persons should...
be able to achieve their well-being without any barriers or obstacles (Nussbaum 2007). However, barriers and obstacles exist. Thus, through these approaches, we can identify disparities and diversity in how peoples’ needs are met based on their identities and positionalities in the socio-cultural sphere. Also important to this study is Glynos and Howarth’s model (2008) of Practices and Regimes, Critical Theory, and Queer and Intersectional Feminist Theory (Crenshaw 1989), shaping recommended interventions. Intersectionality played an important role in my research: I was able to observe identities defined by age, class, race, gender, and sexuality interconnecting with the social, environmental, and cultural systems at play to inform the ways people have access to healthcare and the experiences that they have had. In the following pages, I will outline my ethnographic research methodology, expand upon the theoretical models above, and share the results of my findings, leading to my conclusions and recommendations.

Research Methodology

Using ethnographic analysis, I sought to not only gain an understanding of the people immersed in and affected by challenges to healthcare but to also share and expose realities that may not be known to the wider community and to push for change through sharing testimonies of experience. I hope to raise awareness of LGBTQ+ healthcare issues, the voices of the people it affects, and how we can overcome healthcare discrimination based on sexuality and gender diversity. I spent the spring semester, 2021 as part of an independent research course, designing and conducting semi-structured interviews drawing from a list of questions informed by preliminary research and personal experience with the topic as a queer person. First I focused specifically on people who identified themselves as members of the LGBTQ+ community, aiming to gain a deeper understanding of the ways individuals access and navigate healthcare and how parts of their identities intersect to determine and shape their overall experiences with the systems available to them. The second sample involved interviewing professionals in healthcare and gaining insight into interventions being made to provide culturally competent care to LGBTQ+ people, sensitivity training, and how factors such as a shift in the U.S. presidential administrations impact the practices of these professionals. These interviews used purposive sampling and were conducted online via Zoom webcam.

In the two months I spent conducting interviews for this project, I connected with fellow peers, friends, former students, and members of the community. This study was conducted during the height of the coronavirus pandemic, which I believe negatively impacted the sample size. The pandemic is also the reason most of the interviews took place virtually via Zoom. While they went well, and participants were conversational and open about their experiences, I found that the few in-person interviews I conducted were much more insightful and I was able to connect more with the participants. I am grateful to everyone willing to confide in me and share their testimonies, opinions, and suggestions for the future about a topic that can be difficult and personal. I greatly appreciate their willingness to share their feelings so openly and honestly with me. All suffer in a healthcare system that doesn’t account for the specific needs of patients whose identities impact the way they experience life. I hope that by sharing these perspectives and this data further understanding and intervention can be cultivated in healthcare to be more accommodating to LGBTQ+ people. It is also important to keep in mind that LGBTQ+ is a homogenizing term that does not take into account the distinction between sexuality and gender and the unique circumstances that trans and gender non-conforming people face in healthcare.
This project was so important to me as a queer person who has had negative experiences in healthcare settings involving heterosexism and homophobia. I do not talk often about these experiences and have had a hard time opening up about them. To be able to listen to other people in my community share their own experiences made me feel like I was not facing these obstacles on my own. Since my own standpoint as a queer person was critical in conceiving, designing, conducting, and writing about this research, it falls under the purview of *Native ethnography*, a term that refers to being part of the group you are studying. I believe my self-identification was extremely valuable in conducting interviews. I felt that I was able to connect with participants, since being a member of the group allowed me to relate more to the circumstances that participants faced and hopefully made them feel more willing to share. Certain interviews I conducted involved a lot of venting and letting out pent-up anger and frustration around this system that to me felt cathartic to hear and participate in. Talking to the professionals also gave me a sense of closure and dispelled some of my mistrust from my negative experiences. My sample of LGBTQ+ individuals consisted of seven people gathered through both purposive and snowball sampling. I interviewed participants across the LGBTQ+ spectrum, including queer, gay, bisexual, pansexual, transgender and gender questioning participants.

