Utilizing Healthcare Services: Exploring Lived Experience of LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning) People

“ ….you don’t actually exist”

Research Team

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Background

- Lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ) people experience significant health inequities with well-documented negative health impacts due to their status as a sexual and gender minority population (Mayer, Bradford, Makadon, Stall, Goldhammer, & Landers, 2008).
- Insensitive, negative or discriminatory attitudes towards LGBTQ people within the healthcare system continues to negatively impact access to health services and the overall health and wellbeing of this population (Fredriksen-Goldsen, Kim, Barkan, Muraco, & Hoy-Ellis, 2013, Institute of Medicine, 2011; Mayer et al., 2008; Shipherd, & Abramovitz, 2010).
- Providing health care to LGBTQ persons requires healthcare providers to be sensitive to the historical stigmatization of this population, knowledge about barriers to care, risk factors and health conditions, and awareness of the cultural aspects in all interactions (Mayer et. al, 2008; Rapid Response Service, 2014).
- Research suggests a need to improve the cultural competence in the healthcare system in order to provide sensitive and competent care to better meet the needs of the LGBTQ community (Mayer et. al, 2008; Quinn et al., 2015).

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Objectives

- Examine healthcare utilization experiences of LGBTQ persons in rural Manitoba
- Explore the impact of these health care experiences on the health and wellbeing of LGBTQ persons
- Identify barriers to access and gaps in healthcare services for LGBTQ persons in rural Manitoba
- Identify criteria that promote positive/negative healthcare interactions

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Methodology

- This study was guided by phenomenological-hermeneutic perspectives to understand and attach meaning to one's lived experience in light of the context that surrounds individuals. In phenomenological-hermeneutic research, the lived experience, or lifeworld, is the source of all data, the "heart" of the research.

- In this study participants were asked to describe experiences accessing a variety of healthcare organizations throughout Manitoba in both rural and urban settings - included hospitals, clinics, mental health services, and urgent care centres.

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Recruitment

- The target group for this study are individuals ages 16 and above, who self-identify as being gay, lesbian, bisexual, transgender, or queer/questioning, and has utilized healthcare services in Manitoba.
- Due to the nature of this study, and the unique characteristics of the target population, purposive and snowball sampling were used. Participants were sought through connection with the Sexuality Education Resource Centre Brandon (SERC), and the Rainbow Resource Centre Manitoba and their social networks (e.g., friends and acquaintances).
- 12 participants were interviewed; until data saturation was reached.

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Preliminary Findings

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THEMES

- Stigma and Discrimination
- Judgement and Assumption
- Gender Identities
- Lack of Knowledge
- Limited Access

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Stigma and Discrimination

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Stigma and Discrimination

- **Fear of disclosure**
- **Safety**
- **Emotional Exhaustion**
- **Dehumanizing Experiences**
- **Avoiding Care and Services**

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“What kind of reception am I going to get?”

- “Just some like safety concerns about like, oh I don’t know if we’re going to get lectured about this or do we have to explain, or- more of the personal feeling of safety. Uhm, you never know what someone’s gonna say- What’s the attitudes to folks in rural areas might hold, but we’re just anxious in rural areas but I guess just some folks meddle but… More- more personal feelings of safety.”

- “ I’m kind of left wondering “Ok, what kind of reception am I going to get?” Because I’m coming here for medical help, am I going to face any additional hurdle or this kind of raised eyebrow questioning, and not really believing I am who I say I am?”

- “I think one of them is the general lack of any sort of acknowledgment that they’re welcome to LGBTQ disclosure. - I haven’t noticed anything that kind of indicate that that would be welcome.

Fear of disclosure: When is it safe to be out?

