A Phenomenological Qualitative Research Study

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Relationships and Rural Health Practices

The Experiences of LGBQ+ Women and their Perinatal Care Providers

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Why LGBQ+ birthing women?

Social practices can marginalize certain communities, making them invisible, resulting in negative outcomes.[1,2] The health outcomes of LGBQ+ birthing women are often determined by social processes that inform how they access and experience health services/ resources.[3,4] Rurality is an important consideration with regards to health outcomes in Atlantic Canada, particularly within Nova Scotia, and is emerging as a critical concern[5,6]

LGBQ+ birthing women face multifaceted health care inequities embedded in taken-for-granted and everyday practices of health care institutions and provider-patient relationships.[1,7,8] Institutionalized heterosexism and the assumption of heterosexuality shape the lives of LGBQ+ women and routine practices and policies in rural birthing settings can reinstate, challenge and/or potentially transform health inequities.[1,5,7,8]

Our project offers a critical analysis to show how and why rural health care encounters shape the experiences of providers and patients with the aim of offering innovative and revisionist strategies to shape best practice guidelines, educational curricula, and continuing education for health care providers working with LGBQ+ birthing women. We aimed to address what is largely unacknowledged in health research: gaps in knowledge around how LGBQ+ birthing women access perinatal health services in rural areas.

The Context of the Study

- Thirteen LGBQ+ women who birthed in rural Nova Scotia participated in the study.
- The LGBQ+ women participants presented their sexual orientation(s) and/or gender identities as diverse and fluid over time.
- None were partnered monogamously with male-identified persons at the time of the interviews.
- Ten participants identified as White and the remaining three identified as First Nations, African-Nova Scotian/White and Scottish/French/First Nations.
- Ages ranged from 18 to 42 years of age.
- Data collection included conversational and dialogical semi-structured interviews with each participant having freedom to narrate their own storied birth experiences in rural Nova Scotia and their relationships with perinatal care providers.
- Recruitment criteria for participants were specific to woman-identified persons who had birthed. All participants were cisgender, meaning they identified with the sex they were assigned at birth[9] and were aligned with socially constructed expectations of gender. The research team wish to note their recognition and understanding of the inclusion of transgender people to be necessary when they engage in Lesbian, Gay, Bisexual, Transgender and Queer (LGBTQ+) research studies within larger contexts. These communities are an important representation of the diversity found within LGBTQ+ communities.
- When working with LGBTQ+ communities, language is an essential consideration and point of clarification. Thus, it is important to attend to the use of the acronym, LGBQ+, in the context of this study. The researchers recognize the limitations on, and complexities in, using language to represent the diverse experiences within what are also referred to as "Queer" or "Rainbow" communities. It is with this acknowledgement and understanding that the acronym, LGBQ+, is used to represent how the participants in the study identified.
- Recognizing the complex and diverse ways in which LGBTQ+ persons navigate the daily constraints of heteronormativity, there is both understanding and experience of these constraints shared amongst team members, as some also hold membership in LGBTQ+ communities.

Methodologies: Research Framework

Feminist and queer phenomenological methodologies developed meaningful understandings of perinatal relationships between LGBQ+ women and their health care providers. Informed by the work of existential, feminist, and queer philosophers, the complexities in how women experience birth were explored along four axes of human existence: body, time, space and relation.

The personal experiences of LGBQ+ women told from their perspectives uniquely informed our phenomenological analysis. From this we identified themes of space, invisibility, and relationality as they relate to power, control and autonomy; embodied safety and supportive care; and the importance of trauma-informed care.

Space

The theme of space was threaded throughout our research findings as we consistently returned to the meaning of space for LGBQ+ birthing women. How perinatal care providers either created space with difference or closed such spaces, cultivating exclusory practices that denied LGBQ+ existence. When space was made to feel exclusionary, participants felt alienated, disrespected and often invisible.

"I kind of refer to myself as the invisible queer...[a]nd I kind of don't usually provide a lot of information about myself in terms of polyamory or queer, unless somebody asks. If someone asks, I have no problem telling them. But it's kind of on a need to know basis ... You know, unless it was going to become an issue or something came up related to it, I wasn't really going to, you know, put it out there because I figured it would have just made people uncomfortable or whatnot." -Anne

In the context of our study, the exclusionary nature of the birthing space perpetuated heteronormativity. Minimal space outside the hetero-norm was provided for alternate birthing trajectories. LGBQ+ women who were accompanied by their cisgender male partners were assumed to be heterosexual. For those participants who were accompanied by partners who were women, stories resonated with compelling exemplars of the limitations of language and its discriminatory power during birth; participants felt exposed, vulnerable and often without voice. Findings showed how a lack of autonomy for LGBQ+ birthing women, as members of a marginalized community, often diminished opportunities for embodied safety and furthered participants' feelings of powerlessness.