**Findings from the Interviews**

*LGBTQ+ participants*

In this section, I share the questions I asked and selections of the findings so readers can learn directly from the LGBTQ+ sample. I close the section by summarizing the insights and recommendations. All interviews were conducted between the following dates: April 7th – June 23rd. The first question I asked was split into two parts, the first being: “How do you describe your identity among the following categories?” with gender, race, sexuality, age, class, and any other important part of their identity. The second part of this question was, “Do you feel that parts of your identity intersect when it comes to how you interact with the world and are perceived in specific spaces? If yes, how and in what spaces?” Through these questions, I aimed to better understand how the unique identities of the participants informed their experiences. This sample contained people who were upper-middle class, upper class, middle class, and lower-middle class. Some experiences that stood out to me were Participant A, who said: “trauma is a part of my identity, and it can’t escape me without addressing it.” Participant D brought up his experience being perceived as Black in all spaces he is in and the preconceived notions that different victims of racialization experience from others. Also expressed was the experience of being perceived as queer sometimes based on clothing. Participant B said he felt fortunate to choose how he is perceived and gave the example of choosing to wear nail polish or not and how that changes the way he is perceived in certain spaces.

In the next two questions, I asked participants to explain their overall experience with healthcare in terms of their identity and whether they thought the healthcare system met their needs. I asked them to share any experiences of unprofessionalism or discrimination received from health professionals. A common pattern that participants observed was avoidance of seeking health care, either because of a negative experience in the past or their inability to afford the care they needed. Apprehension or struggle around the act of getting help for sexual health needs was also a common trend. Participant F spoke about their experiences in the following way:

*I had doctors who didn’t consider I was having gay sex. They would ignore and discourage it rather than provide resources and services to*
go about it in a safe way... I’ve had experiences with doctors who were not informed about HIV, who used HIV and AIDS interchangeably...I had a doctor who told me that HIV could be spread through kissing...This all leads to self-diagnosing and ignoring my health concerns.

Participant A described her experience as feeling,

“...like an animal going through an assembly line...I feel like we’re just meant to fend for ourselves but then going to seek help usually backfires...I just felt like they didn’t know how to help me because they didn’t know what I was talking about or experienced...they can try but it just kinda went nowhere but dead silence when I would say things that almost made them uncomfortable.”

A more positive experience was recounted by Participant D, who compared his experiences now, having a gay physician of color, to his college physician who had no knowledge of antiretroviral drugs like PrEP. This participant’s new doctor instead initiated a conversation about PrEP and gave him a detailed questionnaire. Participant G mentioned going to Planned Parenthood and Urgent Care when there is something seriously wrong as opposed to a primary care physician, as well as the difficulty of finding one during the Covid pandemic. Planned Parenthood was, overall, very helpful; however, when he was trying to get access to PrEP, the nurse practitioner canceled via no-call no-show on three different occasions. Lastly, participant C spoke about how stigma acted as a barrier for her to have access to birth control despite needing it to manage PCOS symptoms.

In the fourth question, I asked participants to describe some feelings that came to mind when they thought of the American healthcare system. Their responses included: “overpriced,” “designed to let people suffer,” “for profit system,” and “a guessing game”. Participant C brought up intense feelings of financial guilt when seeking treatment for sicknesses at a hospital due to lower-class status, despite that status being out of her control. She also mentioned a lack of sexual education and conversations around understanding sexuality in her overall experience with healthcare providers and how much those resources would have been helpful growing up. Participant D raised attention to the systemic issue of inequalities attributed to pregnant women’s mortality, and the racial disparities especially affecting Black and Indigenous Women disproportionately. Participant D shared his experience growing up and being taught by his Black elders that he would have to really push for the kind of care he needs when it comes to health. Participant G explained about the healthcare system:

It seems like the idea of Obamacare is subsidized healthcare for all, but there’s weird profiting of the pharmaceutical companies, insurance companies, and the administrative bureaus managing...a captive marketplace. A lot is skimmed off the top by private bodies and it inflates money we have to pay into it...we need a better system but how do you do that?