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“….that’s an exhausting thing to deal with - discrimination”

- “You know I’ve got my own issues, I don’t want to take on I don’t know a social justice issue in this setting. Like I’m here for care. Like being asked, even social justice activism, it takes a lot of energy. It takes a lot of, it takes certain amount of strength. And you know, in those kind of settings usually you’re there, that you don’t have that”.
- “(Physician) might be able to figure out on their own (that he is gay) either way, but I just don’t bother- ‘cause it’s not worth my energy in case they are not a safe person- it can go- it can go many ways I think. It’s just like if it’s homophobia, that’s an exhausting thing to deal with discrimination.”
- “I’ve just also had so many queer and transphobic experiences in medical care that I sort of pick and choose my- or have to historically pick and choose my disclosure- based on necessity and- and emotional boundaries “

Emotional exhaustion: Defending, explaining, enduring from a place of vulnerability

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Judgments and Assumptions

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Judgments and Assumptions

- **Making assumptions about identities**
- **Judgments based on stereotypes, biological gender markers, or personal beliefs**
- **Asking intrusive questions based on curiosity vs need to know**

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- “Like- it’s such an- such an intense experience. Homophobia is such an intense in your own body and like-So, I think shame is the answer, right? Like I- I feel- I feel a lot of shame about it. And I wish I could- I could talk to (physician) without feeling that.”
- “And then it just kinda made it’s like- where I wasn’t like worthy of support or help ‘cause they just kinda pushed me out because of their judgments I guess”
- “I find it very discouraging to access almost any health services to be- to be totally honest”
- “Yeah, it just like- it does a lot to like your- like I feel like a lot of time I have sort of submitted myself to like a lot of these kind of experiences within the system. It wears on your sense of like confidence and stuff like I feel like- I feel like worse because of being with disability in a lot of ways like… I feel way more like uh- broken a little bit by the system...So, like almost like homelessness is like a really freeing option. But it’s like, you don’t have the system breathing down your neck and trying to like make you believe bad things about your health”.
- “like I’ve had like this counsellor trying to convert me and like all kinds of things- to like Christianity or whatever. And like saying that you can’t be checked that kind of thing. So, I just like-I feel like it’s just a pretty not good standard of care”

Dehumanizing Experiences: Lack of trusting or inclusive care

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Gender Identities

- Stigmatization
- Medicalization
  - Process of reducing persons into biomedical terms
  - Using language of biology
  - Facilitates detachment of clinician from patient
- Pathologization
  - Assumption that being LGBTQ represents a defect
  - Reinforces old biases that sexual orientation/gender identities are the problem vs heteronormative social structures disadvantaging LGBTQ people

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- “One of the aspects of their questioning and stuff-was like this really long questionnaire that was probably from like the seventies or something. And it’s like asking you like, “do you prefer reading car magazines or home-making magazines?”, “do you- like would you rather grow up to be a librarian or a mechanic?” And like these really *sexist* type questions”.
- “The pathologization of- of transgender people is harmful and problematic and needs to be viewed differently. The diagnosis of gender dysphorias as a gate-keeping mechanism towards care is- is harmful”
- “was like really negative for me *(crying)*, like- just because it was really- felt like they were asking me to like prove that I was trans or whatever. It was like a person who wasn’t trans who I don’t think really understood about that. I felt- it felt like I had to prove that I had a disorder ‘cause that’s what the process is.”

The pathologization of identity

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“It hurts your credibility”

- “Because transness has been pathologized through the DSM and this pathologization informs the care that trans people receive in the perspective of primarily white cisgender, heterosexual care providers, **our existence, our identities, our experience are pathologized as a mental health condition**, **an inadequacy that hurts our credibility.** So, as soon as you come out, especially as non-binary but also transgender, everything else about your life and your existence and your experience loses credibility. So, your experience in the workforce isn’t seen as credible or your observations about your you know, your heterosexual, cisgender children as less credible”

“The message is you don’t actually exist”