"There was no access to any type of midwifery services, any type of spiritual practices, or any person that would go into the labour to talk about anything - spirituality, gender, sexuality, comfort, comfortability being naked and what the boundaries are for this person who's about to expose their body and to give life." -Jackson

Invisibility

LGBQ+ women offered narratives that allowed us to question the assumptions we make about who has legitimacy to birth and how this is a product of heteronormative cultures of privilege and oppression. This finding about institutional practices provided us with a way to understand how health care providers fail to appreciate how LGBQ+ timelines for birthing deviate from the expectations set by dominant cultures. Women shared how the hospital environment reflected normative assumptions and how birthing spaces often negated, denied and rejected opportunities to partner with difference.

"Yeah, I would say they were typical, you know, heteronormative type of, you know, cisfemale gendered people, I would say. There were some older and some younger. There were some student nurses and whatnot. But there wasn't really anybody who was obviously identifiably different." -Anne

Categories for LGBQ+ women's experiences are often misunderstood and considered in discrete definitions which complicates care provision for providers who are already limited in knowledge around the lives of LGBQ+ women and their specific health care needs.[1,7] For the birthing women who participated in the study, the complexity of identification was found in relationality and emotionality.

"And I was dating a girl when I found out that I was pregnant with my son. And she stayed with me through the pregnancy and the birth. So they knew at the hospital that... You know, not that anyone said this is my girlfriend or this is my partner, but she was there holding my hand and holding my head and rubbing my back, and spent the night. It was never verbalized in any way but she was there for everything." –Maggie

Often unconsciously and without malice, assumptions and biases that shape dominant approaches to care are reinforced by intentions which are designed around expediency to accommodate schedules driven by numbers, safety and timelines. [1,7,8] Unfortunately, this inadvertently contributes to the vulnerability of LGBQ+ women when they access care as it fails to question the construction of health care spaces and how provider-patient relationships are governed by objectification, segregation and compartmentalization.[1,7,8]

Supportive Care and Embodied Safety

Safety was conditional and restrictive. Bisexual women who were birthing with a male-identified partner were assumed to be heterosexual and health care providers would reinforce parenthood according to heteronormative assessments. When women presented with a woman-identified partner, the status of their relationship often went unacknowledged which reinforced the expectation of heterosexuality in birthing spaces.

"...I felt very disempowered. I think that that was a relative experience for me. Like I felt disempowered in certain aspects of my identity. But I mean I was still considered a valid person and I still had really great experiences with some of the nurses, and there wasn't, you know, rude comments made in front of me or... Like I think my experience would have been very different had I been of a different race or class, is what I'm saying. I carried a lot of privilege in the room even though it was a disempowering experience." -Estelle

For LGBQ+ birthing women, supportive relationships contributed to creating safe spaces where they felt accepted and empowered. Those who accessed care in hospitals relied on relationships with doulas, midwives, nurses, family physicians or family members. Many identified with childbirth as a "natural" process and pursued options in home birth. Others armed themselves with knowledge that was accessed through their own research. The vulnerability by which LGBQ+ women moved through heteronormative spaces was relative to their positionality and was often understood to be contextually based.

"I'm fortunate enough that I do feel like I live in a bit of a bubble in the community where I have a really great group of friends that all had babies at the same time, that are all very accepting and wonderful. I am curious to see what's going to happen when our son starts going to school and meets more kids outside of that bubble." -Cecelia

Women shared various strategies in self-protection that assisted in navigating heteronormative practices that made assumptions about their identities, relationships and/or their ability to parent. Women encountered barriers to supportive care and embodied safety when providers imposed essentializing medicalized care measures that failed to attend to diverse experiences.

Power, Control, Autonomy and Relationality

The women were predominantly and overwhelmingly positioned as having less knowledge and power. Feelings of powerlessness were often informed by a patient's lack of privilege within the health care system and perceived social status. There was an overarching theme of perinatal care providers not seeking the consent of LGBQ+ women and failing to consult with patients before they performed procedures on the women and their babies. Language of rigidity perpetuated lost opportunities to consider the diversity in the experiences of women and furthered a failure to fully integrate LGBQ+ health into dominant care practices. There was often no space for difference and paternalistic practices furthered the vulnerability of women from marginalized groups. Some women described how health care providers told them they did not need to review their personal birth plans that they had created which led to feelings of disempowerment.