The fifth question I asked was how participants would rank their level of satisfaction with American healthcare’s ability to meet their needs on a Likert scale of 1-10. The most common numbers were six and eight, the lowest number was two. Participant A chose the number two and explained that while better than other countries “it’s really not about anything other than money, if you have unlimited money than you get better care and that’s just not the way it should work”. Participant F, who chose six says that they have had better experiences lately but its problematic because having bad experiences sets up mental barriers that limit their pursuit of healthcare. Participant D
chose nine because of the positive experiences he has had having a gay physician of color.

The final question posed to the participants asked what solutions they think would make LGBTQ+ people feel safe, comfortable, recognized, and validated in healthcare. Across the board the first response was more LGBTQ+ people in healthcare and more queer affirming doctors. The second shared response was overall more mandatory training and education around treating and meeting the needs of LGBTQ+ people. Participant C said “I wouldn’t even think of seeking a therapist unless they were queer or a person of color, like someone who can have other perspectives. I definitely wouldn’t feel comfortable talking to a hetero cis man or even woman.” Participant F recommended valuing people and their lived experiences over training because it is better to have someone with a perspective from the social location of queerness. They also felt training could not be created by straight people. Lastly participant G recommended more firms that are LGBTQ+ oriented and not just free clinics like Planned Parenthood, stating that there is not enough long-term care for a lot of people who need it. These interviews show, through an array of LGBTQ+ voices, the realities we face in accessing healthcare and the various system-wide barriers that have affected and continue to affect our capability to access the care we need. Social stigma, affordability, heterosexism, miseducation, sexism, lack of adequate resources, racism, and other socio-cultural factors act as barriers to LGBTQ+ getting competent care.

The idea of intersectionality was crucial to this study as evidenced by the ways the interconnectedness of each participant’s identity informed how they navigated healthcare and their opinions on it. The complex multidimensional nature of participant identities represents the diversity of the LGBTQ+ community and recognizes that for care to be competent, it must consider these intersections and provide care that is catered to a patient’s unique lived circumstances. Also, multiple oppressions complicate experiences but also have the solutions to correct them: participant D, a Black queer participant, was able to navigate questions of race and sexuality with his Latinx gay healthcare professional, for example. He was able to choose this doctor specifically and felt that living in NYC made it easier to find access to queer doctors. He also shared that there are many free and low-cost options like Housing Works that provide public health to queer people specifically. This was insightful and made me realize the role that one’s physical location can play in their pursuit of care on top of social positionality.

Sen uses the term “development” in his capability approach to define “an increase in the freedom that citizens have to choose among preferred development options. These preferences may range from development priorities to cultural values preferences to individual identity options or various sustainability efforts” (Jacobson 112). Looking at this study through Sen’s capabilities approach lens, the specific development would refer to the capability of these participants to receive the healthcare that they seek. Martha Nussbaum, building on Sen, created a list of ten central human capabilities. Her approach aims to recognize and outline a pathway to realize universal human rights. I would like to focus on the second part of her seventh capability: “Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, and national origin” (Nussbaum 2006).

Many people in the U.S. healthcare system are not capable of accessing the care they need without facing humiliation or discrimination, and it leads to their inability to achieve what the function of the system should be, namely, having
Participant A shared:

“It’s safe to say trans people tend to spend a lot of time seeking out proper healthcare and have no other choice but to get involved in the system since we need it to live. It’s a gut wrenching feeling to know I have to somehow obtain my medication for the rest of my life regardless of if the world is burning down or society collapses. I am very scared to go down the path of relying on a doctor that I have very little information on; I have to trust them to provide me the care I need and always have the access to it."