- “They’re never adequate and even if there is an opportunity to self-declare your gender or your pronouns, it’s never appropriately carried through the care received.”
- “Uhm, and even things too like you know often they’ll say “Check one, Mr, Mrs, Miss.” Well none of these fit? So then I end up writing in my own little box.”
- “Right well because if a form doesn’t have what you identify as, asks you to identify but it doesn’t provide your identity anywhere and you have to write it in yourself**. The message is, you don’t actually exist . Or we don’t think you actually exist.** Because if they did, that would be an option on the form. If it’s not on the form, ok then you’re, you’re saying the message that you don’t think it’s real.
- “I haven’t changed my gender marker because as a non-binary person, I- **I can’t change my gender marker on any of my ID…To a congruent marker because currently in Manitoba, we only have two binary gender markers that do not match what my reality is.”**
- “there’s just- there’s no adequate system for communicating your gender and how you should be addressed…”

Systemic failure to recognize sexual and gender diversity

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Lack of Knowledge

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Lack of Knowledge

- **Insufficient knowledge**
- **Unwillingness to seek out information**

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“I never had training. I don’t know what to do.”

- “issues around fertility care for- queer and trans people in Manitoba is virtually non-existent and completely inadequate”.
- “I get a lot of like- well, I’m not specialized. I never had training. I don’t know what to do… and I- I understand that to a certain degree but they’re also unwilling to go get the training and *this clinic* literally has a website - section dedicated to showing providers how incredibly easy it is to prescribe”
- “(because I’m trans) Like, they’re scared to prescribe- medications ‘cause they think there’s going to be an interaction, but they’re also unwilling to look it up or call my doctor or you know, and then it becomes all these different questions. Meanwhile, they’re kind of looking at you funny and it’s like, I’m literally just here because like I have the sniffles that are not going away”

Knowledge gaps: Inadequate and Inappropriate Care

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- “I had a new medical provider and I did tell her that I thought I was due for a pap test and she, I think, was trying - how do I put this? Like I- I think she was making a very serious assumption that I was going to be very uncomfortable with it and like sort of traumatized being that I- don’t identify as female. So, she basically just was like, “We don’t really have to do this. It’s not that important.”
- “they have never been in the years that I have been going there consistently gotten my name correct even after it was legally changed, they were still calling me by the wrong name……in front of the rest of the waiting room”
- “in addition to feeling uncomfortable, there’s also this sense that a number of the staff there would not believe that gender queer exists, which gets in the way as well. Because wanting to change it, and usually when I’m going is being I’m sick, I’m not well.”

Knowledge gaps: Inadequate and Inappropriate Care

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- " like something that happens fairly- fairly often, more often that you'd probably think is something that we call in the community transgender 'Broken Arm Syndrome'…- which is- I don't know if you've heard of this, but it's essentially like you go somewhere because of a reason, like for example you arm is broken…And when they find out that you're a transgender, that's all they focus on. Somehow, this is related to you being trans."
- "I definitely didn't receive trans competent care, didn't feel cared for, didn't feel respected, and ultimately never had my medical concern dealt with by medical professionals."

Knowledge Gaps: Inadequate and Inappropriate Care

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Limited Access

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- “ I just like haven’t gone back. I was like-I just like really don’t - I really just hadn’t like- ‘cause in those situations, I feel really pretty vulnerable.”
- “Yeah, it just like- it does a lot to like your- like I feel like a lot of time I have sort of submitted myself to like a lot of these kind of experiences within the system. It makes- it wears on your like sense of like confidence and stuff like I feel like- I feel like worse because of being with disability in a lot of ways like… I feel way more like uh- broken a little bit by the system...”
- “visiting - like walk-in clinics and- and situations like that where, you know, I don’t know what the- the queer or trans competency of the care provider would be - so, those would be things that I would take into consideration (whether to go or not), you know?”