"And I eventually ended up going to a C-section. That experience was fairly traumatic for me. I know a lot of women are like, well, if I birth naturally or by caesarean, it doesn't really matter. The baby is healthy and... But for me, it took a very significant emotional toll on me. And I felt at the time, I lost a lot of agency in my birthing process and was in a lot of pain and distress as they were getting me to sign a consent form to perform the surgery, and I felt like I had no option." -Denise

There was a lack of understanding around how spaces, relationships and hierarchical/paternalistic healthcare knowledge impacted care delivery and contributed to the ways LGBQ+ women experienced birth. The ability of health care providers to establish relationships with women in a way that supported embodied trust[10] determined the capacity of perinatal care relationship to empower. This was often reflective of how the health care provider understood diversity and vulnerability within the context of birthing spaces.

"And they talk about it as if, I don't know, like they're in control. And I think that more women really need to understand that they have the right. Because the doctor just comes in and says you need to have this done but doesn't...they're not educated about it, and they're not educated about the fact that, you know, like they have a choice in the matter." -Skyler

Women have power in their bodies to birth their own babies and nurses have the potential to create possibilities that would empower.[11,12] Providers can begin to identify opportunities with women to support their taking control of a situation and finding agency in places that were made invisible by practices that reinforce institutional power and control.[11,12] Thus, compelling strategies emerged that disrupted heteronormative constraints within our health care spaces, particularly those of birthing.

Structural Trauma and the Importance of Trauma-Informed Care Strategies

Exclusion, inhibition and distancing from non-normative expressions of female sexuality alienate LGBQ+ women from a level of self-knowing and self-trust[13] that heterosexual women take for granted. Alone, in silence, and often blaming themselves for not identifying with the hetero-norm, participants struggled with the pressure of fulfilling heterosexual expectations.

"I classically knew there was something wrong. Not really wrong but that was the perception, there was something wrong, there was something different, yet. And just through a combination of events, buried it, hid it, stuck to the norms of society. And I'm not necessarily saying my family expected it of me either. My mother and my father were really great and always open. So it was just probably something with me, within me." -Karen

Coming out to oneself marked the beginning of a lifetime of acknowledging and declaring a departure from heteronormative alignment.[14] LGBQ+ women had to come out in opposition to the expectation of heterosexuality and were forced to contemplate whether doing so would put their safety at risk.[15] Alternatively, they could keep their LGBQ+ identity invisible however this entailed going back into the closet to mitigate a perceived risk to their safety.[15] Either way, uncertainty and mistrust governed the experiences of LGBQ+ birthing women.

"When it came to the nursing staff that were kind of in and out, I think they processed me and my partner as much as they were willing to engage with us… I think there was one particularly friendly nurse that even kind of asked questions about our relationship. And she seemed like really friendly and we felt like we had a good connection with her. So we really appreciated that. But for the most part, people didn't really acknowledge it in any other way. And so you don't know whether to interpret that as they're not acknowledging it because they're acting like it's normal or they're not acknowledging it because they don't recognize it, or you don't know what the reason is." -Kate

Narratives revealed a re-occurring theme of structural trauma which is theorized to be disproportionately experienced by members of marginalized communities.[15] The effects of structural trauma were evidenced in the experiences of LGBQ+ women who shared storied accounts of health care providers who engaged in practices that failed to consider broader understandings of patient safety.[15] Health care providers have the ability to empower or disempower which is particularly significant in determining the health outcomes of LGBQ+ birthing women.

"But LGBQ+ for me is […] seeing spaces between things or understanding […] the structured nature of the systems around us or that organize us. And so seeing the spaces or seeing the cracks, seeing them for what they are instead of believing in their absolute truth […] and being like […] how I can kind of break that open a little bit more and find the spaces where I feel more myself and feel more empowered and feel like I have agency in my own life and I'm doing what is true for me." -Wyn

The experiences of LGBQ+ women developed trauma-informed care strategies and a redressing of traditional assessment techniques.[15] Strategies aim to address and validate structural trauma by acknowledging that larger systems of privilege and oppression can influence the lives of individuals in diverse ways. Trauma-informed care strategies include inspecting rigid language, validating through reflecting language that patients use to describe their own experiences, and gaining access to relevant information from the patient to build a larger context for the provision of equitable care.[15] Thus, these strategies can be taken up in health practices to reconstruct historically disempowered identities[16] and create opportunities to rebuild relationships into partnerships that are grounded in trust and understanding between LGBQ+ women and their health care providers.