This fear and uncertainty are experienced strikingly by those at the intersections of race and gender. The effects of the economic and social marginalization experienced by trans people of color is documented in the 2015 U.S. Transgender Survey: Report on the Experiences of American Indian and Alaska Native Respondents, 50% of American Indian and Alaska Native respondents who saw a health care provider in the past year reported having at least one negative experience related to being transgender, such as being refused treatment, being verbally harassed, being physically or sexually assaulted, or having to teach the provider about transgender people in order to get appropriate care, compared to 33% in the USTS sample overall. (James 3)

American Indian and Alaska Native respondents also had higher rates of unemployment, homelessness, sexual assault, HIV, and psychological distress based on their identity. This is just one example of how drastically and deeply social and economic barriers, stigma, racism, and transphobia affect the way trans people of color experience inequality. The second part of this study, interviewing healthcare professionals, aims to offer additional
While medical school training recognizes how important compassion is for providers, Dr. A stated that it probably does not do enough direct or mandatory training. Dr. B stated that most medical schools are teaching something in LGBTQ care, but this is highly variable, and the average time dedicated to this topic is only a minimum of four hours.

Since we have seen drastic changes with the shift in presidential administrations from the Trump era to Biden’s presidency, I wanted to learn how these shifts in the larger macrosystem directly and indirectly, affect these two professionals in their areas of care. Dr. A stated: “Immensely. Trump dictated that we couldn’t do anti-bias training and it really limited what we were able to do.” Executive orders under the Trump administration had a direct and harmful impact on how difficult it was for transgender people, and especially Black trans people, to access healthcare needs that extended beyond those seeking gender transition, it affected their ability to access medical help for other issues like sickness or underlying medical conditions during a pandemic. Although in general, these executive orders have not had such an impact, with Trump they did, and it revealed just how fragile and easily lost the rights we have are in this system. Dr. B brought up the Affordable Care Act, and how an administration that improves upon it will improve care and proportionately help LGBTQ people who often lack insurance. Dr. B compared the Affordable Care Act to the Trump administration that, in contrast, was enacting discrimination, “allowing if not even directly advocating for it.” This exemplifies how easily these systems can use their power to restrict, discriminate, and create barriers for LGBTQ+ accessibility to competent and respectful healthcare. Under Trump’s administration, an active effort was made to remove nondiscrimination laws that protected against discrimination based on sexuality or gender identity by the Department of Health and Human Services (HHS).

Insights from Professionals

While my sample of two professionals interviewed for this study is small, these professionals operate in a medical center of a busy northeast city and are directly involved in health equity work. The doctors who took part are involved in a health program that aims to provide competent, non-judgmental, and empathetic care to LGBTQ+ patients. For these interviews, conducted between April 14th-29th, I created a new series of questions aiming to gain a deeper understanding of how LGBTQ+ health disparities are being challenged at the forefront of healthcare by dedicated professionals. I also sought to explore how underlying stigma has acted as a barrier for LGBTQ+ health historically. The first question I asked was how important they thought it was to the health and wellbeing of LGBTQ+ people that their identities and unique circumstances are affirmed and recognized in healthcare and to explain why. Both responded with ten out of ten on the scale. Dr. A responded, “it is so crucial because identity informs life circumstances, how to treat patients, and what to treat them with.” Dr. B stated the importance of respecting patient identity and maintaining a relationship that is open and bidirectional. Dr. B also pointed out the necessity for understanding the full spectrum of identity, as well as acknowledging mistrust as a factor with LGBTQ+ patients due to past experiences and social stigma. Next, I was curious to know what kind of training and interventions were being implemented to mitigate bias, heterosexism, and transphobia in their fields. Dr. A’s response to the question was: “Not enough!” Her hospital division is striving to add a Sexual Orientation Gender Identity (SOGI) field into the electronic record.
Under this rule doctors could refuse and deny caring for a transgender patient using religious or moral beliefs as an excuse. Roger Severino, who acted as the director of the Office of Civil Rights at the United States Department of Health and Human Services (HHS), gave a hollow and ignorant response that validates the way many LGBTQ+ participants feel about American Healthcare.

Severino said at the time, ‘We’re going back to the plain meaning of those terms, which is based on biological sex.’ He also said the rule could save hospitals and insurers and others $2.9 billion over five years since they will be relieved of the requirement to print notices of nondiscrimination in several languages and include them with any ‘significant’ mailings (Simmons-Duffin https://www.npr.org/sections/health-shots/2020/06/12/868073068/transgender-health-protections-reversed-by-trump-administration).