Avoidance of Care and Services

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- “it’s super tough trying to access a counsellor. The only counsellor for miles around is the faith-based counsellor that, probably *(chuckles)* don’t wanna discuss all of this, you know?”
- “we live in a small community and you know, just- you know, it’s- it probably is just a little bit like oh, god you’re also my mother’s doctor and…you know, I taught your kids swimming lessons and I don’t wanna *disclose* right, and just being a little unsure because especially in rural communities, there’s doctors that may not always be from Canada and, even if they are from Canada, you don’t know necessarily what their views are and if it’s a safe place to disclose, so…”

Limited Access to Care and Services

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Affirming Experiences

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- “You know, they wanted to, they asked those kind of questions rather than looking at me and assuming, making assumptions. Which I mean, as well because the services are provided for me that created a rapport immediately because it, you know, there, there was a level of respect there. A level of acknowledgement. A level of knowledge. And so, ok. So I’m not going to have to teach this person about all of this stuff.”
- “(she was) very good around recognizing and acknowledging my gender identity, uhm she did as well. And one of the first things she wanted to know, you know what “honorific” do you use? What, what are your pronouns? And then she very deliberately, and consciously used those during the examination and in the report she wrote.”

Affirming Experiences

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Giving Voice Back: Recommendations from the Community

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“The biggest challenge is the health care system is woefully unprepared to take appropriate care of LGBTQ people”

“Like the dream is health care providers to understand how our sexuality, or gender, our race, our class, our economic level, all are part of our health, you know? How they all intersect”

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Recommendations

- Providing Safe Health Care Settings: No Assumptions, No Judgments
- Building Queer-Friendly Healthcare and Communities: Increasing Access, Information, and Support
- Radical Overhaul: De-pathologizing Gender Identities and Diversity

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- Training and education
  - Improving Knowledge and Sensitivity
    - Ongoing education
      - Improving basic communication
      - Avoiding assumptions and stereotypes
      - Person-centred approaches
  - Upstream Approaches
    - Overhauling the undergraduate education of our healthcare providers
    - BU's approach

1. Providing Safe Care Settings: No Assumptions, No Judgments

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“Places where trans people can be *supported* or whatever. So that if you can’t infiltrate schools and other communities very much like at least that there’s another option in a holistic health sense, I guess. ‘Cause it’s like one thing to just go to like a monthly support group and like your doctor appointment for like testosterone or whatever. But like if I have nowhere else I can be myself then that’s like- it would be bad on my health, I guess. So like having with like really regular community center-type thing would be amazing like the people can go regularly.”

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- Improved transparency for trans healthcare
- Overcoming geographical barriers for queer healthcare services
  - The need for vital services beyond major urban centres
- Building strong communities

2. Building Queer-Friendly Healthcare and Communities: Increasing Access, Information, and Support

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“Like we need to openly acknowledge that the quote-unquote difference between sex and gender aka body versus brain is outdated, not backed by sociological understanding, not backed by medical understanding, that it is erasure, that it is dangerous, that it doesn’t accurately reflect the lived experiences of a large and invisible and marginalized portion of our population -and again, this is part of the holistic change. It needs to be acknowledged in every way possible from forms to medical care to medical education that- that these things are not as simple and binary as we treat them to be.”

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- Challenging Binary as the Norm
  - Non-Binary and Gender Fluidity education
    - Eliminating binary assumptions
  - Advocacy

3. Radical Overhaul: De-pathologizing Gender Diversity

“Like we need to openly acknowledge that the quote-unquote difference between sex and gender aka body versus brain is outdated, not backed by sociological understanding, not backed by medical understanding, that it is erasure, that it is dangerous, that it doesn’t accurately reflect the lived experiences of a large and invisible and marginalized portion of our population -and again, this is part of the holistic change. It needs to be acknowledged in every way possible from forms to medical care to medical education that- that these things are not as simple and binary as we treat them to be.”

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- “at the very heart- every person you would encounter, what a client needs - like the dream is for every person you encounter and for clients to have their (healthcare provider’s) understanding and their commitment to that good care ”
- “like the dream is health care providers to understand how our sexuality, or gender, our race, our class, our economic level, all are part of our health, you know? How they all intersect”

The Dream: Creating Safe, Inclusive Healthcare Environments

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Comments and Questions?

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Thank You