Conclusions and Implications

- Health care providers can better understand how to engage in the ethical duty of reflexive practices that call dominant models of care into question by becoming more aware of how personal assumptions and biases perpetuate inequitable care delivery.
- When heteronormativity is identified as a strategy that diminishes the agency of women, health care providers can begin to recognize the harm that dominant care practices inflict upon LGBQ+ birthing women and develop an appreciation for the role that dominant models of care play in perpetuating health inequities.
- A lack of autonomy can be positioned as an opportunity for health care providers to collaborate with LGBQ+ birthing women. Health care providers can then better understand how they can challenge and disrupt assumptions when they engage in practices with LGBQ+ birthing women that create positive connections with patients that convey a sense of safety and belonging.
- Therapeutic partnerships between LGBQ+ birthing women and their health care providers can be empowering. If women do not have to come out as LGBQ+ in opposition to the expectation of heterosexuality, coming out is reconstructed into an empowering process and health care providers can avoid re-traumatizing structurally marginalized patients.[15]
- Evidence-informed strategies for transformative and equitable care delivery practices could create new points of connection and reconstruct formerly disempowering relationalities between patients who are at risk for structural trauma and their health care providers.[15]
- New strategies will assist in shifting the burden of responsibility from marginalized populations to come out in opposition to the expectation of heterosexuality and educate their health care providers on the unique health needs of diverse populations. This will foster an ability to gain access to equitable care, or to participate in studies and provide data to researchers, thus allowing health care providers to create opportunities that would reconstruct caring and compassionate spaces into places where a diversity of experiences are acknowledged, appreciated, and respected.

"And in rural healthcare, if you're LGBTQ, anything, and you go to the doctor, 9 times out of 10, you have to educate your doctor about what you're talking about before you can even ask for advice. So I mean you can see right there the flaw. If you spend most of your appointment educating them about what you came in to ask for advice, they're surely not in a position to actually give us any professional advice. They don't even have the proper language skills to have these conversations with us." -Sally

References

1. Goldberg, L. (2005/2006). Understanding lesbian experience: What perinatal nurses should know to promote women's health. *AWHONN Lifeline,* 9(6): 463-467.

2. Spidsberg, BD. (2007). Vulnerable and strong – lesbian women encountering maternity care. *Journal of Advanced Nursing,* 60(5): 478-486.

3. Public Health Agency of Canada. (2012).What determines health? Retrieved from: http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php

4. Raphael, D. (editors). (2008) Social determinants of health: Canadian perspectives. (2nd ed.). Toronto: Canadian Scholars Press.

5. Martin Misener, R., Reilly, S., Robinson Vollman, A., (2010). Defining the Role of Primary Health Care Nurse Practitioners in Rural Nova Scotia. *The Canadian journal of nursing research*, 42(2), 30.

6. Nelson, W., Pomerantz, A., Howard, K., & Bushy, A. (2007). A proposed rural healthcare ethics agenda. *Journal of Medical Ethics*, 33(3): 136-139.

7. Goldberg, L., Harbin, A., & Campbell, S. (2011). Queering the birthing space: Phenomenological interpretations of the relationship between lesbian couples and perinatal nurses in the context of birthing care. *Sexualities*, 14: 173-192.

8. Goldberg, L., Ryan, A. & Sawchyn, J. (2009). Feminist and queer phenomenology: A framework for perinatal nursing practice, research and education for advancing lesbian health. *Health Care for Women International*, 30(6): 536-549.

9. Human Rights Campaign. (2017) Glossary of Terms. Retrieved from: http://www.hrc.org/resources/glossary-of-terms

10. Goldberg, L. S. (2008). Embodied trust within the perinatal nursing relationship. *Midwifery*, 24(1), 74-82.

11. Aston, M., Etowa, J., Price, S., Vukic, A., Hart, C., MacLeod, E., Randel, P. (2016). Public health nurses and mothers challenge and shift the meaning of health outcomes. *Global Qualitative Nursing Research* 3, 1-10.

12. Aston, M., Price, S., Etowa, J., Vukic, A., Young, L., Hart, C., MacLeod, E., Randel, P. (2015). The power of relationships: Exploring how public health nurses support mothers and families during postpartum home visits *Journal of Family Nursing* 21(1) 11-34 DOI:10.1177/1074840714561524

13. Young, I. M. (2005). *On Female Body Experience: "Throwing Like a Girl" and Other Essays*. Oxford University Press, Inc., New York.

14. Ahmed, S. (2006). *Queer Phenomenology: Orientations, Objects, Others.* Duke University Press, Durham.

15. Searle, J., Goldberg, L., Aston, M., & Burrow, S., (2017). Accessing trauma-informed care with queer birthing women in rural Nova Scotia. *Journal of Clinical Nursing*, n/a-n/a. doi:10.1111/jocn.13727.

16. Crenshaw, K. (1990-1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, 43(6), 1241-1300.

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