This is a response that focuses solely on financial gain and completely disregards the impact this will have on human lives and the well-being of people who are marginalized in healthcare. Luckily these withdrawals have since been reversed in the Biden administration, and LGBTQ+ people legally have the right to not be discriminated against medically because of their sexual orientation or gender. This also means that the HHS will investigate cases of discrimination and providers can face sanctions if this law is violated (US reverses Trump policy, restores LGBTQ healthcare protections https://www.aljazeera.com/news/2021/5/10/us-reverses-trump-policy-restores-lgbtq-healthcare-protections). It is a relief that these protections have been restored; however, it is also terrifying and disheartening knowing how quickly they can be taken away.

To understand how a doctor can affect individual patient realities, my next question asked, how much of a role do practitioners have in shaping individual patient’s wellbeing. through what they choose to reinforce. Dr. B’s response was that,

*It’s hard to say. An individual-dependent physician who is affirming can have a profound influence on validating patients. A physician who does not will make it very difficult to live fully. Depending on how comfortable the patient is with this physician they could even push them back into the closet. This all depends on the individual person and how much it will affect their ability to live fully and openly.*

Dr. A stated, “it is all dependent on whether they are accepting, helpful if they have policies and language that affirm LGBTQ+ people…bathrooms and helpful forms as well.” She also described how even though she is not comfortable conducting hormone replacement because she wasn’t trained to, she ensures there is someone in that environment who is. “There are not enough doctors who are good with it.” This was insightful for me in understanding the scope of experience and confidence needed for doctors to feel comfortable in carrying out these complex procedures but also the need for more training and awareness in these areas. Despite Dr. A not being trained, she always makes sure someone can perform this process to accommodate transitioning patients.

My last question asked how these professionals have been trained to provide care for LGBTQ+ individuals throughout their careers, and if there have been times in their education that these topics were regarded differently. Dr. A recounted her days of training in the 1980s during the HIV/AIDS epidemic in a hospital ward. This setting was heavy and somber, but it taught an understanding of the sensitivity required for LGBTQ+ issues. “Antiretrovirals changed everything”, and because of them her ward was no longer needed for patients with HIV and instead became
fact that changing societal values can have such power over LGBTQ+ peoples’ capability to access healthcare reveals a serious problem, and underscores how capabilities are either limited by or enhanced by those values. The fight for recognition, respect and validation for LGBTQ+ people in healthcare must continue, and our right to have access to the care we need must be secured. Interventions must be made that go beyond solely the individual and must impact the larger systems of our socio-cultural environment that reinforce discrimination and social stigma around LGBTQ+ people. Recommended are more LGBTQ+ and queer affirming doctors, more sensitivity training and education of LGBTQ+ issues, more funding for programs designed to help LGBTQ+ people, and more affordable care. The Capability Approach also affirms that it is our human right to have access to this care. Nussbaum advises: “The Capability Approach has raised awareness that you do not secure the necessary ingredients of democracy without at the same time focusing on material issues such as health care and the provision of universal primary and secondary education” (Nussbaum 22).

Working on this study was challenging emotionally at first: reading about difficult realities that LGBTQ+ people have had to face in their experiences accessing health made me feel hopeless at times. That feeling slowly morphed into optimism over time as I continued to connect with various voices in the community and the healthcare industry. I saw their drive and dreams of a future where we don’t have to worry about facing stigma or any other socio-environmental barriers when we seek health, and that is very inspiring.

Conclusion

It is crucial to emphasize the importance of not collapsing all experiences of gender and sexuality together in this study. Different bodies and gender and sexual identities create different kinds of healthcare issues and needs. Though they all face discrimination and stereotyping, there are different circumstances and experiences which are necessary to understand to develop effective healthcare interventions and support systems. The
About the Author

Tyler Davis is a senior anthropology major. They conducted research over the spring and summer of 2021 under the guidance and mentorship of Dr. Diana Fox. They are passionate about exploring the experiences of LGBTQ+ people in health and would like to pursue opportunities in LGBTQ+ health and health advocacy.

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